

Extending care to all families affected by autism

A new initiative led by the UC Davis MIND Institute aims to make evidence-based interventions more widely available for the millions living with autism spectrum disorder — including the half-million U.S. adolescents poised to plunge off a ‘services cliff,’ and the adults who are already at the bottom.

One in 59 children nationwide is currently diagnosed with autism spectrum disorder or ASD, almost triple the number at the turn of the millennium. Yet many of today’s more effective evidence-based treatments aren’t yet widely available to families who need them.

Meanwhile, over the next decade about half a million teens on the spectrum will transition into adulthood — where a sudden drop in institutional support, widely known as the “services cliff,” presents another glaring social problem.

That’s because most school-based educational interventions cease at age 21 or 22, and many adults may not qualify for further assistance. But autism remains a lifelong condition, and statistics show that many adults

with it will be unable to find meaningful employment, live independently or form lasting friendships. Many will entertain thoughts of suicide.

Overall, the economic cost of caring for Americans with autism — some \$268 billion in 2015 — will rise to \$461 billion by 2025 without more-effective interventions and lifespan support, according to the nonprofit Autism Speaks.

“Everyone knows someone affected by autism, and it’s time for us as a society to take responsibility for the growing number of families in need of quality care,” said Leonard Abbeduto, Ph.D., director of the UC Davis MIND Institute and Tsakopoulos-Vismara Endowed Chair in the UC Davis School of Medicine’s Department of Psychiatry and Behavioral Sciences.

Taking a lifespan approach

With those challenges in mind, Abbeduto and other leaders at the MIND Institute — known as one of the world’s leading neurodevelopmental research, clinical, educational centers — are launching a new effort to pioneer a first-of-its-kind lifespan approach to autism.

The goal is to assist individuals and families with ASD across age groups, geography and socioeconomic factors. The long-term project is one of several formal “Big Idea” initiatives at UC Davis—



20 years of discovery

Since its founding in 1998, the MIND Institute has achieved international recognition as a leader in research and innovative treatment approaches for neurodevelopmental disorders. MIND Institute faculty members have:

- Helped to identify the biological bases of neurodevelopmental disorders
- Discovered biomarkers for autism, including larger brains in some infants
- Identified genetic and environmental factors that increase risk, including the mother's health
- Elucidated the critical role of the immune system in autism
- Developed and helped implement educational and behavioral interventions — such as the Early Start Denver Model — and innovative technologies
- Advanced treatments for fragile X syndrome, the most common cause of inherited intellectual impairment
- Identified related but previously unrecognized disorders, including primary ovarian insufficiency and fragile X-associated tremor/ataxia syndrome (FXTAS)
- Led some of the first and largest studies of their kinds, such as CHARGE, MARBLES, and the Autism Phenome Project
- Shown that California's autism increase is not solely due to better diagnosis or diagnostic substitution
- Developed widely used assays to characterize and track disorders, and their responsiveness to new therapeutics

a series of forward-thinking, interdisciplinary programs prioritized because of their potential to transform the world for generations to come.

In the case of neurodevelopmental disorders, the Autism, Community and Technology Big Idea aims to create widespread change by uniting two distinct, yet overlapping areas of growth. The first thrust aims to develop and scale up evidence-based interventions — making them available to more people through innovation in affordable support technologies, widened community partnerships, and enhanced training for health providers, families, teachers, employers and families.

The second thrust will develop new ways of helping adults with ASD to gain meaningful inclusion in the community. Helping them to participate in the educational, employment, and social experiences of adulthood will require better understanding of their needs, MIND Institute experts say, and tailored support delivered in new and expansive ways.

Making evidence-based approaches accessible

The initiative is designed to build on existing research and clinical care at the MIND Institute — which recently celebrated its 20th anniversary (see sidebar, this page) — and to leverage UC Davis' unique strengths in neuroscience, engineering, education and social sciences. UC Davis Health runs one of the nation's largest telehealth services, for example.

The MIND Institute itself directly serves more than 6,000 patients per year for diagnosis, treatment and education around autism, fragile X syndrome, ADHD, and other neurodevelopmental disorders. It's also known internationally for research on causes and innovative treatments. In 2017, it ranked first in the

Zoe Eiselt, 19, and father Kurt at the MIND Institute. Zoe dreams of college, getting married, having a family and traveling.



nation for autism research funding from the National Institutes of Health, and last year three faculty members appeared in a global list of researchers in the top 1 percent by citations in their fields.

One of these faculty members was Sally Rogers, co-creator of the Early Start Denver Model or ESDM — a renowned early intervention with strong evidence about effectiveness in improving language, cognition and social skills of children with autism as young as 18 months. Unlike many traditional behavioral interventions, ESDM involves therapists but also heavy emphasis on everyday interactions with parents and others as well.

We're working to create technologies that will take MIND Institute expertise and extend its reach to impact families everywhere.

LEONARD ABBEDUTO, MIND INSTITUTE DIRECTOR

An ongoing clinical study is already evaluating the effectiveness of ESDM video training for parents of children with ASD, and the Big Idea aims to expand similar efforts to bring therapies to families — inexpensively and equitably — through apps, virtual reality, or even smart homes (see sidebar).

“For example, families in rural areas may not be able to see experts without traveling long distances. That creates a financial burden — or a practical one, for children with challenging behaviors — and can delay treatment,” Abbeduto said. “We're working to create technologies that will take MIND Institute expertise and extend its reach to impact families everywhere.”

Embracing a forgotten population

As a means of proactively reducing future suffering, many autism studies and interventions understandably target infants, children and adolescents. About 1 percent of autism research funding is currently focused on adulthood and aging, according to a 2017 report from the Interagency Autism Coordinating Committee. But at the same time, adults with ASD face a multitude of challenges around factors like social communication, behavior and ASD-related physical health conditions.

Abbeduto and colleagues such as MIND Institute researchers Marjorie Solomon and Robin Hansen already have efforts underway to help — for instance, a 20-week intervention focused on preparing for independence, and a large new NIH study on successful transitions from high school (itself made possible with charitable seed funding from a committed family). The Big Idea aims to support more such activity. “There is a tremendous need nationally for research about how to best support adults with neurodevelopmental disorders and their families — to improve their quality of life and their independence,” Abbeduto said. “We want to be leaders in this area, and agents of change.”

» Help improve quality of life for individuals living with autism and their families

To advance the Autism, Community and Technology initiative, UC Davis seeks to partner with donors, corporations and foundations to:

- Create an innovation hub for new technology development, clinical care and research
- Support partnership grants that foster participation of self-advocates, family members and diverse community providers
- Establish an endowed chair and several endowed faculty positions to recruit thought leaders

To learn more, please contact Elizabeth McBride, senior director of development, at ekmcbride@ucdavis.edu or 916-703-0221.



bigideas.ucdavis.edu

UC Davis MIND Institute researchers are already working on a variety of projects that

help adults with ASD to live better lives

adults with autism

Adult life — with its bosses, coworkers, roommates and romantic partners — can be tough enough. Then add the hallmark social and executive-function challenges of autism spectrum disorder.



An estimated 5 percent of adults with autism have ever been married

Depression affects an estimated 26 percent of adults with autism **3 times the U.S. average**



Many young adults with autism don't receive any health care for years after they stop seeing a pediatrician

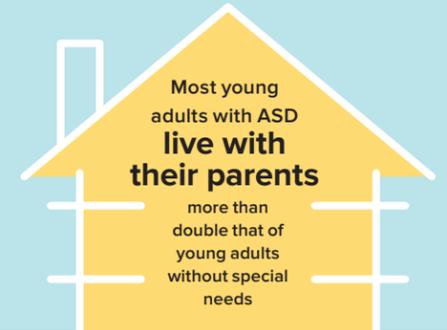


More than half of young adults with autism remain unemployed and unenrolled in higher education in the two years after high school

An estimated one in four to one in five is unemployed



As many as one-third have epilepsy



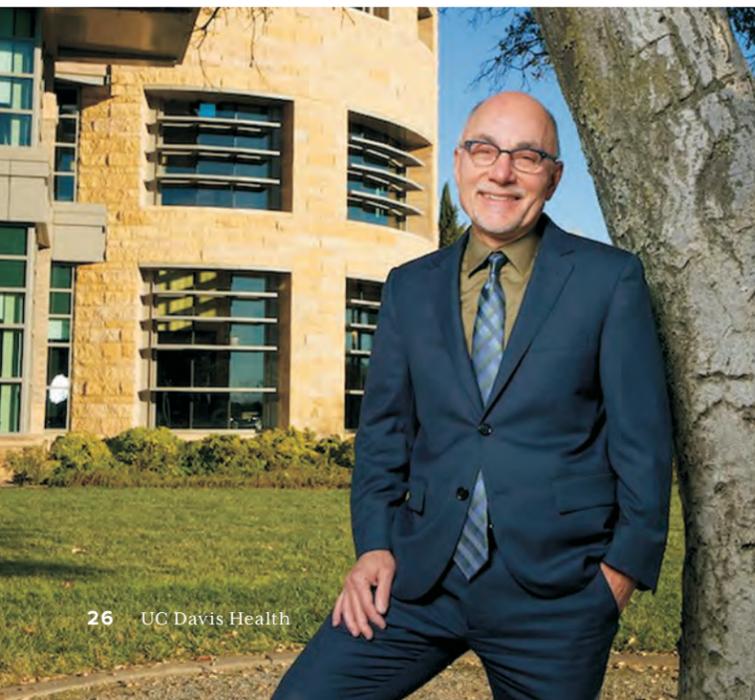
Most young adults with ASD live with their parents more than double that of young adults without special needs

Understanding successful transitions to independence

MIND Institute researchers received a five-year, \$3.1 million NIH grant to research youth with fragile X syndrome as they progress from high school to adult life. The condition, also known as FXS, is the most common cause of inherited intellectual disability and the leading single-gene cause of autism.

MIND Institute Director Leonard Abbeduto is leading the study, which aims to better understand what makes transitions

Leonard Abbeduto, MIND Institute Director



to independence more or less successful. By investigating the school and home experiences, skills, and challenges of adolescents with FXS, Abbeduto hopes to help parents and teachers learn to facilitate smoother transitions.

“We think that language and literacy skills upon completion of high school will play an important role in employment, socialization, leisure and housing outcomes for young adults with FXS,” said Abbeduto, who received the American Psychological Association’s 2017 Edgar A. Doll Award for career contributions to understanding intellectual or developmental disabilities. “If we can demonstrate that relationship, I think we’ll have a strong case for schools to increase the intensity of speech and language therapies and literacy education.”

Support from a committed family

A \$100,000 gift from the Canel family helped to establish the MIND Institute’s Program for Transition into Adult Life, and allowed Abbeduto to conduct pilot research to secure the NIH grant. Some of the program’s aims include:

- Designing service coordination models that help families create individualized “life plans”
- Identifying innovative programs in post-secondary education, vocational training, employment and housing, and barriers to access
- Creating a national clearinghouse for information about adult transitions
- Advocating for policy changes that bring promising approaches to scale

A special intervention program for young adults



Marjorie Solomon

Researcher Marjorie Solomon, the MIND Institute’s Oates Family Endowed Chair in Life Span Development in Autism, is leading development of a special intervention program to help young adults with ASD transition more effectively to adult life.

Known as the Acquiring Career, Coping, Executive-Control and Social Skills (ACCESS) program, the 20-week curriculum is based on interventions used in adults with schizophrenia, who have similar problems adapting to adulthood.

ACCESS employs a combination of cognitive behavioral and social skills group-therapy techniques, with modules around key areas such as planning, workplace communication, stress coping, goal setting, problem solving and self-advocacy.

Small trials suggest ACCESS creates improvements in global adaptive functioning, communication, self-direction and self-determination. Solomon and colleagues eventually hope to publish a manual for an intervention that could be widely used anywhere. The curriculum also incorporates insights from colleagues at UCLA.

“Although it’s never too early to help people with autism develop the adaptive, social, vocational and self-determination skills they’ll need in adult life, some of these skills may need to be relearned at key transition periods,” Solomon told Spectrum News last year. “Many of our participants had been members of our child and adolescent social-skills groups, but they needed to learn to adapt the skills for adult contexts.”

A center for community partnerships



Robin Hansen

The MIND Institute is home to one of California’s three federally designated Centers for Excellence in Developmental Disabilities. Known as CEDDs for short, the centers serve as links between universities and communities to maximize independence, productivity and inclusion of people with developmental disabilities.

MIND Institute faculty member Robin Hansen founded and leads the UC Davis center, which operates through advocacy, community partnerships, interdisciplinary training, and translation of research into practical applications. Examples:

- CEDD works to expand access to appropriate assistive technology or “AT” — tools such as tablets, visual schedules and video modeling that can help people with autism communicate and plan. The center offers educational and inspirational videos, and helped a local nonprofit launch an AT training center.
- The center provides more than 100 training opportunities each year for service providers, students, professionals and family members.
- The center’s Northern California Business Advisory Council promotes partnerships with local businesses and helps to guide workforce-development programs.
- A (philanthropy-funded) supported decision-making project helps people with disabilities choose trusted people to assist with legal decisions about their lives.

Leveraging technology and partnerships to help more families with autism

MIND Institute researchers are studying how emerging technologies can bring evidence-based therapies, educational programs and support systems for autism “to scale.” Using that technology can simultaneously create a treasure trove of new data, helping research efforts even more.



Virtual reality

UC Davis researchers are testing virtual reality to deliver proven exposure therapy and habituation learning techniques to highly distractible children, such as those with ADHD. VR headsets are broadly available and growing more inexpensive, creating opportunity for widespread use.

Video games

MIND Institute researchers are leading several studies that explore whether scientifically designed games can improve the hyperactivity of ADHD or the limited spatiotemporal cognition common in neurodevelopmental disorders. Digital games could be powerful-yet-inexpensive treatments that are easily accessible and reach more children.

In one example, a recent UC Davis-led study found that large-scale in-home cognitive interventions using computer memory training games are feasible — and may be beneficial — for kids with fragile X syndrome.

Virtual support groups

Virtual support groups can connect people with autism or their families to additional social skills workshops, helping them move to independence and easing some of the burden on caregivers.

Telehealth

MIND Institute researchers are using telehealth to teach and coach parents in their own homes about language learning support for children with fragile X syndrome. The utility of combining such distance-delivered interventions with medications is currently being tested in a large multi-university NIH study.

For community hospital clinicians who care for kids with ASD, the institute's ECHO® Autism Teleconferencing Program offers one-on-one telementoring with UC Davis specialists and CME credit.

Program development is underway for a telehealth model that will train rural physicians in evidence-based screening and identification procedures for ASD, and provide ongoing consultation for challenging cases.

Assistive communication technologies

The MIND Institute supports a variety of education, training and research activities around existing and emerging assistive technologies, such as behavioral and scheduling aids for mobile devices.

Since a third of people with ASD are nonverbal or very limited verbally, one emphasis is “augmentative and alternative communication,” or the use of personalized approaches and devices to increase communication ability. Methods can range from picture cards, to voice output devices that play prerecorded messages, to eye-gaze trackers indexed to messaging.

Distance education

Virtual classes, conferences and workshops can help train parents, providers, teachers and administrators. The MIND Institute helps operate the California Early Start Support Network, a collaborative project that uses regular videoconferencing to train and support practitioners providing early intervention services.

The institute's CEDD also develops free online training programs, such as the Autism Distance Education Parent Training (ADEPT) series designed to help enhance independence and community integration. The 10-lesson interactive online learning module provides parents with tools and training to more effectively teach functional skills to their child with ASD, using applied behavior analysis techniques.

Policy development

The MIND Institute facilitated the creation of the California Autism Professional Training and Information Network, a group of more than 350 professionals that developed the interagency collaborations needed to carry out a statewide plan for improving youth services.

Smart homes

Technologies integrated into the home might provide prompts when it's time for medication, grooming, work or a meal. Autism experts partnering with engineers could also utilize robotics to realize new ways of providing therapies and medications.