Mr. Chairman, on behalf of the Association of University Centers on Disabilities (AUCD), I am pleased to submit this written testimony for the record both as a means to thank you for the Committee’s support of our Centers over the past several years, and as a way of alerting you to the exciting developments happening now across the national network of University Centers for Excellence in Developmental Disabilities, Education, Research and Service (UCEDDs) and Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs. The network of UCEDDs and LENDs is a showcase for unique and effective models for gathering new knowledge in the field of developmental disabilities and applying this knowledge both nationally and internationally, as well as in our own states, to improve the lives of people with developmental and other disabilities. I am William Kiernan, PhD, Director of the Institute for Community Inclusion, the University Centers for Excellence in Developmental Disabilities at the University of Massachusetts. I am submitting this testimony in my role as President of the AUCD Board of Directors.

First, let me describe the UCEDDs, one of the member networks of AUCD. The mission of the UCEDDs is to work with people with disabilities, members of their families, state and local government agencies, and community providers through training, technical assistance, service, research, and information sharing to build the capacity of communities to sustain all their citizens.

Since the early 1960s, when Congress established a small number of research centers to study mental retardation, UCEDDs have grown into a national network of 67 Centers where each has developed its own area(s) of expertise based on the needs of the local community, state, and the evolving expectations of people with disabilities nationwide to be more included in community life. Authorized by the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402) UCEDDs currently focus on serving as a national education, service, research, and information dissemination resource for our nation. The DD Act mandates that UCEDDs promote opportunities for individuals with developmental disabilities to exercise self-determination, and be independent, productive, integrated and included in all facets of community life. The UCEDDs meet these objectives by conducting research, providing training and technical assistance, and providing exemplary evidence-based direct services and supports to people with developmental disabilities, their families, and communities. This includes state-of-the-art diagnosis and evaluation as well as support services for children and adults in a wide range of areas including health, cognitive and behavioral development, education, daily living, and employment.

Congress’s investment in this valuable and effective network has been instrumental to the inclusion of people with disabilities in American communities. AUCD urges the Congress to
provide sufficient funds to continue to take advantage of this highly efficient and productive national network to address emerging critical national needs, such as the alarming numbers of individuals diagnosed with Autism Spectrum Disorders. Nearly every UCEDD program is currently providing autism-related services to some degree, including direct services, research and evaluation, information, technical assistance, and/or interdisciplinary training of professionals. However, the potential of the UCEDD network to provide additional autism-related supports has only begun to be tapped.

We also need to address our nation's racial and ethnic health and mental health disparities as well as inequities in access to services and supports related to minority populations. It is well-documented that children and adults with developmental disabilities experience poorer health and more difficulty finding and paying for health care compared with other populations. Therefore, our network proposes to partner with Minority Serving Institutions which would increase our focus on research, education and services for African Americans, Hispanic Americans, Native Americans, Pacific Islander and Asian Americans. Each of these populations has unique cultural issues including language, customs, and traditions that must be considered as well as different levels of incidence and prevalence of diseases and disabilities that must be studied in order to better serve these populations. With assistance from existing UCEDDs, institutions of higher education that serve minority populations would be well positioned to train future leaders, conduct the necessary research and disseminate pertinent and culturally relevant information targeted to these populations.

We are respectfully seeking an appropriation of $41,000,000 under the ACF/DD program for University Centers for Excellence in Developmental Disabilities (a $4 million increase) which would allow up to four capacity-building grants of $250,000 to enable up to four UCEDDs to work in partnership with collaborating Minority Serving Institutions (as defined in the Higher Education Act) to focus on research, health, education, and services for African Americans, Hispanic Americans, Native Americans, Pacific Islanders, Asian Americans, and other ethnically and culturally diverse populations. The increase would also help UCEDDs address critical, emerging national needs, such as the growing number of individuals with Autism Spectrum Disorders and related neurodevelopmental disorders; allow the Administration on Developmental Disabilities to expand National Training Initiative grants; and provide for a cost-of-living increase to the Centers.

Now I will address the Leadership Education in Neurodevelopmental and Related Disabilities programs. LEND programs are improving the health status of infants, children and adolescents with or at risk for neurodevelopmental and related disabilities and their families. This is accomplished through the interdisciplinary training of professionals for leadership roles in the provision of health and related care, continuing education, technical assistance, research, and consultation. The LEND program focuses on the special health care needs of children with a wide range of neurodevelopmental, metabolic, and genetic disorders, including autism spectrum disorder. Currently, there are 34 LENDs in 27 states and D.C. All LEND programs operate within a university system and most have collaborative arrangements with local university hospitals, children’s hospitals, and/or health care centers. Each LEND receives core funding from the Maternal and Child Health Bureau of the Health Resources and Services Administration of the U.S. Department of Health and Human Services.
In 2006, Congress passed and the President signed the Combating Autism Act (PL 109-416) authorizing the Secretary to expand existing and develop new LENDs in states that do not have such a program. The intent of Congress was to provide autism spectrum disorder-related training in each of the existing 34 programs directed to developmental pediatricians, clinical psychologists, and other diagnosticians and interventionists. In states that do not have a LEND program, Congress intended to provide funding to establish such programs. The $5.4 million appropriated for FY 2008 as part of the Autism and Other Developmental Disorders within HRSA begins this expansion by providing funds to expand up to one-half of the existing LEND programs for this purpose and adding up to four new LEND programs in states that do not currently have one.

Therefore, we are respectfully seeking an increase in funding that is specifically set aside for LEND programs to $26,200,000 (a $2 million increase) for the LEND program within the HRSA Autism and Other Developmental Disorders program. This additional funding will enhance the capacity of up to five more of the existing LEND programs to expand their training of professionals in the interdisciplinary care and treatment of children with autism spectrum disorder and related neurodevelopmental disabilities as well as provide funds to develop up to two new LEND programs in states that do not have one. This $2 million would be part of the $42 million authorized for HRSA activities in FY 2009 under the Combating Autism Act.

As I have stated, the UCEDD and LEND networks engage in education and training at the university and community level, conduct translational and applied research, and offer services to individuals and families. Please allow me this opportunity to provide you with some examples.

**Education** – Quality of life in the community for individuals with disabilities depends upon well-trained professionals. Positioned within the university, LEND and UCEDD programs provided interdisciplinary education to professionals-in-training and provide continuing education for professionals practicing in multiple fields relating to disabilities. Whether the focus is on leadership, direct service, family centered care, advocacy, cultural competence, clinical or administrative personnel training, these pre-service and continuing education programs are geared to the needs of students, fellows, practicing professionals, and families and have been essential in raising and defining the educational standards of service across health, education, employment, and social service systems. Each year, UCEDDs and LENDs collectively provide education and training to approximately 500,000 health, education, mental health, and policy-making professionals, as well as people with disabilities and their families. UCEDDs and LENDs in communities nationwide provide this essential education and training.

*One UCEDD in Oregon houses the Center on Positive Behavioral Intervention and Support. The Center assists local schools in identifying, adapting, and sustaining effective behavioral practices, including school-wide discipline programs. Results from their replication efforts in over 400 schools nationwide indicate that their technical assistance and research has enhanced schools’ capacity to address behavioral challenges, diminish disruptions, reclaim instructional time, and enhance quality and effectiveness of instruction.*
Research – UCEDDs engage in cutting edge research on a wide variety of issues related to individuals with developmental disabilities and their families. By studying areas such as brain development, autism spectrum disorders, and early literacy, UCEDD researchers are learning how children and adults learn and how best to teach them. UCEDDs lead in developing and evaluating new ideas and promising practices that improve the lives of children and adults with disabilities and their families and increase their access to quality services. Many participate in federally established research projects on the causes and prevention of disabilities and chronic conditions. UCEDDs and LENDs also translate research into practice through the development and dissemination of informative products. The network operated 1,064 projects with a research component and produced 6,020 products in 2007.

The University Center for Excellence in Wisconsin is working to develop research to practice in the area of autism spectrum disorders. The Early Autism and Communication Research Clinic (EACRC), provides developmental, communication, and diagnostic evaluation services to children between ages 2 and 3 years old who have been diagnosed or are suspected to be on the autism spectrum and who participate in the Toddler Talk Project. The Wisconsin Center also has a project to develop a National Medical Home Initiative on Autism. The Initiative will serve as a model that demonstrates and promotes how the principles of the medical home can be applied to achieve early identification and intervention for children with ASD, with an additional benefit to show how the approach can assist in the developmental surveillance of all children, and thereby increasing the identification of children with other developmental delays.

Training – LEND programs train interdisciplinary professionals for leadership roles in the provision of health and related care, continuing education, technical assistance, research and consultation.

The UCEDD at University of Southern California (USC) at Children’s Hospital Los Angeles is developing a model training program for medical providers when counseling families of children with Down Syndrome. The UCEDD at USC has also recently developed a Planning Guide for Dental Professionals Serving Children with Special Health Care Needs. The Planning guide is available online and includes the following five sections: preparations for dental visits; oral assessment and prevention; specialized treatments techniques; indicators of quality dental care; and linking with community resources.

UCEDDS have extensive and reciprocal collaborative relationships with state agencies that work with individuals with developmental disabilities. In a 2007 survey, a substantial percentage of Centers reported having working arrangements with their state MR/DD agency to provide training and technical assistance to state employees, Part C early intervention providers, and providers of adult services in the areas of person-centered planning, positive behavioral supports, employment supports, family support, communication, and abuse/neglect. The Institute for Community Inclusion, the Massachusetts UCEDD, is supporting the State Employment Leadership Network with now 18 state MR/DD agencies belonging and working on increasing employment options for consumer that are served by those agencies in their respective states.

Service – UCEDDs and LENDs provide direct services and supports to people with developmental and other disabilities, their families, and communities. This includes state-of-the-
art diagnosis and evaluation as well as support services for children and adults in a wide range of areas including health, cognitive and behavioral development, education, daily living, and employment. Moreover, through technical assistance to other providers, they magnify the impact of their programs, reducing disparities among individuals and communities. In FY 2007, the AUCD network of centers and programs provided clinical services to 11,294 individuals and made 144,697 consults.

In Ohio, the UCEDDs and LENDs work in partnership with families living in rural counties of Ohio who encounter many barriers to accessing quality care for their children. Because most services for children with disabilities are in urban areas, families in Appalachia were traveling 100 miles to the city for multiple evaluations by individual disciplines. This resulted in a great expense in time and money for the family. The Center now sends teams of providers to rural areas to provide interdisciplinary care to families. They provide evaluation of children, training for local healthcare providers, and support for the families through a system of rural clinics. These clinics are improving access of needed services to families and providers and help local providers to better diagnose developmental disabilities such as cerebral palsy, fetal alcohol syndrome, autism and other genetic disorders.

**Responding to National Needs** – UCEDDs and LENDs are equipped to respond quickly to emerging national needs. They are currently expanding their work in the areas of aging and disability, and supports for veterans returning with disabilities. They continue to work with the federal government on policies and initiatives on emergency preparedness for people with developmental and other disabilities. Other national issues that have been addressed by UCEDDs and LENDs have included positive behavioral interventions and supports, reading disorders in children, design and dissemination of training programs for direct support personnel in developmental disabilities, and provision of training in methods to support employment for individuals with disabilities.

I again ask that you consider our request for funding of $41 million for the network of UCEDDs and $26,200,000 for the LENDs so that we may expand our network to more adequately serve our nation’s growing population of Americans with developmental and other lifelong disabilities and to address our nation’s health disparities.

Thank you for the opportunity to share this information about the UCEDDs and LEND programs. Your careful consideration of our appropriation requests is appreciated and we are happy to share more detailed information with you at your request.

Sincerely,

William E. Kiernan  
President, AUCD