



## **Priority Disability Recommendations**

**Meeting with the Obama-Biden Transition Team  
December 16, 2008**

The Association of University Centers on Disabilities (AUCD) is a national non-profit organization representing a national network of university-based, interdisciplinary programs. AUCD members include:

- 67 University Centers for Excellence in Developmental Disabilities (UCEDD) funded through ADD
- 38 Leadership Education in Neurodevelopmental and related Disabilities (LEND) programs
- 21 Intellectual and Developmental Disabilities Research Centers (IDDRC), most of which are funded by the Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD)

AUCD members represent every state and territory in the United States. They engage in a range of interdisciplinary activities, including:

- Model program development and the provision of exemplary services for children, adults, and families
- Academic preparation at the undergraduate, graduate and post-doctoral levels
- Basic and applied research, program evaluation, and policy analysis
- Continuing education, community and professional development, and technical assistance to schools, agencies, communities, and all levels of government
- Translation of research findings into evidence based practices for parents, professionals and community providers
- Dissemination of emerging and current best practices and information resources

### **Health Care Reform**

AUCD looks forward to working with President-Elect Obama and incoming Health and Human Services Secretary Daschle on comprehensive health care reform that includes the needs of individuals with disabilities. As you move forward on health care reform, there are several key recommendations we would like to offer.

- First, over the last several decades greater emphasis has been placed on health promotion and prevention of secondary conditions associated with disability. Compared with the general population, individuals with disabilities have higher rates of obesity, lack of physical activity, smoking, diabetes, and oral disease. Other common preventable health

conditions include pressure sores, depression, poor nutrition, high blood pressure, osteoporosis, and osteoarthritis.

We urge you to increase health promotion efforts, which will not only increase functioning and participation of individuals with disabilities within society but also can produce significant health care savings over time. One cost effective approach would be to build on the existing infrastructure available in a few states to augment and **expand the State Disability and Health program within the National Center on Birth Defects and Developmental Disabilities within CDC**. Currently, 16 states are funded to implement projects. Expansion of resources to existing projects and extending the network to more states and territories with increased training and technical assistance would enhance efforts nationally and would result in improving the lives of people with disabilities.

- Second, we would like to highlight the national need for interdisciplinary training of health professionals in the area of disability. As noted in the Surgeon General's 2005 *Call to Action to Improve the Health and Wellness of Persons with Disabilities*, individuals with disabilities frequently report the need for better training of health professionals regarding the needs of individuals with disabilities, misconceptions about disability, and communication with patients with disabilities. Quality patient-provider relationships are key factors that contribute to a medical home and the provision of preventative services. The **Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs** funded through the Maternal and Child Health Bureau have provided a successful model of providing interdisciplinary, culturally competent training of health professionals providing services to children with special health care needs. Unfortunately, there are currently only 33 states that have LEND programs to conduct this critical training and there is no equivalent training for professionals providing services to adults with disabilities. Individuals with disabilities and their families frequently report continuing to see their pediatric physicians well into adulthood. Within the health care reform, we urge you to take steps to complete the LEND network by supporting a LEND program in every State, expanding LEND training to include adult health care providers, and **improve the transition of youth with disabilities from the pediatric to adult health care system and the continuing education of health care professionals in the area of disability**.
- Third, there is a need to address our nation's racial and ethnic health and mental health disparities, disparities in prevalence of disabilities, as well as disparities in access to services and support 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 is seeking resources to assist with our plan to partner with Minority Serving Institutions to focus on research, education and services for African Americans, Hispanic Americans, Native Americans, Pacific Islander and Asian Americans with disabilities. Each of these populations has unique cultural characteristics 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 understood in order to better

serve them. Institutions of higher education that serve minority populations are in a position to train future leaders, conduct the necessary research and disseminate pertinent and culturally relevant information to these populations throughout our network of Centers.

- Fourth, we urge you to also **address long-term care services and supports within health care reform**. Two key proposals that AUCD and President-Elect Obama **support are Community Choice Act and Community Living Assistance Services and Supports (CLASS) Act**.

### **Medicaid**

Medicaid is a lifeline for millions of low income children and adults with disabilities. It provides essential health and long-term services and supports. During economic downturns, states frequently make cuts in Medicaid services and supports which put individuals with disabilities at significant risk. According to a recent Center on Budget and Policy Priorities report, at least 25 states are planning cuts in medical, rehabilitative, home care, or other services. Cuts in Medicaid also result in job losses for professionals and erode the infrastructure to provide services and supports.

- **AUCD strongly supports providing at least \$40 billion over two years for a temporary FMAP increase tied with provisions requiring states to not cut eligibility or services**. In addition, **AUCD recommends that the economic stimulus package contain an additional FMAP increase in the range of \$5 to \$10 billion targeted specifically to Medicaid home and community based services and supports**. Over a two-year period, a \$5 billion dollar investment could create an estimated 122,000 new full-time jobs for direct support professionals. In addition, it would help address the needs of hundreds of thousands of individuals with developmental and other disabilities on waiting lists for services. It would help correct the institutional bias within the Medicaid program which is a long-standing goal of AUCD and a common goal of President-Elect Obama.
- Over the course of the last two years the Bush Administration has proposed or made final seven harmful Medicaid regulations that are harmful to individuals with disabilities and would worsen the economic situation facing states. **We urge the Obama Administration to act quickly to permanently rescind these harmful Medicaid regulations**.

### **Postsecondary Education**

Access to postsecondary education is vital to experiences and skills needed to participate in today's global economy. Unfortunately, individuals with disabilities face significant environmental, economic, and attitudinal barriers to postsecondary education. Moreover, until very recently doors to postsecondary education for individuals with intellectual disabilities were completely closed. Last year, President-Elect Obama supported passage of the *Higher Education Opportunity Act*. For the first time, the needs of individuals with disabilities were significantly addressed in major higher education legislation. Relevant provisions include: demonstration

projects to support postsecondary faculty, staff, and administrators in educating students with disabilities; model comprehensive transition programs for students with intellectual disabilities and a national coordinating center; programs to support improved access to materials for students with print disabilities and an appointed commission; and a national technical assistance center on disability and postsecondary education.

- **We urge you to include funding within the FY10 Presidential Budget for each of the above provisions, consistent with the Consortium for Citizens with Disabilities (CCD) funding recommendations.**
- We strongly recommend that individuals knowledgeable in the area of disability and postsecondary education are placed within the Department of Education and the Office of Postsecondary Education.

### **Autism Spectrum Disorders**

There are no widely accepted or implemented service guidelines for Autism Spectrum Disorders (ASD) and significant gaps in knowledge exist among the professionals serving these individuals. Additionally, there is a lack of trained professionals and providers to appropriately serve children and adults with autism with the latest evidence-based information and effective practices. Similarly, adults with autism face long waiting lists and many barriers in obtaining appropriate community-based supports and services to enable them to participate fully in society.

**Individuals with ASD and their families need access to accurate information about scientifically based interventions. The training of a wide range of interdisciplinary professionals also needs to be a top priority so that the findings coming out of our research institutions can be translated and made available to parents and providers across the country as quickly as possible.**

AUCD urges the Obama Administration to:

- Provide full funding for all parts of the Combating Autism Act and significantly increase funding to the NIH, CDC and HRSA Combating Autism Initiatives' budget over the next four years.
- Provide additional funding for Part C Infants and Toddlers Program and Part B of IDEA to meet the growing needs of children with ASD as early as possible.
- Require insurance coverage for ASD interventions.
- Champion legislation to increase the availability of evidence-based services and interventions for individuals with autism across the lifespan by funding direct service, information dissemination, and interdisciplinary professional development activities.

### **Research**

Investment in scientific discovery is crucial to improve the nation's health and economy in both the near- and long-term. AUCD thanks you for your strong support for science and research and for your commitment to double the funding for key science agencies, including the National Institutes of Health (NIH) over the next ten years.

- Because you understand the crucial role the life sciences play in the economic and physical health of the nation, we urge you to **include at least \$1 billion in NIH funding**

**in any immediate economic-stimulus effort, and include this funding in the base for subsequent budget years.**

Over the last four decades there has been a huge payoff in the federal investment in the Intellectual and Developmental Disabilities Research Centers funded by the National Institute for Child Health and Human Development (NICHD). Numerous disorders that cause intellectual disabilities can now be prevented or treated to improve developmental outcomes. The Centers' scientific achievements have helped improve quality of life for individuals and families affected by disabilities. Among the most exciting aspects of this work are the fundamental biological and environmental triggers for many of these disabilities that are being revealed and promises for breakthrough research on prevention and intervention strategies are close at hand.

- During the last few fiscal years critical research being conducted at **Intellectual and Developmental Disabilities Research Centers (IDDRCs)** has slowed due to cuts in the NICHD budget. Recently funded IDDRCs experienced significant budget cuts, even though they received outstanding scientific merit scores. **To address our concerns, we urge the Obama Administration to increase funding by approximately 6.6% to \$1.34 billion for the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) in the FY 09 Labor, Health and Human Services appropriations bill and support the restoration of funding to the IDDRC network.**

Research contributes to the economic strength of the nation by creating: skilled jobs in communities nationwide, new products, and improved technologies. The nation's medical schools, teaching hospitals, universities, and research institutes where much of this research takes place are among the largest employers in their respective communities. According to a June 2008 Families USA study of FY2007 federal NIH investment:

- **Every dollar of NIH funding generated more than twice as much in state economic output:** an overall investment of \$22.846 billion from NIH generated a total of \$50.537 billion in new state business.
- **NIH grants and contracts created and supported more than 350,000 jobs that generated wages in excess of \$18 billion in the 50 states.** The average wage associated with the jobs created was \$52,000.

### **The Developmental Disabilities Act**

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), last reauthorized in 2000 (PL 106-442), focuses on the needs of the nation's most vulnerable citizens, the approximately 4.5 million people with developmental disabilities. The purpose of the Act is to enable individuals with developmental disabilities to achieve *independence, productivity, integration and inclusion* into their communities. Developmental disabilities are severe, life-long disabilities attributable to mental and/or physical impairments, manifested before age 22, that result in substantial limitations in three or more areas of major life activities. The law authorizes the University Centers for Excellence in Developmental Disabilities; the Developmental Disabilities Councils; the Protection and Advocacy Systems; and the Family Support program.

- AUCD urges the Obama Administration to **support the reauthorization of the DD Act and to provide increased funding to allow the DD Network to meet the critical and emerging needs of people with disabilities.**
- Due to expanding need, limited alternative resources, and the increasing number of returning affected veterans and aging Americans, University Centers for Excellence are increasingly called upon to address the needs of individuals with disabilities from birth to old age, including developmental disabilities, autism, traumatic brain injury, mental illnesses, and physical disabilities. UCEDDs are a unique Congressionally created National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service that provides an infrastructure in each State that can serve as a conduit to address critical State and National needs in an efficient and cost-effective manner. **AUCD urges the Administration’s support to double the authorization for appropriations for the National Network of UCEDDs to realize this expanded mission of research, training, education and service for people with developmental and other complex, acquired lifelong disabilities.**
- Family supports are key to keeping families together and supporting individuals to live, work, and recreate in the community. To this end, AUCD urges you to **support Title II of the DD Act and provide a formula grant to every state so that a nationwide family support program can be realized** as envisioned by Sen. Harkin when the program was first established in 1990.
- Finally, we are very hopeful that President-elect Obama will appoint a dynamic, progressive, visionary leader as Commissioner for the Administration on Developmental Disabilities. It will be critical that the selected person values our goal of assuring that individuals with developmental and other complex disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, interdependence, participation, and inclusion in all facets of community life.

### **Conclusion**

AUCD is eager and prepared to work with the Obama Administration to implement its comprehensive and ambitious legislative and policy agenda. With Centers in every state and territory that have extensive expertise and established leadership in research, education, exemplary services, systems change and public policy, we believe that we have a national infrastructure in place that can be of significant support in implementing your disability, health, employment, early intervention, education and research agendas in an efficient and cost-effective manner. In addition, by investing in universities you will make higher education more accessible to young people, support the commitment of new young professionals to the field and increase jobs in the communities throughout the country. AUCD stands ready to work with the Obama-Biden administration to improve the lives of people with disabilities and to support its member networks to train and educate the next generation of national leaders in disability-related research, training, service delivery, and to provide technical assistance and education to the public and policymakers.