

# **Report of the Commission on Services to Persons with Disabilities**

*In Response to NRS 439 of the 2011 Nevada Legislature*

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## *Executive Summary*

This report has been written in response to NRS 439 of the Nevada Legislature. It meets the statutory requirement for the Commission on Services for People with Disabilities (CSPD) to advise the Director of the Department of Health and Human Services in the delivery of disability services using Master Tobacco Settlement Funds (MTSF) through the Fund for a Healthy Nevada.

In response to the Commission's statutory mandate under NRS 439, this report examines the value and need for the three key services outlined in the statute: respite, independent living, and positive behavior supports. These services remain absolutely vital. **The Commission recommends to the Director that the FHN funds allocated to Nevadans with disabilities be evenly divided between Respite, Independent Living and Positive Behavior Supports.**

## *Introduction*

Senate Bill 421, passed during the 2011 Legislative Session, changed the manner in which MTSF supporting the Fund for a Healthy Nevada are distributed in Nevada. NRS439.630 requires the Nevada Commission on Service for People with Disabilities (CSPD) to submit a report to the Director of Health and Human Services, with recommendations regarding MTSF to support the needs and priorities of people with disabilities.

The statute limits the distribution of FHN dollars to three services targeted to Nevadans with disabilities, in addition to pharmaceutical subsidies:

- Programs that provide respite care or relief of informal caretakers;
- Programs that provide positive behavioral supports; and
- Programs that assist persons with disabilities to live safely and independently in their communities outside of an institutional setting.

## *Respite Services*

Respite services remain a tremendous benefit to family caregivers, care recipients, and all of those affected by disabilities and/or aging. These services also have a significant impact to the communities in which they are imbedded. Due to the impact and benefits of respite, Nevada has joined other states in the quest of making quality respite services accessible and available regardless of age, condition or location. Over the last few years, Nevada has implemented innovative ideas by utilizing data collection and technologies as well as new programs and training so Nevada's caregivers can continue their efforts in caring for their loved ones.

With Nevada's unique challenges, it has received a number of federal and state grants over the last several years, which have been used to build a solid network of services.

In addition to grants, other important respite activities have occurred in the past few years. The Nevada Lifespan Respite Care Coalition, which is a non-profit organization with volunteers, formed to represent respite stakeholders throughout the state. The coalition has plans to expand to include more family members. Goals included making respite available to all families who need it, regardless of location or condition.

## ***Positive Behavior Support Services***

The Nevada Positive Behavioral Interventions and Supports Technical Assistance Center (Nevada PBIS) is located at the University of Nevada, Reno in the Nevada Center for Excellence in Disabilities. The inaugural focus of today's Nevada PBIS was Positive Behavior Support-Nevada (PBS-NV), a project that has been delivering behavior support services to individuals with disabilities and their caregivers since 1999. In a response to the changing needs of Nevada's Aging and Disability Services Division, Nevada PBIS has developed a new training model to provide support to individuals 60 years and older with neurocognitive disorders. This project, named Positive Behavior Support-Nevada Aging Services (PBS-NV Aging), provides training and consultation to caregivers of individuals living with cognitive loss due to Alzheimer's disease and other neurodegenerative conditions.

A five series workshop-training model was developed for caregivers of individuals living with neurocognitive disorders. This workshop model allows caregivers to come together to share experiences and learn from the trainers and from each other. In contrast to support services that provide general information only and do not tailor education to the individual family's situation, PBS-NV Aging also offers individual consultation throughout the course for individualized support. In effect, PBS-NV Aging is a first step toward involving the individual living with the disease in person-centered planning. This is an important component of PBS and sets it apart from other caregiver education services. Each workshop session lasts for two hours, for a total of ten hours of group training. An additional hour of individual consultation is provided after each session, accumulating to a total of 15 hours of support per family.

## ***Independent Living Services***

The term "independent living service," unlike respite or positive behavior supports, does not describe a distinct and specific service. Independent living services can be tangible, like a wheelchair ramp or housing, or intangible like employment training. As a result, it can be difficult to quantify the aggregate impact of independent living services. The common theme among independent living services is the empowerment of people with disabilities, seniors and their families to maximize independence and minimize reliance on public services.

Independent living services and supports have become a means of empowerment for persons with disabilities, and a means of diversion from public disability services. The core values of individual sovereignty, self-reliance, and equal access have been the foundation of the Congressionally-authorized independent living program, and of service models developed and implemented throughout Nevada. Independent living services are aimed at assisting citizens with disabilities in increasing their personal independence through the elimination of physical, architectural, economic and attitudinal barriers that prevent people with disabilities from living fully integrated and productive lives.

As much as independent living services have a direct human and social impact, they have an equally significant fiscal impact by leveraging free resources from friends and family, diverting people from public services, and empowering people to work and pay taxes.

### ***Recommendations***

Respite, independent living and positive behavior support services have one vital attribute in common; they help people with disabilities and their families to help themselves. A family that gets an occasional break from care giving can continue to provide thousands of hours of valuable care at no cost to taxpayers. A wheelchair user who receives transportation or a ramp at their home can continue to work, volunteer and, more significantly, become more independent. Positive Behavior Support-Nevada Aging Services, provides training, and support to caregivers of individuals living with cognitive loss due to Alzheimer's disease and other neurodegenerative conditions.

There is an interrelationship between the services of respite, independent living, positive behavioral supports. All help reduce the care demands on caregivers who are supporting someone with disabilities or special health care needs. However, a caregiver might not be able to access respite, for example, if a behavioral challenge makes it difficult to provide care. Independent living skills might reduce some of the care needed, but that does not completely eliminate a caregiver's need for respite. Similarly, any relief to a caregiver will not be achieved if an individual's Independent Living goal to work is prevented by a behavioral issue that isn't addressed first.

**In reviewing the significance of each area and the great needs for services in each of the three areas, the Commission believes that people with disabilities in Nevada will be best served by dividing the Fund for a Healthy Nevada allocation evenly among Respite, Independent Living and Positive Behavior Supports.**

The Commission further recommends that equity be considered between North, South, and rural areas for statewide coverage when grants are awarded. In addition, special attention should be given to populations such as those who are deaf and hard of hearing, or blind or visually impaired; to ensure organizations that are awarded grants have accessible programs to serve all populations.

The Commission would welcome the opportunity to present this report and discuss our recommendations.