



Testimony of Michael Gamel-McCormick, Ph.D.,
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Representing the

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Before the

House Appropriations
Labor, Health and Human Services, Education Subcommittee

March 18, 2009
10 a.m. – Noon
Room 1358-C Rayburn House Office Building

This testimony summarizes the activities of and provides funding recommendations for the 67 University Centers for Excellence in Developmental Disabilities (UCEDD) funded by the Administration on Developmental Disabilities (ADD) within the Department of Health and Human Services and the 38 Leadership Education in Neurodevelopmental Disabilities (LEND) Programs funded by the Maternal and Child Health Bureau (MCHB) within the Health Resources and Services Administration.

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. These programs serve and are located in every U.S. state and territory and are all part of universities or medical centers. They serve as a bridge between universities and their communities, bringing together the best of what current science has to offer to the challenges of children and adults living with disabilities in the community. By working together, programs engage in significant research that informs national policy and best practices. The network emphasizes national and international implementation of innovations in disability-related education, health care, and supports and services. It offers leadership on major social problems affecting all people with disabilities or special health needs.

I am Michael Gamel-McCormick, Ph.D., Interim Dean, College of Human Services, Education and Public Policy at the University of Delaware. 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, their families, state and local government agencies, and community providers by engaging in training, technical assistance, service, research, and information sharing to build the capacity of communities to sustain all their citizens.

Since the 1960s, when Congress established a small number of research centers to study mental retardation, UCEDDs have grown into a national network of 67 Centers, each of which has developed its own area(s) of expertise based on the needs of the local community, their state, and the evolving expectations of people with disabilities to be full members of their communities. Authorized by the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402), UCEDDs currently serve 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 to be independent, productive, integrated citizens 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. 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, and employment.

Congress's investment in this valuable and effective network has been key to expanding 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 provides autism-related services; 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. It is well documented that children and adults with developmental disabilities experience poorer health and more difficulty finding and paying for health care as compared to other populations. Our network proposes to partner with Minority Serving Institutions of higher education to better engage our research, education and service efforts for African Americans, Hispanic Americans, Native Americans, Pacific Islander and Asian Americans. Each of these populations has different levels of incidence and prevalence of diseases and disabilities that must be studied and unique cultural issues including language, customs, and traditions that must be considered in order to better serve these populations. In partnership with existing UCEDDs, Minority Serving Institutions of higher education would be well positioned to train future leaders, conduct the necessary research, and disseminate pertinent and culturally relevant information targeted to diverse populations.

We are respectfully seeking an appropriation of \$44,000,000 under the ACF/ADD program for University Centers for Excellence in Developmental Disabilities (a \$6 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 on emerging national issues; and provide for a cost-of-living increase to the Centers.

Now I will address the Leadership Education in Neurodevelopmental and Related Disabilities--or LEND--programs. LEND programs are improving the health status of infants, children, and adolescents who have 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 38 LENDs in 31 states and the District of Columbia. All LEND programs operate within a university system, many as part of a UCEDD or other larger entity, and are commonly affiliated with university hospitals, children's hospitals, or health care centers. This collaboration provides the programs with expert faculty, facilities, and other resources necessary to provide exceptional interdisciplinary training and services. 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. As a network, LENDs develop and promote best practices, produce exceptional clinicians and leaders in a variety of disciplines.

In 2006, Congress passed and the President signed the Combating Autism Act (CAA, PL 109-416) authorizing the Secretary to expand existing and develop new LENDs in states that did not have such a program. The intent of Congress was two-fold: to increase Autism Spectrum

Disorder-related training directed at developmental pediatricians, clinical psychologists, other diagnosticians, and interventionists in states with LEND programs, and to establish new LEND programs with this charge in states that did not have a LEND program. . HRSA began this expansion with the \$5.4 million appropriated in FY 2008 as part of its Autism and Other Developmental Disorders program by establishing four new LEND programs in Arkansas, Colorado, Connecticut, and Illinois and awarding 18 supplemental grants to existing LENDs to increase their Autism Spectrum Disorder-related training. The FY 2009 appropriations bill will provide \$2 million to continue this expansion by allowing competitions to establish up to two new LENDs and up to five supplemental grants for existing programs. These additional resources will increase the number of professionals who are able to identify, assess, diagnose, and serve children with Autism Spectrum Disorders and other developmental disabilities. Much more needs to be done, but the CAA has helped LEND programs begin to better address the challenge of the increased numbers of children with autism.

Therefore, we are respectfully seeking an increase in funding that is specifically set aside for the LEND program to \$28,200,000 (a \$2 million increase) within the HRSA Autism and Other Developmental Disorders program. This additional funding will enhance the capacity of up to five 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 \$47 million authorized for HRSA activities in FY 2010 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.

Training and Education – Nearly every aspect of individuals with disabilities’ quality of life can be traced back to the work of well-trained professionals—teachers, clinicians, community service providers, etc. Positioned within universities, LEND and UCEDD programs provide interdisciplinary education to professionals-in-training and provide continuing education for professionals practicing in multiple fields. 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, 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. In 2008, the network provided training to 3,560 students and fellows.

The Kansas Center for Autism Research and Training was initiated by the UCEDD in Kansas in 2008 to support research and training on the causes, nature and management of Autism Spectrum Disorders. The Center has already launched an ambitious new The Autism Training Program geared to autism specialists, respite providers, family support providers and others working with individuals with Autism Spectrum Disorders and their families. The training program also is working with the state Department of Social and Rehabilitation Services to train skilled providers for the state’s first Autism Waiver Program. With more trained providers,

Kansas families struggling with the effects of Autism Spectrum Disorders will receive services where they need them, in their own homes and communities.

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 studying how persons with disabilities learn and how best to teach them. UCEDDs lead in developing and evaluating promising practices that improve the lives of children and adults with disabilities and their families. Many are engaged in federal research projects on the causes and prevention of disabilities and chronic conditions and translate research into practice through the development and dissemination of informative products. In 2008, UCEDDs and LENDs operated 1,163 projects with a research component, including investigations into the efficacy of educational, behavioral, health, and technological interventions, policy analysis, and clinical trials.

In recent years, researchers working on neurodegenerative diseases such as Alzheimer's, Lou Gehrig's, and Parkinson's have focused on astrocytes in their quest to help the brain protect itself from stressful conditions that are deadly to neurons. By shifting a normal protective mechanism into overdrive, a scientist at the UCEDD at the University of Wisconsin-Madison has completely shielded mice from a toxic chemical that otherwise would have caused Parkinson's disease. If scientists can determine how to fix a sick astrocyte, or even prevent a carrier from getting sick, they could offer profound protection against numerous neurodegenerative diseases.

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 and support services for children and adults in a wide range of areas including health, cognitive and behavioral development, education, daily living, and employment. In 2008, the network provided clinical services to 105,388 individuals and magnified this impact with an additional 146,438 consults on promising practices and supports to other providers.

The Delaware UCEDD's Early Learning Center is a nationally accredited, comprehensive early care and education clinical research facility serving 240 children, ages 6 weeks to 12 years, and their families, and specifically targeting children with risk factors, including poverty, foster care, and disabilities. In its fourth year, the Early Learning Center expanded to provide quality early care and education program for infants and toddlers in Wilmington's Southbridge area; provided a site for observation, practicum, and research to more than 5,00 undergraduate and graduate students from six UD colleges; and conducted more than a dozen interdisciplinary research projects on such topics as language acquisition, early literacy, parental discipline, maternal depression, and healthy eating and physical activity of preschoolers. The Early Learning Center's robot-assisted mobility study has been featured in a Discovery Channel documentary and has attracted private partnership funding to help create mobility devices for children with disabilities under three years of age.

Another example of the services provided by the network is the State Employment Leadership Network, lead by the Institute for Community Inclusion, a Massachusetts UCEDD, with the state MR/DD agencies of 18 states. This multi-state initiative of the UCEDD provides technical

assistance and promotes practices and policies to increase employment options for persons with disabilities.

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 adult-acquired disabilities, particularly related to aging and military-combat, and they continue to work with the federal government on policies and initiatives to address the needs of people with disabilities in emergencies and disasters. Other national issues that have been addressed by UCEDDs and LENDs include positive behavioral interventions and supports, reading disorders in children, 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 \$44 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 LENDs. Your careful consideration of our appropriation requests is appreciated and we are happy to share more detailed information with you at your request.

Sincerely,

A handwritten signature in black ink, appearing to read "M. T. Gamel-McCormick". The signature is fluid and cursive, with the first letters of the first and last names being capitalized and prominent.

Michael Gamel-McCormick
President, AUCD