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# NASDDDS

## **Health Care Reform: Long-Term Services and Supports for Citizens with Developmental Disabilities**

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As it becomes increasingly clear that a vigorous effort toward reforming the nation's health care system will be an important part of the policy landscape in the near future, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) seeks to ensure that health care reform efforts fully consider the needs of individuals with developmental disabilities and their families. Adults and children with developmental disabilities rely heavily on the national Medicaid program not only for physical and mental health services, but also for long-term services and supports that enable them to live and participate in their communities.

Approximately 4.5 million adults and children with developmental disabilities live in the United States. Developmental disabilities may become evident at any time from birth to 22 years of age and are expected to last throughout a person's lifetime.

Developmental disabilities are a diverse group of chronic conditions consisting of both intellectual and/or physical impairments that may affect, to varying degrees, essential life activities such as thinking, learning, problem solving, communication, mobility, self-care, work, and social interaction. Developmental disabilities may result from several factors including genetic disorders (Down syndrome and Fragile X syndrome); inadequate prenatal care (prematurity and developmental delays); maternal use of alcohol (fetal alcohol syndrome); malnutrition and neglect (delayed development); trauma and abuse (emotional and physical disabilities); environmental pollutants such as lead and mercury (epilepsy and brain impairments); and childhood accidents (traumatic brain injury). The causes of some developmental disabilities, such as autism, are not yet fully determined and require ongoing research.

It is essential, however, to think beyond diagnoses. People with developmental disabilities are citizens first: they go to school; work, pay taxes, and vote; shop in local stores; have friends; volunteer in their communities; and worship in their chosen faith. Adults and children with developmental disabilities belong to all ethnic and socio-economic groups. They are sons, daughters, brothers and sisters, aunts and uncles, our child's playmate in preschool, the woman working in our office, and the neighbor next door.

Services and supports that assist with major life activities are critical to people with developmental disabilities and their families. Well designed community-based supports and services – personal assistance, habilitation and training, employment supports, respite care,

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out-of-home day services, homemaker services – made available based on a person’s needs and adapting as they change over time, have proven to be effective in both achieving good personal outcomes and reducing the need for most costly models of service.

Long-term services and supports are not covered by private insurance. Public services are the only option for all but the wealthiest. In 2007, over 558,000 people with developmental disabilities received services totaling over \$32 billion. For this reason, broad reform of the U.S. health care system could profoundly impact the ability of individuals with developmental disabilities to access the supports and services they require in order to live productive and quality lives.

As the national health care reform discussion intensifies, policy leaders must bear in mind the significant stake that individuals with developmental disabilities hold in the outcome. As the reform agenda unfolds, the following factors must be considered to prevent individuals with developmental disabilities and their families from being left behind:

- **The ultimate outcome of supports and services should be a good everyday life in the community.** This end differs from the goal of simply reducing the need for institutional care. Health care reform efforts must presume that people with disabilities will live in their communities and so must create strategies to make life in the community successful. This aim can best be accomplished by offering a broad range of flexible, high quality, personalized supports that honor individual choice and promote involvement in the community. The supports required are not primarily medical in nature, but rather encompass a gamut of services designed to provide training and assistance in major life activities.
- **People with developmental disabilities must have control over their lives.** Service systems must honor individual preferences and offer services designed to achieve personal goals as determined by the person. Respecting the right of self-determination and promoting real choices are vital if service systems are to enable individuals to enjoy meaningful lives in their communities. Making it possible for individuals and their families to tailor services to meet their distinct needs recognizes the individual’s personal preferences and allows them to preserve their cultural heritage and family traditions. Valuing each person’s right to self-determination in the design and delivery of services will lead to greater competencies and independence and consequently, less costly services.
- **Employment is a central feature of independence and life in the community.** The majority of adults with developmental disabilities are working age. Employment not only enhances an individual’s sense of self-worth and improves his or her economic well-being, but also frequently reduces service needs and costs – sometimes dramatically. Employment provides opportunities to build relationships that allow individuals to become contributing, valued members of the community. Health care reform must eliminate barriers to employment; i.e., both providing the support services needed to

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maintain employment and removing the risk of losing eligibility to the very services needed to remain employed.

- **Families play a central role in supporting both adults and children with disabilities.** Their role and need for assistance must be factored into the design and provision of supports. Most people with developmental disabilities live with their families well into adulthood, many for their entire lives. With increasingly limited public resources and a shortage of working-age adults to provide direct service, there is a growing reliance on families for caregiving and support. Family members provide individuals with developmental disabilities with both a home and support that are critical to leading a full life in the community. To successfully provide support, family members need direct assistance such as information, counseling, training, and someone to coordinate services.

Paying family members/relatives to provide care in certain situations should be an element in any reform effort. The dwindling numbers of support providers and their occasional unreliability has compelled many states to develop policies and practice guidelines to allow payment to family members who provide support. As the population of the United States ages, the shortage of workers who provide supports will intensify. Family members will be left to struggle as they leave their jobs to support a family member with a disability.

Family members who provide support, particularly family members who are aging, may themselves have a disability and need their own support services. Policies should allow caregiving agencies to support more than one person with a disability in a household as a sensible and cost-effective strategy to avoid the need for out-of-home care.

- **Waiting Lists must be addressed.** While many people and their families receive support services in the community, many others do not. The existence of waiting lists for services is generally considered an anomaly in Medicaid, but is indeed a reality for those who need Medicaid-funded home and community-based services. Almost every state currently struggles with a waiting list with the numbers varying from a few hundred to thousands. While states ensure that those with the most desperate needs get served first, the fact still remains that hundreds of thousands of adults and children with serious needs for support are unable to access the service system. As health care reform will surely seek to address the broader issue of covering the uninsured, it should also seek to ensure that individuals currently on waiting lists for services and receiving little to no publicly funded support can access the array of services they need.
- **Services must be coordinated and managed.** Daily life presents many complications and challenges for people with developmental disabilities and their families. Simply making services available is not enough to ensure that services are accessible, that they are delivered as intended, that early signs of risk are detected and planned for, that emergency situations and crises are responded to promptly, and that services are coordinated to avoid duplication or contradictory practices. A coordinated and

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cost-effective system would provide assistance to explore and identify the types of supports that would be most helpful to the person and their family, to help them access generic services and supports in the community as well as specialized services, to assist the person through transitions in life, and to coordinate with other systems.

- **Disability-specific expertise must be retained as part of the service system.** While long-term supports can be conceptualized as a generic set of services, the needs of people who rely on those supports are not generic. A 72-year-old grandmother with dementia and a 22-year-old high school graduate with autism may both need personal assistance services, but the provision of those services will require radically different competencies. A system of life-long services and supports must have the capacity to respond to these differences.
- **Quality of services and supports are an essential feature of a service system.** Assuring health and safety are key features of quality, but quality must go beyond protecting health and safety. It must measure the effectiveness of services in achieving personal outcomes. People must be better off for having received services. Quality improvement mechanisms must be designed to ensure that supports and services maximize the achievement of desired outcomes in participants' lives based on their personal experiences as well as measured results.
- **Information technology is an essential element to both delivering services and managing quality.** Technology applications can streamline labor-intensive activities of assessing need and risks, service planning, and monitoring. Individuals and families could better direct their own services, enabling public managers to monitor utilization and cost. Collection of data on utilization, satisfaction, and personal outcomes would inform policy development and service design. Just as in acute care, investment in information technology must be a core feature of any system of long-term supports and services.

People with developmental disabilities have the capacity to contribute to the social and economic well-being of their communities and the nation. That capacity can be enhanced through providing adequate supports and services. Over the past 40 years, state developmental disability systems have designed and tested best practice models such as supported employment, person-centered planning, self-direction, and positive behavioral practices. By valuing these advances and engaging state leaders, health care reform efforts can transform past accomplishments into a better future.