

## **NACDD Position Statement and Policy Recommendations Long Term Services and Supports**

National caregiver studies estimate that more than 85 percent of individuals with developmental disabilities reside with and rely on their families for care. Families that care for individuals with disabilities range from young parents learning to care for children with physical and mental disabilities, to parents caring for teenagers and young adults with disabilities, to frail and elderly parents of aging, dependent adults with disabilities. Emotional, social and economic challenges accompany a family's commitment to their family member with a developmental disability. To provide sustained care for a child, a sibling, or an adult with disabilities, families need access to long term services and supports.

Long term services and support have a dual focus: to support the health and integrity of family units, and maximize the strengths and potential of individuals with disabilities to independently participate in and be included in their communities. During childhood, support services are intended to strengthen the family's role as primary caregiver and prevent institutional placement of individuals with disabilities. Throughout an individual's life span, long term services and supports are intended to strengthen and maintain family connections while fostering self-determination, independence, and participation in school, job, recreational and community settings. Adequate support services must be available to people with disabilities so that they can remain in the community rather than face inappropriate institutional placements.

**NACDD believes that individuals with disabilities should have access to opportunities and the supports needed to be included in community life, have interdependent relationships, live in homes and communities, and make contributions to their families, communities, the state, and the nation. In addition, NACDD believes the federal government should encourage the development of long-term supports and services in the home and community to serve people with developmental and other serious disabilities outside of Medicaid.**

### **Policy Recommendations for Long-Term Services and Supports in Addition to Medicaid**

- Improve protections for people with disabilities who are dual (Medicaid and Medicare) eligibles to ensure that they have timely and affordable access to all medically necessary medications under Medicare prescription drug plans;
- Expand the tax credits or tax deductions allowed to include expenses incurred for long term care supports and services for individuals with developmental disabilities who are eligible but on the wait list for Developmental Disabilities Home and Community Based Waiver Services.
- Develop a federally-led coordinated, comprehensive approach to long-term supports and services in the home and community, in addition to those under Medicaid.
- Fully implement the Community Living Assistance Services and Supports (CLASS) provisions of the Affordable Care Act so that workers can have access to affordable, long-term cash benefits while avoiding the need to impoverish themselves to qualify for Medicaid;

- Expand, modernize, and maintain national policies that provide individual services and supports that encourage individual control of services, self-sufficiency, and personal responsibility of people with developmental and other disabilities;
- Develop incentives to community-based organizations to utilize innovative technologies to enhance delivery of services and supports, such as home monitoring and communications technologies;
- Amend federal law to allow military and other federal employee pension and survivor benefits to be paid to a trust established for an individual with disabilities, to allow for the long-term support of the individual; and
- Protect and improve the ability of families and individuals to establish trusts to benefit Medicaid eligible beneficiaries and ensure the integrity of pooled trusts which serve such families and individuals.