

Report of the Commission on Services to Persons with Disabilities

In Response to NRS 439 of the 2011 Nevada Legislature

June 2014

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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 appointed a subcommittee to study the subject and make a recommendation to the full CSPD, which was done at the CSPD's April 29 meeting. **The Commission recommends to the Director that the FHN funds allocated to Nevadans with disabilities be equally divided between Respite, Positive Behavior Supports and Independent Living.**

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.

Overview of the Commission's Information Gathering

The Commission appointed a subcommittee to study and make a recommendation to the full Commission regarding funding allocation for the FHN dollars. The subcommittee was made up of CSPD chair Brian Patchett, vice-chair Mary Bryant and member Nicole Schomberg. With the assistance of ADSD staff, the subcommittee gathered information through existing community surveys, fact sheets, strategic plans, and annual reports. The results of the Grants Management Unit needs assessment were not yet available. The details of the reviewed instruments are as follows:

GMAC Disability Services Subcommittee Score Sheets 2013 – These score sheets for the GMAC Disability Subcommittee reveals the number of programs applying for funding in each of the three categories (Respite, Independent Living, PBS), and how much finding was available. Also listed is the name and location of each, which programs were funded (and amounts) and not

funded and the scores they received. It also allowed us to see if the organization was previously funded or a new grantee hopeful.

Family Ties of Nevada Fact Sheet – Information about Nevadans living with special health care needs.

2014 State of the Nonprofit Sector Survey – Informed the committee that Nevada’s non-profit organizations list the top three community needs as strong, well-performing schools, job availability, and affordably housing. Of these NPOs, 84% believed their program/service demand would increase in 2014 and 87% indicated they would not be able to meet the demand.

Vocational Rehabilitation Employment Achievements and Link to Annual Report – Informed the committee regarding the number of people with disabilities accessing employment services from Vocational Rehabilitation and the number of successful closures from various disability groups.

ADSD Caseload Statistics - January 2014 – This document informed the committee about the great number of people with disabilities on waiting lists for services. Most notable were:

- Home & Community Based Waiver for the Frail Elderly – 247
- Homemaker – 18
- Autism Treatment Assistance – 357
- Independent Living - 337

NRS Committee Survey Results - NNRRF – Northern Nevada RAVE Family Foundation sent out a survey to families served regarding the usage of and importance of respite, independent living and positive behavior support serves. This informed the committee that while respite was the most important to these families, many of these families had used or anticipated using PBS and IL services in the future

The Case for Positive Behavior Supports in Nevada April 2014– This document, penned by Don Jackson and Ashley Greenwald, detailed the national and state needs for PBS. Explaining the current expanded models of service in Nevada and the opportunity PBS has to intervene for people currently on various wait lists (ATAP and other mental health services) was of great interest to the committee.

Nevada’s Strategic Plan for Integration of Developmental Services and Early Intervention Services into ADSD – This new plan outlines the path for ADSD to combine Early Intervention and Developmental Services into one division and includes results of a stakeholder survey about critical issues.

Lifespan Respite Program Strategic Plan 2014-2019 – This plan identifies the respite needs in the state, as well as the challenges and strategies that ADSD will use to address those challenges.

Nevada State Plan for Independent Living (SPIL) 2013 - This state plan outlines joint plans for SNCIL and NNCIL as well as other stakeholders to assist Nevadans with disabilities to live

independent lives.

The following four documents are reports that indicate the numbers of people served by SNCIL and NNCIL for Independent Living services:

RSA-704 (H132A930108) Southern Nevada Center for Independent Living (SNCIL)

RSA-704 (H132A940031) Southern Nevada Center for Independent Living (SNCIL)

RSA-704 (H132A930109) Northern Nevada Center for Independent Living (NNCIL)

RSA-704 (H132A930552) Northern Nevada Center for Independent Living (NNCIL)

Findings Related to Respite Services

According to the 2014 Lifespan Respite State Plan, 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 jointed other stated 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. Among these were:

- \$288,550 three year Lifespan Respite grant to develop a network of services, including training for caregivers and service providers, and outreach to volunteers.
- \$172,015 Lifespan Respite expansion grant to build up and expand existing services.
- \$333,425 Lifespan Respite Care Program grant to complete projects that were started including the ARDC web portal, training modules and other resources.

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. Nevada held its first Respite Summit in 2012. There were 102 participants of various stakeholders from all regions of the state. Goals were set and ADSD has assigned strategies to achieve these goals. Goals included making respite available to all families who need it, regardless of location or condition.

Findings Related to Positive Behavior Support Services

According to PBS Nevada, with more than 7% of all children displaying serious emotional and behavior problems and up to 15% of individuals with intellectual disabilities engaging in aberrant behavior, the need for behavior support services in Nevada and across the nation is high.

Behavior problems interfere with an individual's ability to learn, be self-sufficient, hold a job, have relationships and be an active member of the community. A family member or care provider's inability to effectively address the challenging behaviors often result in a high use of state resources, and in Nevada, out-of-home and out-of-state placements are increasing. There is a growing body of evidence that documents both the need for behavior support services and the effectiveness of Positive Behavior Support practices in reducing challenging behaviors, preventing the future occurrence of challenging behaviors, increasing independence, and increasing quality of life for the individual and their social support system. In the state of Nevada, where disability-specific support services have long waitlists and are often perceived as inaccessible, the Positive Behavior Support programs offer alternative resource to families and providers in need.

“Kids with disabilities represent three-quarters [75%] of children physically restrained and 58 percent of those placed in seclusion or some other form of involuntary confinement at school, the Education Department said. Such children are also more than twice as likely to receive an out-of-school suspension. What's more, federal officials found that children served under the Individuals with Disabilities Education Act account for a quarter of all students who are arrested and referred to law enforcement by schools. Meanwhile, kids with disabilities represent just 12 percent of the nation's students,” (Diament, 2014).

“Challenging behaviors such as tantrums, self-injury, and aggression are highly prevalent among children with autism spectrum and other developmental disorders (e.g., Einfeld & Tonge, 1996; Emerson et al., 2001). Serious forms of these behaviors (including those that cause harm to the person and others) are estimated to be present in 10% to 15% of this population (Lowe et al., 2007)... Problem behaviors interfere with efforts to help these individuals live more independently by disrupting educational and vocational efforts as well as home life (Fox, Vaughn, Wyatt, & Dunlap, 2002).

Findings Related to 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.

In the document review, there was much concern for the waiting lists for services that enable people to live life more independently, especially the Home & Community Based Waiver, Homemaker Services and Autism Treatment. It was thought that, in addition to PBS assisting with behavior issues for people on the waiting lists, Independent Living grantees could also assist people on the waiting list for services.

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. Having a strong statewide PBS program is crucial to continuing to build local capacity so parents, teachers and service providers can receive positive behavior support training and utilize those vital skills to continue their nurturing, despite extreme behaviors.

There is an interrelationship between the services of positive behavioral supports, respite, and independent living. 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.

During the last biennium, half of the money was awarded to Respite, with the remaining half divided between PBS and Independent Living. The timing was good to allow Respite programs to grow and an effective statewide coalition to form. With the great growth PBS has recently experienced and the growing demand for services throughout the state, there is a need for expansion in order to meet the demand and to also provide services to people waiting for more intensive services from the state. In addition, Independent Living Services comprise such a variety of services that serve many needs of people with disabilities and assist them to be productive members of our community. And like PBS, some of these independent living services assist people on the waiting lists for state services.

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 equally among Respite, Positive Behavior Supports, and Independent Living.

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.