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TO: Kareem Dale, Disability Coordinator/Liaison
Sharon Lewis, Education Agency Review Team

FROM: Michael Brogioli, CEO, NACDD

RE: **NACDD Policy Concerns for President-elect Obama's Transition Team**

DATE: December 11, 2008

Thank you for inviting the National Association of Councils on Developmental Disabilities (NACDD) to the December 12 transition meeting, and for seeking our input on significant policy concerns that affect our members and constituents.

NACDD

The National Association of Councils on Developmental Disabilities is a national membership organization representing 54 State and Territorial Councils on Developmental Disabilities. NACDD is a 501(c)3 organization with the purpose of promoting and enhancing the outcomes of our member councils in developing and sustaining inclusive communities and self directed services and supports for individuals with developmental disabilities.

DEVELOPMENTAL DISABILITIES

More than five million Americans live with a developmental disability -- a severe, chronic disability that begins any time from birth through age 21 and is expected to last for a lifetime. Developmental disabilities may be cognitive, physical, or a combination of both. While not always visible, these disabilities can result in serious limitations in every day activities of life, including self-care, communication, learning, mobility, or being able to work or live independently. Developmental disabilities can occur in any family, no matter what their ethnic, economic, religious or political background.

Such disabilities are almost sure to result in a lifetime of dependence on publicly funded services, unless families receive sufficient support, children receive appropriate education, and adults receive appropriate services that enable them to live and work in their local communities.

COUNCILS ON DEVELOPMENTAL DISABILITIES

For more than thirty years, Councils have played a critical role at the State and Federal level in helping States and Territories develop, improve and expand the system of services and supports for people with developmental disabilities. Councils work to ensure that these

individuals participate fully in their communities through full integration and inclusion in the economic, political, social, cultural, religious and educational mainstream of our nation. DD Councils strive to improve the quality of supports and services for these individuals in a more family friendly manner, regardless of where they choose to live.

Councils must develop a State Plan every five years based on public input regarding the specific needs in the State. Once the needs are identified, Councils develop innovative and cost-effective ways to meet those needs. Councils can choose to work on a variety of issues that will improve the lives of individuals who have DD in areas such as quality assurance, childcare, housing, transportation, faith based programs, recreation, education, health, and employment.

KEY CONCERNS:

1. Funding and Reauthorizing the Developmental Disabilities Assistance and Bill of Rights Act (DD Act)

Last reauthorized in 2000, the DD Act focuses on the needs of our most vulnerable citizens—more than 5 million individuals with developmental disabilities. The DD Act promotes the full inclusion and participation of individuals with DD in all facts of community life. Among its major provisions, the Act authorizes funding for State Councils on Developmental Disabilities.

Unfortunately, appropriations to Councils have remained flat in recent years. The current Continuing Resolution, in effect until March, 2009, freezes funding at the FY 2008 level (\$72 million.) We hope that the Obama Administration will support funding to *at least* the authorized level of \$76 million. Furthermore, we hope the incoming Administration will support reauthorizing the DD Act at a significantly higher funding level in light of the growing number of people with developmental disabilities and the greater burdens placed on them and their families in this difficult economic climate.

Councils work on broad range of issues and initiatives, in accordance with the DD Act, including employment, education, child care, health, housing, transportation, recreation and quality assurance. Indeed, Councils are uniquely positioned to assess and address issues that affect people with DD in communities and states and have strong track records as catalysts for policy change to improve lives of people with DD and promote true inclusion: Increasing funding support now and in the years ahead is critical to Councils' success in improving systems and building capacity in the States and Territories.

2. Addressing the employment crisis among people with developmental disabilities

As mentioned, Councils work on a broad set of often overlapping policy concerns, such as Medicaid financing and delivery of services to people with developmental disabilities, access to transportation, early intervention--the precursor to education and the efforts of Councils to remedy the crisis in direct care worker recruitment and retention. These and other issues are all of high importance to our constituents. *Furthermore, community-based employment is an*

especially timely and important concern to our membership. As you know, the challenge is great, since approximately 80% of people with developmental disabilities are unemployed.

Access to training and transition to work programs, and higher education (including community as well as four-year colleges) are among the employment-related issues our Councils address in the States and Territories. NACDD promotes employment at the national level through its participation in the Collaboration to Promote Self-Determination and the Alliance for Full Participation. We are also a member of the Consortium for Citizens with Disabilities and enjoy a collaborative relationship with our DD Act "sister" agencies, the Association of University Centers on Disability and the National Disability Rights Network, as we seek solutions to the employment crisis.

We applaud the Obama Administration's pledge to effectively implement an executive order to hire an additional 100,000 federal employees with disabilities within five years, and urge that people with developmental disabilities are fully included in this effort. We hope that as the new Administration works on a major economic stimulus package, it will support strengthening the human infrastructure of the nation, including direct care workers and others who provide services and supports to people with developmental and other disabilities. Finally, though federal funding for Councils and our partner organizations remains relatively modest, these federal funds do flow with efficiency and accountability to the states and communities through grants, and in themselves represent economic stimulus and development.

3. Strengthening the position of developmental and other disabilities within the federal government and improving interagency coordination

People with developmental disabilities have historically been marginalized. As the new Administration assesses all departments, agencies and initiatives, it is critical that developmental disabilities not be "lost" in broader disability concerns. While programs and policies geared towards people with developmental disabilities can and do benefit the broader disability community, our constituents warrant extra consideration and effort given the long history of marginalization and the unique challenges they face. Indeed, the DD Act was enacted in large part because of this understanding.

NACDD is hopeful that President Obama will appoint a dynamic, progressive and visionary leader as Commissioner of the Administration on Developmental Disabilities, and that the incoming Commissioner will share the broadly-held values of community integration and full inclusion, and view Councils as partners for positive change.

Strengthening the position of, and resources for, developmental and other disabilities within the Department of Health and Human Services would be welcomed, and we hope the new Administration will increase interdepartmental collaboration to better leverage existing and new resources and initiatives. We urge the Obama Administration to designate a full-time person who is on point on disability issues within the White House Office of Domestic Policy to increase coordination.