Autism, Community and Technology

A UC DAVIS BIG IDEA
Autism Spectrum Disorder (ASD) has captured the attention of the world. Today, one in every 59 children in the United States is diagnosed with ASD. And with more than 1 percent of the world population now classified as autistic, the challenge of supporting this growing population from birth through the aging process is truly a global crisis.

Intensive behavioral intervention in the preschool years can lessen the social impairments, repetitive interests and behaviors that define ASD. There is no cure, however, and living with ASD does not necessarily become easier over time. In fact, many individuals who receive full-time, in-home therapy as toddlers and intensive special education services through grade 12 are as adults unable to find meaningful employment, live independently or have friendships beyond their immediate family. Leaving the school environment and entering the adult world is often a disorienting, isolating experience for people with ASD.

As the number of individuals and families affected by autism steadily grows, there is an urgent need to develop new methods of serving this population over the long term. Doing so will require both a better understanding of needs and more tailored services, delivered in new ways. Unlike cancer or heart disease, ASD is a behaviorally diagnosed disorder that varies for each individual. The assessments that take place in a clinic or research lab are by necessity brief, which may limit insight into an individual's symptoms and the ways the condition affects their daily functioning. Moreover, the behavioral manifestations of ASD may change significantly over time.

The UC Davis MIND Institute has earned an international reputation for its work with ASD.
With four federally funded centers focused on intellectual and developmental disabilities and an interdisciplinary team of 60 faculty, the MIND Institute is one of the world’s leading centers for autism research and clinical care.

Now, UC Davis has a vision to build a consortium that significantly accelerates the understanding of ASD over the lifespan and revolutionizes treatment at every stage, enabling all citizens to receive high-quality services regardless of race, ethnicity, geography or economic circumstances. The Autism, Community and Technology (ACT) consortium will make new scientific discoveries possible and benefit individuals, families, professionals and paraprofessionals as they address the changes and challenges that ASD manifests over a lifetime.

We believe that technology, informed by the mission of cultural equity, can be leveraged to reimagine the study of ASD and how we serve those living with the condition. Technological tools—such as wearables, digital games, virtual reality and more—can better track behavioral patterns and tendencies in the many contexts and communities in which a person with ASD participates. These tools also create rich, real-time data that will provide a thorough picture of the disorder as it naturally unfolds in the home, workplace, classroom and community.

By integrating innovation with our expertise in ASD and providing culturally competent care, the ACT consortium will set the stage for groundbreaking scientific discoveries. We invite visionary philanthropic partners to join us in transforming the lives of all families affected by autism through innovations in technology and community-based care.
MIND Institute researchers and their partners have already pioneered the use of powerful tech tools that can support those living with ASD, including self-administered digital games for cognitive enhancement, virtual reality classrooms for improving social skills, and telehealth technology to train and support parents so that they can address the behavior and development of a child at home. This integration of technology, science and practice enhances diagnosis, broadens treatment options, leads to better-coordinated services, and empowers families.

Additionally, technology offers the potential for monitoring behavior, physiological and emotional reactions, social interaction patterns, visual processing and attention, and other manifestations unique to an individual with ASD. These data will be the basis for monitoring progress and for adjusting supports, and will allow the many professionals who form the care team for an individual with ASD to better personalize treatment, education and services.

Launching the Vision
The ACT consortium will require support for leadership, faculty and staff, as well as for student fellowships and new programs. Infrastructure upgrades will also be necessary to adapt telehealth technology for ASD needs.

With your gift, UC Davis will be able to create:

- An endowed chair leadership position of international prominence in the areas of ASD, technology-driven health care delivery and community implementation
- An expansion of the existing MIND Institute space to create a laboratory for technology development and community partnerships
- Three to five new faculty positions to add knowledge and expertise to our interdisciplinary team, with an emphasis on junior faculty
- Resources to develop and adapt technology and gather rich, nuanced, real-time data
- Community partnership grants that support the participation of self-advocates, family members and community partners in developing innovative demonstration sites for implementing new technologies and care delivery systems
- Annual pilot grant competition funds that will encourage and support proposals for studies conducted by interdisciplinary faculty teams
- Postdoctoral and graduate student fellowships for promising early-career scholars
The socially isolating nature of ASD limits independence and an individual’s capacity to contribute to their community. Technology can address this by facilitating real-time virtual coaching in the workplace, for example, or by providing real-time prompts to help individuals with ASD accomplish daily tasks in their own homes. Digital tools can enable independence at key moments, including in post-secondary educational settings. Digital gaming, virtual reality, eye tracking, webcam-based teleconferencing and even robotics can be used to deliver supports outside the clinic, with varying degrees of clinician participation.

Care partners and communities are essential for advancing the emotional, behavioral and physiological success of a person with ASD. In-home technology can greatly improve the resources available to those who provide care—as well as their confidence. Technology in schools, workplaces, libraries, community centers and places of worship can be used to build a large support team around an individual. Different professionals serving the same individual can coordinate, easing the burden on families and opening the possibility of more focused complementary services rather than isolated, and at times conflicting, approaches to treatment and care.

This cost-effective, high-tech/high-touch approach does not replace excellent clinical care, but rather extends it. Through portable technology, expertise moves from the clinic to follow the individual. Individualized care is possible when real-time, real-place information is provided to clinicians.

Reaching the Community

With your support, the ACT consortium will make breakthroughs in community access to ASD resources and empower patients and families to manage their own care, in their own communities, regardless of location or economic status. The consortium will work actively to engage communities in partnerships that allow us to understand unique needs, reduce disparities and promote equity.
Digital technology enhances the equitable delivery of services, particularly for communities whose access is limited by geography. The consortium will work actively to engage communities in partnerships that allow us to understand their needs and reduce disparities. We will harness the constant stream of data from new technologies to make iterative improvements to the systems supporting communities of all kinds, in all places. Mindful that different people will need different tools, the consortium will work to create technologies that prevent inequities.

The power of our new model lies in its adaptability and versatility—and therefore in its capacity to deliver individualized care. The same fundamental technologies can be customized to serve a wide variety of individuals with ASD and their care partners, whether the person is an English-speaking ASD caregiver who lives in a rural town, a Cantonese-speaking child with ASD who goes to school in a major city, or an adult with ASD navigating the transition from school to work. Technology developed by the consortium could also be integrated into broader initiatives—addressing issues such as public safety and access to healthy food by networking with community centers, for example, or access to general telehealth services by partnering with public libraries.

Importantly, technology-delivered care is also more affordable. When care happens at home, the school, the workplace and the broader community, costs to the system decrease. Empowering individuals and families with greater knowledge and virtual tools lessens their dependence on experts and creates family and professional partnerships, increasing the quality of care an individual with ASD receives while broadening the impact of each professional.
Using technology to extend care to communities will lead to the creation of a large and complex dataset. Mining these data will allow us to fine-tune specific treatments, make better predictions about the course of an individual’s symptom trajectory, and study the broad disorder of ASD at an unprecedented pace.

The Big Data generated by the consortium’s work will serve to accelerate discovery and deepen scientific knowledge of autism. In addition, the analytics needed to understand these data will invite partnerships with industry, especially major corporations defining the digital space of the future.

Ultimately, the consortium’s work has the potential to catalyze changes with implications far beyond ASD. For instance, the new model of behavioral health care that will emerge from our work will change current models of health care reimbursement. Regulations and guidelines do not yet exist to inform decisions about when technology should be used to deliver care and who should pay for it. We must push these boundaries, however, as rising health care costs strain our economy and threaten to exacerbate economic inequities.

Driving Innovation and Change
The ACT consortium’s work will create unprecedented amounts of real-time data. As a whole, these data will:

- Support groundbreaking, accelerated research into ASD
- Expand available treatment options for individuals with ASD and their care partners
- Inspire new partnerships between academia and industry
- Inform policy debates at local, national and international levels
UC Davis: Poised to Lead in Autism Innovation

Now is the time to make gains in the diagnosis, treatment and support of individuals with ASD, and UC Davis is uniquely poised to lead this effort. In addition to the renowned MIND Institute, our university is home to a peerless constellation of expertise that includes the Center for Health Technology, the Center for Mind and Brain, the College of Engineering, the Center for Reducing Health Disparities, School of Education and faculty partners from the social sciences and the humanities.

Establishing the ACT consortium in the state of California will be especially meaningful. Autism is the fastest-growing disability in the state, and 100,000 of California’s school-age children have been diagnosed with ASD or a developmental disability. In addition, California’s racial, ethnic and linguistic diversity is higher than national averages, as is the state’s proportion of low-income residents. Recent studies in California have shown that access to ASD services is not equitable. Instead, access varies along racial, ethnic, geographic and economic divides. These demographics create an imperative to explore accessible, individualized care for people with ASD.

In a world in which technology is developing rapidly, UC Davis has a proven track record of delivering solutions through the use of rigorous science and inclusive partnerships. The increased understanding of ASD and the innovation in care that will result from the consortium’s work will help to build more effective and accessible systems locally, nationally and globally.
Philanthropy has always been key to UC Davis' success in moving great ideas forward. We have the vision and the expertise to, with your partnership, transform quality of life and access to care for individuals with ASD and their families.

Thank you for your consideration of this exciting Big Idea. We look forward to discussing how your philanthropic goals may be achieved through this groundbreaking initiative.

An Invitation

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Ways of Giving

We respect that, for each donor who wishes to provide significant philanthropic support, there are personal, financial and gift planning aspects to consider. We will work with you to realize your philanthropic vision and develop the gift plan that best meets your needs. At your request, we can also work with your tax and financial advisors. Following are various gift types and their associated benefits. You may wish to consider a mix of gift types to help you achieve both your philanthropic and financial objectives.

Cash Gifts
- Are the simplest and most popular giving method
- Are tax deductible in the year they are given

Gifts of Securities
- Include stocks, mutual funds and bonds
- Avoid capital gains taxes
- Provide an income tax deduction for the full fair market value of long-term, appreciated securities

Gifts of Real Property
- Include land, farms, personal residences, and rental or commercial property
- Avoid capital gains tax on appreciated assets
- Provide an income tax deduction for the full fair market value of long-term, appreciated property
- Eliminate property expenses and taxes
- Can provide continued use for life through a retained life estate gift

Bequests and Living Trusts
- Establish the UC Davis Foundation as a beneficiary of your estate
- Provide an estate tax deduction equal to the value of the gift
- Offer flexibility by allowing you to provide for family first

Retirement Plan Gifts
- For current gifts, utilize the IRA Charitable Rollover provision (for donors aged 70½ and older)
- Name the UC Davis Foundation as a beneficiary
- Eliminate income tax on the plan distributions
- Preserve the plan’s full value for gift purposes

Life Income Gifts
- Include charitable remainder trusts and gift annuities
- Provide potential tax savings on income, estate and capital gains
- Generate income for you and/or your loved ones for a fixed period of time or until your passing
- Distribute the remaining assets to the UC Davis Foundation