

Center for Disability Rights, Inc.

CDR Policy Position: Long Term Services and Supports

Many people with disabilities and seniors want to stay in their home but cannot accomplish necessary daily tasks by themselves, such as getting out of bed or bathing, so community-based long term services, like personal care, help seniors and people with disabilities to maintain their freedom and independence at home. Forty percent of long term care spending is by Medicaid. Many people with disabilities rely on services provided through the State Medicaid program such as Home and Community-Based Waivers, which “waive” the federal mandate to provide long term care in an institution. Community-based services support people to engage in everyday life activities including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment. The Center for Disability Rights is committed to ensuring that all people with disabilities - of any age and with any disability – have the civil right to access community-based services.

Services must be provided in the most integrated setting as the norm, not the exception.

The U.S. Supreme Court established in the *Olmstead v. L.C.* decision [527 U.S. 581 (1999)] the civil right that people are entitled to receive long term care services in the “most integrated setting” appropriate to their needs, which means the setting that allows the greatest involvement and interaction with the broader community. Long term care systems tend to reinforce traditional and costly facility-based approaches, when community-based services produce both higher consumer satisfaction and more cost-effective outcomes. On average, community-based services are less costly than institutional services and provide the means for people with disabilities to participate in economic, family, and social activities.

The independent living model must be promoted over the medical model.

While people with disabilities may have complex medical needs, their lives are not confined to the medical system and should not be controlled by medical providers. Long term care has traditionally meant nursing facility care which emphasizes a medical approach to meeting needs, often involving unnecessary high cost professionals. The independent living philosophy advocates a social model of disability. It vests control of services in the consumer rather than the professional, because people with disabilities are the best experts on their own needs. Many of the services that are widely perceived as “medical” are simply a part of daily life to a person with disabilities. For example, catheter care is no more a medical need to be performed only by a registered nurse to a person with disabilities than an insulin shot is to a person with diabetes. The independent living paradigm supports an integrated life in mainstream community.

Entry, eligibility and services must be based on functional needs, not diagnosis or age.

The current system attaches specific services only to certain diagnosis. A more efficient and effective system would apply services directly to the needs of individuals – such as assistance with dressing, bathing, money management, medication administration, etc. – regardless of diagnosis. This applies

to outreach and point of entry, eligibility, and service provision. The current system is fragmented based on classifications of diagnosis and age, stemming from social and political accidents of history, and now reflects an outmoded, confusing and impractical approach to meeting very real human needs. For example, cueing and supervision assistance should be available to anyone who needs it, such as a person with Alzheimer's disease or a person with a Traumatic Brain Injury. However, the person with Alzheimer's may be denied such assistance due to lack of funding in the Alzheimer programs, while the latter receives the needed assistance through the Traumatic Brain Injury waiver. Similarly, it is a misconception that all people with the same disability have the same needs. For example, one individual with Multiple Sclerosis may have a completely different set of needs and abilities than another individual with Multiple Sclerosis. Programs based on functional need would help overcome inaccurate assumptions and address harmful service gaps.

There must be statewide consistency of services.

There are vast disparities in services offered and authorized from community to community across the state. There is little state enforcement of regulations and the counties make inconsistent decisions, sometimes directly in violation of federal and state mandates. The disparities in the system affect the information disseminated to consumers, the hours of services provided, and the programs and service options available in each community. Individuals with the same needs should be able to access the same services regardless of the county in which they reside.

Consumer directed services must be the first choice.

The traditional model of agency controlled long term care services is outmoded, expensive, and paternalistic. Nursing home care does not mean 24-hour care. Staffing limitations and large numbers of residents mean that individual residents only get a few hours of direct service per day. Consumer-directed care provided in the community gives individuals control over their own care and empowers them to get the care they need and have the direct care worker be of their choosing. Empowering consumers has proven to lead to better physical and mental health outcomes and cost savings. When people control their services, they get better care.

Housing and transportation must be addressed as essential components to the system.

One of the biggest barriers for individuals who want to transition out of an institution is the lack of accessible, affordable, integrated housing. Too often, a costly but otherwise unnecessary facility is the only form of shelter available. Without housing, transition efforts are stymied. In addition, accessible transportation is paramount to an integrated, community life. Without transportation, homes become one-person institutions. Enforcement of housing and transportation laws and regulations is essential, as well as further efforts to prioritize these critical needs as new programs are developed.

Alternatives to Medicaid managed care must be available to individuals with significant needs.

People with significant needs do not fit well into a capitated managed care system. The independent living model supports people in making their own decisions in managing their services, whereas, in contrast, traditional managed care organizations are more likely to treat people as passive participants in the provision of services, wasting money on case managers, nurses, and other expensive personnel to schedule and otherwise manage services for consumers and family members who are able to handle these tasks independently. The Consumer Directed Personal Assistance Program (CDPAP) is a unique model that allows the consumer/representative to assume responsibility for administrative and supervisory duties, and CDPAP direct care workers are permitted to perform certain health related tasks that normally require higher paid personnel. CDPAP's cost-effectiveness would be lost in a managed care system, which requires greater reliance on highly paid professional involvement. In

addition, Medicaid waivers, such as the Nursing Home Transition and Diversion waiver, currently provide services to people with disabilities to live independently in the community and these *are* capped service models. Managed care models have not proven to be able to serve people with significant needs and there must be alternative community-based programs for people to avoid unnecessary institutionalization.

Consumers must have the right to choose their service provider.

Long term services and supports, particularly personal and home care services, are both vital and intimate. It is a person's right to be able to choose who comes into their home and touches their body. To support an individual's right to choose providers requires an adequate provider capacity. This means that there must be enough service providers in each region to offer choice and the service providers must be able to serve new clients with a range of needs. In addition, there needs to be an adequate, qualified workforce that is supported by competitive wages and benefits. This issue of capacity is particularly pertinent as the senior population increases.

The system, including providers and the services delivered, must be disability-competent.

Disability-competency refers to the understanding of disability needs, culture, and communication issues. Too often, people with disabilities are viewed as incompetent and unable to direct their own services; when, in fact, people with disabilities want to be trusted to control their lives in the same manner as their nondisabled peers. Disability-competency encompasses, but is not limited to: physical accessibility of provider facilities; written materials provided in alternative formats, such as large print or Braille; knowledge of assistive technologies, such as communication devices; commitment to providing services in the most integrated setting; and the practice of empowering individuals to participate in the planning and administration of services.

The Center for Disability Rights, Inc. (CDR) is a non-profit service and advocacy organization devoted to the full integration, independence and civil rights of people of all ages with all types of disabilities.