

M.I.N.D. Matters



SUMMER 2008

New Center for Excellence in Developmental Disabilities: Focusing on quality of life

Two years ago, UC Davis was designated as a new University Center for Excellence in Developmental Disabilities (UCEDD) by the U.S. Health and Human Services Administration on Developmental Disabilities. The new center, the only UCEDD in Northern California, joined a network of 66 other UCEDDs across the country. The mission of the UC Davis Center for Excellence in Developmental Disabilities (CEDD) is to work with people with disabilities and their families to improve quality of life and community inclusion.

“Resources in California have not kept pace with the growing population of people with developmental issues who need services to live fuller lives,” said CEDD Director Robin Hansen. “Our mission complements the M.I.N.D. Institute’s and provides additional resources for expanded interdisciplinary training opportunities, advocacy and community partnerships and translation of research into practical applications.”

“Resources in California have not kept pace with the growing population of people with developmental issues...”

Collaboration is a key CEDD focus. UC Davis internal partners include the M.I.N.D. Institute, the Center for Health and Technology and the Schools of Medicine and Education. Other partners include California State University, Sacramento, the UCEDDs at UCLA and the University of Southern California, the state Council on Developmental Disabilities and Protection and Advocacy, Inc.

Associate Director Lori Llewelyn said a critical component of the CEDD’s success is the contribution of the Consumer Advisory Committee that includes individuals



CEDD leadership: Front row, left to right: Lori Llewelyn, associate director, administration; Robin Hansen, director; Randi Hagerman, associate director, research; Back row, left to right, Gina Gaurneri, community service coordinator; Ruth LeBlanc, data coordinator.

with disabilities and their families, advocates for people with developmental disabilities, and other professionals who support them.

“The Advisory Committee is a great group to work with ... knowledgeable, dedicated, and with a lot of ideas for new projects. Young people on the committee have suggested starting a youth networking group to help youth with disabilities to develop their communication skills,” Llewelyn said. “We’re also looking into establishing a summer camp. Older kids with developmental disabilities rarely have been away from home overnight, so this type of camp can

(continued page 2)

Inside

Sally Rogers: Leadership in autism early intervention	3
Peter Mundy: Bridging the gap between autism research and classroom practice	4
Autism Speaks “Walk Now for Autism”	5
M.I.N.D. Institute 10 th Anniversary Celebration	5
2008-09 Distinguished Lecturer Series	6
Executive Director’s message	8

Center for Excellence in Developmental Disabilities *(from page 1)*

offer them a first-ever opportunity,” she said.

Working in collaboration with the Infant Development Association and the California Association of Professors of Early Childhood Education, the CEDD is taking the lead in launching a new blog site this fall that will create a virtual network for geographically isolated early interventionists.

“The site is designed for people who work with infants and toddlers with disabilities,” said project lead Gina Guarneri. Guarneri said the three sponsoring organizations will post questions and case studies to create a virtual community of practice that will allow interventionists to keep up-to-date on best practices.

Led by CEDD co-founder and Associate Director of Research Randi Hagerman, the Center is facilitating the regional expansion of assistive technology (AT) services for people with developmental disabilities – an important benefit to children and families who need technology to communicate.

Hagerman is also overseeing several research projects designed to advance cognitive technologies, including “Use of AT to Expand Written Expression in Individuals with Neurodevelopment Disorders.” She is working with UC Berkeley Associate Professor Greg Niemeyer on development of video learning games for children or adults with fragile X and/or fragile X-associated Tremor Ataxia Syndrome (FXTAS).

In the area of training programs, the CEDD supports a three-year developmental behavioral pediatrics fellowship training program. The CEDD is also developing a program in developmental disabilities designed for doctoral and masters-level students in human and child development

at UC Davis and for special education, school psychology, behavioral psychology, speech, audiology and school nursing students at CSU Sacramento.

Training videos for professionals, service providers, and families are now in production on such topics as assistive technology for teachers, a primer for physicians on a condition known as 22q deletion syndrome, and an overview for parents of children with autism

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spectrum disorder on managing difficult behaviors.

Several programs help the CEDD fulfill its goal of community service, including expansion of regional health-care options for individuals with developmental disabilities. For example,

- CEDD faculty Liz Miller and Diane Baker are completing a needs assessment of barriers to quality of care in Southeast Asian communities, with the goal of improving health care for children and adults with developmental disabilities in this community.
- Miller is also leading a team of CEDD faculty to evaluate the effectiveness of using telemedicine in rural school-based clinics to provide support for children with special health-care needs in schools with limited or no school nursing support, in partnership with the Center for Health and Technology.

- CEDD funding has provided support for expanding assessment and treatment services for children with developmental disabilities, including autism spectrum disorders, fragile X syndrome, 22q deletion syndrome, ADHD, learning disorders, and other neurodevelopmental disorders.

- The Feeding Recovery Clinic, developed over the past year and led by CEDD faculty member Mary Beth Steinfeld, provides intensive feeding intervention services for children with severe feeding difficulties.

- CEDD helps basic researchers translate their findings into information for the lay public, particularly for families involved in research studies or who utilize university services.

“From my perspective in basic research, the CEDD has been an incredible resource,” says Tony J. Simon, a M.I.N.D. Institute researcher and director of the M.I.N.D. Institute’s Cognitive Analysis and Brain Imaging Laboratory.

“While developing a research program in cognitive analysis and brain imaging over the last few years, I have felt the need to provide research subjects’ families with 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 regarding the application of our research findings for families.”

Despite all the achievements in such a short amount of time, no one at CEDD is resting on their laurels – far from it.

“Our biggest challenges,” says Hansen, “are to continue to obtain additional support, grants, and contracts that will allow us to meet our goals while further developing our identity in the developmentally disabled community, in the region, and across the state.”

Sally Rogers: Leadership in autism early intervention

\$15 million Early Steps study to test intervention in the youngest children

Under the leadership of world renowned researcher Sally Rogers, the M.I.N.D. Institute has embarked on the largest and most comprehensive behavioral intervention study of children with autism ever conducted, in any age group, utilizing any method: The \$15.3 million Early Steps study.

This groundbreaking study will examine whether intervention earlier than 24 months of age is effective in reducing – or even completely circumventing – the language impairments and social deficits associated with autism. Researchers will also determine the factors that help predict whether a child will respond well to early treatment.

“There are reports that this type of intensive treatment early in life significantly improves the development of useful speech and decreases the severity of cognitive impairments in children with autism,” said Rogers, principal investigator of the study and a professor in the UC Davis Department of Psychiatry and Behavioral Sciences.

“However, most interventions are designed for older preschoolers. It’s time to find out if they work or need to be adjusted for the very young. This is especially important as we are able to diagnose autism at increasingly earlier ages,” she said.

The Early Steps study will test an intervention approach that Rogers developed with colleagues including Geraldine Dawson, a study consultant and professor emeritus at the University of Washington, and their collaborators at the University of Washington,

the M.I.N.D. Institute and the University of Colorado Health Sciences Center.

The approach, known as the Early Start Denver Model, integrates relationship-based, developmental and systematic teaching practices derived from the behavioral sciences.

“The Early Steps study will test the Early Start intervention that I and several colleagues developed that fuses approaches from three different orientations into an integrated whole, unlike any other intervention of which we are aware,” Rogers said. Those approaches include intensive teaching and developing the social-communicative skills that are so affected by autism, she said.

The Early Steps study will test an intervention approach that Rogers developed with her colleagues.

Rogers is joined in the Early Start investigation, also known as the “ACE Network Treatment Study,” by co-principal investigator Annette Estes, an assistant professor of psychiatry and co-director of the University of Washington Autism Center; and Catherine Lord, a professor of psychology and psychiatry and director of the University of Michigan Autism and Communication Disorders Center.

The model is distinguished from other approaches by the use of learning science to help children learn skills, coupled with a strong social and developmental component, according to Estes.

“The first randomized controlled trial of the Early Denver Model took place at the University of Washington with Dr. Dawson and Dr. Rogers working



Sally Rogers

together,” Estes said. “We knew it was important to continue the work because that original trial was very promising, so we’re excited that Early Steps allows us to move forward.”

The five-year Early Steps grant is funded by the National Institute of Mental Health and the National Institute of Child Health and Human Development. For the study, 108 toddlers with autism, who are under age two and living near one of the three centers, will be recruited. The children will be randomized into two groups, with one receiving the intervention intensively over 25 hours per week for two years in various settings, while the other receives interventions that are already practiced in their communities.

“We understand that social communicative development grows from emotional relatedness, so there’s an equal emphasis on relationship building and understanding communication as an emotional exchange between people,” Rogers noted. “These things are done side-by-side in the Denver model.”

“We’ll follow the development of the children over the five-year period and, based on the earlier trial, we expect to see effects in social, language, cognitive, and

(continued page 7)

Peter Mundy: Bridging the gap between autism research and classroom practice



Peter Mundy

Renowned developmental and clinical psychologist Peter Mundy takes a break from writing a unique grant proposal to ponder his experience at UC Davis since joining the faculty last January.

“Since I’ve gotten to know and work with the people at the M.I.N.D. Institute and the School of Education, I’m more excited than ever about the potential innovations and collaborations that can come from the two groups working together,” Mundy says.

In fact, innovation and collaboration well describe that grant proposal, a study of the use of virtual reality to improve training of higher-functioning children with autism. It’s designed to recreate virtual reality labs that have been developed at the University of Southern California (USC) and Stanford University that show great promise for helping older, higher-functioning children with autism learn the social and educational skills needed to improve their quality of life.

For the project, Mundy, a leading autism expert, has established a collaboration with the USC Institute for Creative Technologies and with the Virtual Human Interaction Lab at Stanford University, which studies social interactions in virtual reality. In the mix as well are groups at the M.I.N.D. Institute with expertise in social skills training and at the School of Education with expertise in learning science, all of whom are interested in uses of virtual reality technologies for these children.

It’s all in a day’s work for Mundy, who holds a joint appointment as a professor in the School of Education and as director of educational research at the M.I.N.D. Institute, the latter

position supported by the Lisa Capps Endowed Chair in Neurodevelopmental Disorders and Education.

In his dual posts, Mundy is finding new ways to accelerate the conversion of neurodevelopmental research into new curricula and teacher training by working closely with M.I.N.D. Institute neuroscience researchers and School of Education Learning and Mind Sciences faculty.

Mundy’s first few months at UC Davis have been busy indeed. In addition to his teaching duties, he is on the faculty of the new National Center for Professional

Mundy’s studies have contributed to the current understanding that joint attention impairments are indicators of the early onset of social deficits of children with autism.

Development on Autism Spectrum Disorders, for which he’s focusing on developing training for those who work with older children with higher-functioning forms of autism.

Mundy’s studies have contributed to the current understanding that joint attention impairments – that is, impairments in the ability of children to direct their visual attention to the same object or event as another person – are indicators of the early onset of social deficits of children with autism. This observation has contributed to improvements in the early identification, diagnosis and treatment of autism.

Mundy’s work on defining the nature of autism began more than 25 years ago at

the UCLA Neuropsychiatric Institute (now the Semel Institute). In recent years, he has begun to turn his attention to understanding and treating problems in the social and emotional development encountered by higher-functioning children and adolescents with autism. A standing member of the National Institutes of Health Biobehavioral and Behavioral Science Subcommittee, he has published more than 100 papers on autism, early social development and developmental psychopathology.

“We’re delighted to have Peter’s help in strengthening the bonds between the M.I.N.D. Institute and the School of Education,” says M.I.N.D. Institute Executive Director Robert Hendren of Mundy’s appointment. “At the institute, we are dedicated to learning as much as we can about neurodevelopment, and we look forward to Peter’s valuable assistance in translating that knowledge into such broad settings as clinics, medical facilities, teacher training and classrooms.”

Adds School of Education Dean Harold Levine, “Not only will Peter be instrumental at the Triumph Preschool,” the focal point of an innovative educational partnership between the M.I.N.D. Institute, the St. Hope Foundation and the School of Education “but he also will be pivotal in the development of a proposed multi-disciplinary doctoral program on developmental disorders offered jointly by the School of Education and the M.I.N.D. Institute. We are excited to have him on board.”

(continued page 7)

M.I.N.D. Institute 10th Anniversary Celebration Journey of the M.I.N.D. Gala

On Saturday, March 29, the M.I.N.D. Institute celebrated its 10th anniversary, honoring the Institute's contributions to the understanding and treatment of neurodevelopmental disorders, as well as honoring the State of California, six founding families, and other visionaries who were instrumental in creating the M.I.N.D. Institute.

The Gala was held at the M.I.N.D. Institute in a beautifully decorated tent. Over 350 guests enjoyed a cocktail reception, gourmet dinner and wines, Latin jazz by guitarist Ivan Najera, an operatic performance by the Three Waiters, an energetic auction, featuring travel and art packages and lively dance music by HipService. The evening was hosted by KCRA's Edie Lambert and Kelly Brothers. Special

guest, Secretary of Health and Human Services, Kim Belshé accepted an award on behalf of the State of California. A special ceremony honored the six founding families, the Beneto, Hayes, Gardner, Rollens, Tsakopoulos and Vismara families, for their extraordinary vision in the creation of the M.I.N.D. Institute.

Funds raised from this event will support the M.I.N.D. Institute's research on neurodevelopmental disorders. For more information on how to support the M.I.N.D. Institute, contact Terri Contenti, development officer, (916) 703-0289 or theresa.contenti@ucdmc.ucdavis.edu.



Left to right: Chairs and Board Members Nancy Brodovsky and Maria Kaufman



Left to right: Sacramento Mayor Heather Fargo, M.I.N.D. Institute Executive Director Robert Hendren, D.O., Vice Chancellor and Dean Claire Pomeroy



Left to right: Kyriakos Tsakopoulos, former California Governor Gray Davis, Kevin Johnson, Angelo Tsakopoulos

Autism Speaks "Walk Now for Autism"

On Sunday, September 28, the Sacramento community will participate in Autism Speaks "Walk Now for Autism," a fundraising walk being held in communities throughout the United States and Canada. This year's inaugural walk will begin and end at the UC Davis M.I.N.D. Institute. More than 2,500 people are expected to participate in the Sacramento event.

"We are excited about this opportunity to partner with Autism Speaks, to help raise awareness of autism and to provide a venue where the autism community can come together to support this event," said Robert Hendren, executive director of the M.I.N.D. Institute.

Walk Now for Autism is the nation's largest grassroots autism walk program. In addition to the 2.5-mile walk, the event will feature a community resources fair, with educational resources, therapists, schools, recreational organizations and creative child-friendly activities on site at the Institute.

The Sacramento fundraising goal is \$300,000. Participants form corporate teams, family and friends' teams and individual walkers may collect donations from friends, family, co-workers, and employers. Businesses and corporations may also sponsor the event. To learn more about how to participate, visit <http://www.walknowforautism.org/sacramento> for more details.

The goal of Autism Speaks is to change the future for all who struggle with autism spectrum disorders, the fastest growing developmental disorder, affecting 1 in 150 children born today. Despite the high prevalence and growing health care costs associated with caring for a child with autism, autism research receives less than 5 percent of the research funding of many other, less prevalent, childhood diseases. More children will be diagnosed with autism this year than with AIDS, diabetes and cancer combined.

2008-09 Distinguished Lecturer Series

Join us for another season of inspiration and ideas from prominent contributors to our understanding of autism and other neurodevelopmental disorders. Lectures are free, open to the public and held in the M.I.N.D. Institute auditorium.

October 8, 2008

Ann M. Graybiel, Ph.D.

Massachusetts Institute of Technology

- 4 p.m. Learning and memory mechanisms of the basal ganglia
- 6 p.m. Our habitual lives: how the brain makes and breaks habits

November 12, 2008

Eric Hollander, M.D.

Mount Sinai School of Medicine

- 4 p.m. Neuropsychopharmacology of social deficit and repetitive behavior domains in autism spectrum disorder
- 6 p.m. New developments in autism disorders

December 10, 2008

Susan E. Levy, M.D.

University of Pennsylvania and The Children's Hospital of Philadelphia

- 4 p.m. Are complementary and alternative medical treatments for children with autism evidence-based?
- 6 p.m. How do or should parents and caregivers choose treatments for children with autism?

January 14, 2009

Pat Levitt, Ph.D.

Vanderbilt University

- 4 p.m. Translational studies on the MET tyrosine kinase receptor system in the autisms
- 6 p.m. Where are we with the autisms: an update on genetics and neuroscience advances

February 11, 2009

John L.R. Rubenstein, M.D., Ph.D.

University of California, San Francisco

- 4 p.m. Patterning in the frontal cortex
- 6 p.m. Insights into developmental mechanisms that contribute to neuropsychiatric disorders

March 11, 2009

Marshalyn Yeargin-Allsopp, M.D.

National Center on Birth Defects and Developmental Disabilities, CDC

- 4 p.m. The epidemiology of autism: a global perspective
- 6 p.m. Autism spectrum disorders: perspectives on surveillance, research, and early intervention

April 8, 2009

Andrew W. Zimmerman, M.D.

Kennedy Krieger Institute

- 4 p.m. Effects of fever in autism: clues to pathogenesis and treatment
- 6 p.m. The "fever effect" and search for the Holy Grail in autism

May 13, 2009

Thomas Bourgeron, Ph.D.

Institut Pasteur

- 4 p.m. Synaptic and clock genes in autism spectrum disorders
- 6 p.m. Toward a better understanding of the genetic susceptibility to autism spectrum disorders

June 10, 2009

Adele Diamond, Ph.D.

University of British Columbia

- 4 p.m. Prefrontal Cortex and Developmental Neuropsychology: Genetic and Environmental Influences
- 6 p.m. Cognitive Control in Young Children and Ways to Improve It

For information about the Distinguished Lecturer Series and to view recordings of past lectures, visit our Web site: www.mindinstitute.org.

Sally Rogers *(from page 3)*

emotional development. We expect to see the severity of autism symptoms decrease, and development rates accelerate in those receiving the intensive interventions,” Rogers said.

National Professional Development Center on Autism Spectrum Disorders

Rogers also is leading the western hub of a new, multi-university center to promote the use of empirically tested teaching methodologies for children with autism spectrum disorders: The National Professional Development Center on Autism Spectrum Disorders.

The Center is designed to improve the delivery of educational interventions for children from preschool through adolescence. It assists selected states in helping their teachers to use evidence-based practice – approaches that have been carefully studied and whose results have been reviewed and published.

The idea for the project originated with Sam Odom, director of the Frank Porter Graham Institute at the University of North Carolina. The project is a joint effort of the Frank Porter Graham Institute and two other university centers, the Waisman Center at the University of Wisconsin, Madison and the M.I.N.D. Institute at UC Davis.

“As we began writing the grant application,” said principal investigator Odom, “we knew it would be important to build in regional sites. For the West, the M.I.N.D. Institute was the first place we thought of because of its outstanding autism spectrum disorder research and because I so respect Dr. Rogers and her colleagues.”

The Center, a five-year, \$5 million project funded by the Department of Education’s Office of Special Education

Programs, was launched last July. At its heart is the dissemination of evidence-based research through wide-ranging training programs in 12 states, four each for the three regional sites.

Rogers, who serves as the principal investigator for the western hub of the Center, said that training already has started in New Mexico, using online and in-class course work, interactive video modules and hands-on coaching in model schools. Summer institutes are now taking

place in each of the regions, including a recent institute in New Mexico. Related activities in California are also beginning.

“We’re working with those who can help children at all ages and their families,” Rogers said. “The focus isn’t solely on education – the three R’s – but also on children’s communication, social and recreation skills as well as their work habits, that is, all the factors that schools help kids master so that they can become full, contributing citizens.”

Peter Mundy *(from page 4)*

Mundy most recently served as professor of psychology at the University of Miami, where he was the founding director of the University of Miami Center for Autism and Related Disabilities and founding co-director of the Marino Autism Research Institute.

He moved from Coral Gables, Florida, to the Sacramento area in January, temporarily leaving behind his wife, Kim Fuller, who remains in Miami until their 17-year-old daughter completes her schooling this spring. Fuller serves as director of the University of Miami Psychological Services Center, a community mental health training clinic. In his spare time, Mundy is an avid hiker and who enjoys his easy access to the American River from his apartment.

The chair in the M.I.N.D. Institute is named after the late Lisa Capps, who was a rising star in the autism field before her untimely death in 2000 at the age of 36. As a graduate psychology student at UCLA, she studied emotional relatedness and communication in autism, challenging long-held views that children with autism were incapable of emotional relatedness and attachment.

Mundy was at UCLA from 1981 to 1991, holding a variety of posts on his path from postdoctoral fellow at the Neuropsychiatric Institute to associate director of the University-Affiliated Program in Developmental Disorders. That’s the same time frame during which Capps was doing her seminal work, although the two never had the opportunity to meet. “I think the fact that I was invited to hold a chair named after this esteemed colleague from the same campus is a sign that I was meant to be here,” muses Mundy.

“Although I’ve been working in research with children with autism since 1981, this has been the most stimulating six months that I’ve ever had in terms of in-depth discussions about autism and community involvement,” he adds. “The mix of neurodevelopmental and educational resources at UC Davis is unique in the country, if not the world, so this is absolutely the best place for me to be at the moment.”

Education and the M.I.N.D. Institute: Standing on solid ground



When we think of translation we generally imagine making information in one language comprehensible to speakers of another. Translation has a different meaning in academic medicine – it means moving information from research into clinical practice. Put more simply, it means placing research discoveries in the hands of caregivers and patients to improve health and well being. One way of translating research into practice is through education. That is the subject of this issue of *M.I.N.D. Matters*: The efforts currently underway to share M.I.N.D. Institute research with clinicians and caregivers, people with developmental disabilities and their families and the community.

Director of Clinical Programs Robin Hansen is spearheading one critically important effort –

the recently established M.I.N.D. Institute University Center for Excellence in Developmental Disabilities Education (CEDD). This wide-ranging endeavor will offer a direct link to M.I.N.D. Institute research through training information for professionals, service providers and families, as well as development of assistive technology, in consultation with a community advisory committee. The CEDD is an important vehicle that will help the M.I.N.D. Institute rapidly advance translating research into therapies for people with developmental disorders.

And, earlier this year, Peter Mundy joined the M.I.N.D. Institute as director of educational research. A renowned expert in education and social issues for children with high-functioning autism, Mundy will emphasize connecting the latest research on neurodevelopment and education. He will also work closely with another educational partnership, the new preschool established through a partnership of the School of Education, the M.I.N.D. Institute and St. Hope Public Schools.

This emphasis on education does not mean that the M.I.N.D. Institute is slowing the pace of its primary research mission – as recent grants to Sally Rogers in the area of early intervention and Randi and Paul Hagerman in the area of fragile X research will attest. These grants and others will continue to fuel the pace of discovery at the M.I.N.D. Institute and yield new discoveries with far-reaching implications for treatment of neurodevelopmental disabilities. They have paved the way for recruitment of key researchers in diverse but related fields who fill now every office, lab and cubicle, and promise the next wave of research discoveries.

The analogy of the three-legged stool is often used to describe academic medicine, with the three legs representing the three missions of research, patient care, and education. With these recent advances in our education efforts the M.I.N.D. Institute continues to stand on solid ground.

Robert Hendren
Executive Director

M.I.N.D. Matters

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