Dear Friends and Colleagues,

Join us in celebrating five productive and exciting years of service as a university center for excellence in developmental disabilities!

The Center for Excellence in Developmental Disabilities (CEDD) at the UC Davis MIND Institute, established in 2006, is one of 67 federally designated university centers (UCEDDs) across the country. These centers are authorized by the Developmental Disabilities Assistance and Bill of Rights Act and funded by the Administration on Developmental Disabilities (ADD), part of the Administration for Children and Families within the U.S. Department of Health and Human Services.

CEDD brings added resources to expand the activities and impact of the MIND Institute, serving as a resource in the areas of education, research and service, and providing a link between the university and the community to improve the quality of life for individuals with developmental disabilities.

We are pleased to present this summary report of our current work. This report captures both our long-standing, continuing initiatives and some of the newer projects on which we are just embarking.

Our work involves important collaborations with many partners, including self- and family-advocates, community groups, other colleges and universities, and state and federal agencies, all of which have helped make our first five years so successful. We’ve tried to summarize our projects and capture a handful of stories about some of the people whose lives have been touched by CEDD in our first five years.

On behalf of the faculty and staff of CEDD, thank you for taking the time to learn more about our work. With gratitude and respect for our partner agencies, colleagues, families and friends, we are looking forward to our next five years. Whether you are a self-advocate, parent, professional, or student – please let us know what you think; your feedback helps us shape our goals and projects to the needs of our community.

Robin L. Hansen, MD
Director, Center for Excellence in Developmental Disabilities
UC Davis MIND Institute
Our VISION

Our vision is to provide leadership in education, service and research to maximize the independence, productivity, and community inclusion of individuals with developmental disabilities.

Our MISSION

The Center’s mission is to collaborate with individuals with developmental disabilities and their families to improve quality of life and community inclusion. The Center accomplishes this mission through advocacy, community partnerships, interdisciplinary training, and the translation of research into practical applications.

Our VALUES

- Access
- Accountability
- Compassion
- Diversity
- Empowerment
- Family-centered
- Hope
- Inclusion
- Partnership
- Person-centered
- Quality
- Reducing disparity
- Self-determination
- Synergy
Our mission and values are reflected in the goals we pursue and the projects we undertake. This report includes information on several projects that span the Center’s four core functions of 1) community support and advocacy, 2) interdisciplinary training and leadership development, 3) research, and 4) information dissemination. As you review these projects, you will note a focus on improving quality of life for individuals with disabilities from infancy through adulthood. If you would like more information on any of the projects in this report, please write to us at ddcenter@ucdmc.ucdavis.edu.

COMMUNITY SUPPORT AND ADVOCACY

SELF- AND FAMILY-ADVOCACY. CEDD is working to strengthen advocacy skills for individuals with disabilities and their families, with special emphasis on the Latino and Southeast Asian communities. CEDD promotes self- and family-advocacy via outreach, workshops, networking, training materials, technical assistance and website resources. Recent activities have included training opportunities in political advocacy in preparation for Capitol Action Day; Spanish language sibling workshops; and parent training videos in both English and Spanish.

Alvaro Rodriguez, age 17, was Master of Ceremonies at a presentation by Joaquin Fuentes, M.D., on “El Autismo: Investigaciones Recientes y Opciones ed el Tratamiento” (Autism: a summary of recent research and treatment options).

“We are very grateful for the opportunity given to Alvaro to be Master of Ceremonies. He was very happy to see all of the parents because they talked to him and congratulated him. It gave them hope for their children by seeing him. He felt like he was a role model. He said that he learned more about the autism spectrum disorder that affects him from Dr. Fuentes’ presentation. Alvaro is very proud of his bilingual skills, and having the opportunity to memorize his speech in Spanish was something very special.”

– Parents of Alvaro Rodriguez
COMMUNITY TRAINING. CEDD provides more than 100 training opportunities each year for consumers, families, service providers, and professionals to increase their knowledge and skills in the areas of developmental disabilities, early identification, service provision, inclusion, and other medical, legal, social and policy issues related to disabilities.

STATEWIDE INITIATIVE FOR IMPROVING SERVICES FOR PEOPLE WITH ASD. CEDD is working at the systems change level to increase training opportunities for professionals across the state. CEDD staff are facilitating the Interagency Autism Planning Group, consisting of representatives of the California Departments of Developmental Services, Education, and Public Health, and other stakeholders, which has developed the infrastructure and interagency collaboration to implement a state plan for improving services for children and youth with autism spectrum disorder (ASD).

MIND INSTITUTE NEURODEVELOPMENTAL DISORDERS CLINICS. The clinics offer assessments for autism spectrum disorders, fragile X syndrome, 22q11.2 deletion syndrome, attention deficit hyperactivity disorder (ADHD), learning disorders, and other neurodevelopmental disorders. The clinics serve about 1,200 patients per year, providing interdisciplinary diagnostic evaluations, intervention recommendations and medical management.

REDUCING HEALTH DISPARITIES. CEDD faculty have partnered with the Hmong Women’s Heritage Association and the United Iu-Mien Community, Inc. to study barriers to quality care among Southeast Asian communities, with the goal of improving health care and access to services for children and adults with developmental disabilities. Based on the findings, project staff and community partners developed a public service campaign aimed at increasing the awareness of developmental disabilities, early identification and services for the Southeast Asian communities.

PROMOTING INCLUSIVE PRESCHOOL. CEDD partners with Sacramento’s Triumph Preschool on the development of a high quality, inclusive, early childhood program. CEDD staff provide support for children with disabilities and/or challenging behaviors through individualized recommendations,

“One young man told us, “People think I am not as smart as them, because my words don’t match what is in my head.” We are privileged to guide people in finding alternative communication systems that enable self-expression and prevent isolation. Not being able to speak does not mean you have nothing to say.”

– Bonnie Mintun, Training Coordinator and Family Specialist, Communication Technology Education Center
staff training, and parent support. Triumph has implemented the Center for Social Emotional Foundations of Early Learning (CSEFEL) model and is collecting data on the impact on teacher skill and confidence in supporting children with challenging behaviors.

**YOUTH TRANSITION TRAINING AND MENTORING.** In partnership with the California Health Incentives Improvement Project (CHIIP), CEDD has undertaken the Success Defined project to provide training, mentoring, and resources for youth and young adults with developmental disabilities who are interested in exploring options for post-secondary education, purposeful work, volunteer service, and community living.

**THINK COLLEGE.** CEDD has taken the lead role in organizing a regional Think College subgroup consisting of representatives of area community colleges and universities and in working to develop resources that aid students with autism and other developmental disabilities to succeed in post-secondary education. CEDD also participates on the statewide California Consortium for Post-Secondary Education led by the UCLA Tarjan Center.

**ASSISTIVE TECHNOLOGY.** CEDD is working to expand knowledge of and access to appropriate assistive technology for individuals with developmental disabilities and their families. CEDD helped to start the Supported Life Institute’s Communication Technology Education Center (CTEC), which provides no-cost opportunities for hands-on exploration of communication devices and assessment and training in their use.

**THE COMMUNITY OF EARLY INTERVENTION PRACTITIONERS.** This is a collaborative project of CEDD, the Infant Development Association, and the California Association of Professors of Early Childhood Special Education. A home visit blog provides the framework for an interactive, support community for practitioners and families.
INTERDISCIPLINARY TRAINING AND LEADERSHIP DEVELOPMENT

FELLOWSHIP PROGRAM IN DEVELOPMENTAL BEHAVIORAL PEDIATRICS. CEDD offers a three-year program of intensive specialty training in Developmental Behavioral Pediatrics to Pediatrics fellows.

INTERDISCIPLINARY, PRE-SERVICE TRAINING IN DEVELOPMENTAL DISABILITIES. CEDD offers a one-year intensive specialty training program in serving individuals with developmental disabilities to graduate students in medicine, nursing, special education, psychology, and/or related fields. Trainees receive instruction and practical experience in training/teaching, community service, research, and the translation of research into practical applications. Trainees increase their knowledge of developmental disabilities and exposure to medical, legal, social and policy issues related to disabilities. Trainees have the option (required for Pediatric fellows) of a four-month, one day a week, rotation at Triumph Preschool, a CEDD partner and model inclusive early childhood program.

TRAINING IN AUTISM SPECTRUM DISORDERS. CEDD offers a certificate program in Autism Spectrum Disorders (ASD) through UC Davis Extension. The intended audience is primarily educators, but the first three courses are available to students in any field and to members of the community.

“The rotation at Triumph Preschool was an opportunity to learn about child development experientially beyond the textbooks. Working with teachers whose approach to teaching and providing structure – using positive reinforcement and developmentally appropriate interventions – served as a model for me.”

– Psychiatry fellow, on CEDD training rotation at Triumph Preschool

Lori Llewelyn and Dan Boomer, Community Advisory Committee meeting
RESEARCH

CEDD faculty are involved in basic science and clinical research projects, helping to better understand and treat a variety of developmental disabilities. We are dedicated to collaborative research that supports community participation and inclusion.

FRAGILE X RESEARCH AND TREATMENT CENTER. The Center performs clinical evaluations and treatment of patients with fragile X and studies the association between molecular variations in the fragile X gene and the physical, behavioral and cognitive features of both children and adults affected with fragile X syndrome and in those who carry the premutation form of the gene. The Center staff includes specialists in molecular biology, pediatrics, molecular genetics, psychiatry, psychology, neurology, genetic counseling, speech and language pathology, occupational therapy, neurobiology, pathology and social work. Randi Hagerman, M.D., Principal Investigator.

NEUROTHERAPEUTICS RESEARCH INSTITUTE (NTRI). NTRI develops targeted therapeutics, including molecular interventions, for neurogenetic disorders. The Institute is the hub of an interdisciplinary research consortium which brings together clinical and basic scientists from the Erasmus Medical Center (Rotterdam, The Netherlands), University of Washington, University of Colorado Health Sciences Center, and Scripps Research Institute. Investigators are currently focusing on fragile X syndrome and fragile X-associated tremor/ataxia syndrome. Paul Hagerman, M.D., Ph.D., and Randi Hagerman, M.D., Principal Investigators.

PARTNERS IN AUTISM INTERVENTION RESEARCH (PAIRS) PROJECT. This study evaluates the effects of coaching parents on the use of interactive strategies on increasing their children’s social communication. The project has developed a parent-friendly training package of both written and video materials for professionals and parents on the Early Start Denver Model, a developmentally based comprehensive intervention for very young children (age 12-36 months) with autism. Sally Rogers, Ph.D., Principal Investigator.
MARKERS OF AUTISM RISK IN BABIES-LEARNING EARLY SIGNS (MARBLES) PROJECT. The MARBLES Project studies how autism unfolds during its earliest phases, beginning with pregnancy. The goals of the project are to 1) identify early signs of autism, 2) understand the earliest possible causes of autism, and 3) develop diagnostic tests and interventions that can limit the effects of autism or prevent it altogether. Irva Hertz-Piciotto, Ph.D., Principal Investigator, and Robin Hansen, M.D., Co-Investigator.

CHILDHOOD AUTISM RISKS FROM GENETICS AND THE ENVIRONMENT (CHARGE). CHARGE is a case-control study of over 1,000 children, looking at gene-environment interactions that increase the risk for autism. Irva Hertz-Piciotto, Ph.D., Principal Investigator, and Robin Hansen, M.D., Co-Investigator.

CHROMOSOME 22Q11.2 DELETION SYNDROME (VCFS/DIGEORGE) PROJECT. This research project involves 1) theory-driven experiments that test the functioning of specific brain circuits under different conditions, using computer games, 2) brain imaging to characterize the changes in brain development that affect neural structure, connectivity and function, and 3) neurobiological and clinical assessments of anxiety and its impact on intellectual and adaptive function and risk for psychiatric illness. Tony J. Simon, Ph.D., Principal Investigator.

ADHD RESEARCH. The ADHD translational program undertakes research activities in etiology, assessment, treatment, and outcomes, using neuroscience and behavioral methods. Julie Schweitzer, Ph.D., Principal Investigator.

VIRTUAL REALITY PROJECT. This is a collaborative project, with the UC Davis Computer Science Department, USC Institute for Creative Technologies, and Stanford University Department of Psychology, to examine the use of virtual reality to improve social skills treatments for children and adults with autism. Peter Mundy, Ph.D., Principal Investigator.

“From my perspective in basic research, the CEDD has been an incredible resource. With the development of my research program in cognitive analysis and brain imaging, I have felt a strong need on the part of participating families for information and clinical support. The CEDD has given me the structure and resources to meet those needs, and has opened a whole new world to me.”

– Tony J. Simon, Ph.D., Director, Cognitive Analysis and Brain Imaging Laboratory, MIND Institute
“When my son, Jared, was born, I took on a new role – mother of a disabled child. …Becoming informed is critical for parents, which is why I became involved with the CEDD Website Committee. The Internet has given families the ability to connect with each other, familiarize ourselves with professionals in the field, review information about medications, check for ongoing research projects, and have better access to services.”

– Debi Pfeifer, Member, Community Advisory Committee
INFORMATION DISSEMINATION

MIND SUMMER INSTITUTE. CEDD takes the lead in planning for the annual MIND Summer Institute on Neurodevelopmental Disabilities. The Institute is intended for a wide range of professionals, including educators, psychologists, physicians, nurses, occupational therapists, physical therapists, and speech and language pathologists, as well as caregivers, parents, and students. Presenters address issues related to early identification, diagnosis, assessment, and treatment of neurodevelopmental disorders. These presentations are available in video format on the CEDD website.

CEDD WEBSITE. CEDD provides online resources and reference materials on topics related to health and wellness, developmental disabilities, early identification and intervention, education, assistive technology, post secondary education, employment, and other quality of life related topics.

ON-LINE TRAINING PROGRAMS. CEDD has developed several training programs that are available, free of charge, via the CEDD website (www.ucdmc.ucdavis.edu/ddcenter):

- The Autism Distance Education Parent Training (ADEPT) focuses on “Adaptive Skills Teaching,” which enhances independence and positive behavior and increases opportunities for community integration. It is available in English.

- The Chromosome 22q11.2 Deletion Syndrome Educational Video Series (three videos) is designed for health professionals and patient families, explaining the disorder, medical care and guidance, and family support. Titles in the series include: 1) An Introduction to Medical Issues, 2) The First Year and a Half: Clark Family Interview, and 3) The First Sixteen Years: Heran Family Interview.

- The Assistive Technology Training video focuses on assistive technology applications and intervention strategies for individuals with neurodevelopmental disorders. It is available in English and Spanish.
“I am on this committee to offer my support for the next generation of people with disabilities – for our future. As a consumer and as a minority, I can speak to the need to make services available for all people. I want to be a voice for children with disabilities. They are not given the chance to advocate for themselves. Our system is set up to make many decisions for people, especially children. I think kids need to be heard during the planning process and encouraged.”

– Lisa Cooley, Member, Community Advisory Committee
Community Advisory Committee

Our Community Advisory Committee includes people with disabilities, family members, and advocates and professionals from the community, including:

Catherine Blakemore  Ron Huff  Laurie Newton
Linda Blong  Karen Leventhal  Kathryn Page
J. Daniel Boomer  Veronica Lopez-Villasenor  Debi Pfeifer
Linda Brekken  Scott Lorigan  Debbie Sarmento
Lisa Cooley  Allison Mair  Bari Schlesinger
JoEllen Fletcher  Catharine Mikitka  Ayde Syed
Barbara Guerrero  Bonnie Mintun  Patrice Yasuda
Laurie Hoirup

California Developmental Disabilities Network

The center is a member of the California Developmental Disabilities Network. Together the network partners work to address state and national issues that affect the quality of life for individuals with developmental disabilities. Network partners include:

• Center for Excellence in Developmental Disabilities at the UC Davis MIND Institute
• Tarjan Center at UCLA
• University Center for Excellence in Developmental Disabilities at the University of Southern California
• State Council on Developmental Disabilities
• Disability Rights California

Faculty and Staff

The center is comprised of the following faculty and staff from UC Davis and California State University Sacramento:

Robin Hansen, M.D., Director
Randi Hagerman, M.D., Associate Director – Research
Lori Llewelyn, M.P.P., Associate Director – Administration
Kathy Angkustsiri, M.D.
Susan Bacalman, L.C.S.W.
Dian Baker, Ph.D., R.N.
Maurine Ballard-Rosa, Ph.D.
Bernice Bass de Martinez, Ph.D.
Elliott Beaton, Ph.D.
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Terri Contenti, B.A.
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For more information

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Celebrating Five Years
(2006–2011)

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