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Testimony by Donny Loux on Behalf of the Nevada Councils on Independent Living and
Developmental Disabilities and the Nevada Forum on Disability... to the Senate
Committee on Legislative Affairs and Operations
March 11, 2003

Chairman Washington and members of the Committee

More than 375,000 Nevadans are people with disabilities. Nevada has experienced a dramatic increase in its disability rate in the past decade, currently ranking number one among states in the rate of increase in disability. Although the total disability population in the U.S. declined by 2% between 1990 and 2000, Nevada's disabled population rose by 157%.

Of those 375,000 disabled Nevadans, only about 21,000 receive Medicaid benefits. That does not mean they can afford or are able to access health care and critical services like personal assistance. For many, it just means they go without or wait, sometimes for years. More than 40,000 of these residents with disabilities are students, 2,000 of whom are exiting school each year for adult life.... 20% by dropping out.

A thirty day snapshot of 1,613 Nevada nursing home residents identified 216 with a potential for discharge within 30 to 90 days. Few, if any, will receive comprehensive assessments for the services and supports they will require to return to their community. Many will never leave because neither they nor their caregivers are even aware of the resources available to help them transition.

In assessing these and other unmet needs during development of the Strategic Plan, the Task Force and its subcommittees listed 185 barriers faced by people with disabilities in accessing the assistance and information they require. The majority of issues emerging from those identified barriers are not new.... they have been noted in study after study over the past twenty years.

Many of these same issues were again restated by our national consultant to the Plan on Olmstead issues, Tony Records. Tony also served as Olmstead consultant to the federal Office of Civil Rights. Among his findings were these:

- For many people with disabilities in Nevada, the choice to receive services in the most integrated setting does not exist;
- Community options for people with brain injury or autism are extremely limited;
- There appear to be significant Olmstead compliance issues with regard to people in Nevada nursing homes;

- There are more than 100 people with disabilities living in out of state residential programs without access to Nevada programs and families;
- There are thousands of transitional age Nevada students with disabilities who do not receive the services they need to prepare for an adult life of independence putting them at risk of future institutional placement;
- Despite the many attempts of state programs to establish information and referral systems, the lack of an effective overall information system remains a primary problem;
- Nevada's entire system of services for people with disabilities is grossly under funded.

As we reviewed Tony's findings, findings of the Task Force committees and findings of previous studies against establishment or expansion of initiatives to address those findings, there was absolute consensus that the Nevada legislature has always been at the heart of progress in disability issues.

Since 1982 legislators have guided the fate of people with disabilities and have, more often than not, been their sole recourse for access, expansion and innovation. It is safe to say that without the attention, creative proposals and intervention of legislators over the years, Nevada would be in an untenable position in complying with the disability laws and court decrees of our nation.

It was Nevada legislators who answered the pleas of people with disabilities to provide access to personal assistance for severely disabled people caught between income eligibility and ability to pay.... legislators who established Nevada's only brain injury program offering free and cost effective rehabilitation to middle income families without third party recourse.... legislators who made the telephone system accessible to deaf people even before the FCC mandate.

Legislative initiatives created supported housing in Nevada, the new Medicaid Buy-In program, assistive technology loan services, the deaf resources and blind enterprise programs. Legislative intervention assured that autistic people will receive state services to which they are entitled, that manufacturers and retailers will be responsible for defective equipment sold to people with disabilities, that homeless people with disabilities will receive therapeutic services and that new disabilities will be prevented by subsidized health care for kids, motorcycle helmet laws and donated dental services.

Eight years ago it was legislators who originated the concept of the State Office of Disability being considered in this session and who established the nation's first and only legislative subcommittee on disability with lay members. Even in those times when legislative proposals have failed to do what they set out to do, they have advanced the

disability agenda. Three sessions ago legislation was proposed to create a new Medicaid waiver for people with the most severe disabilities. The initiative did not succeed but it resulted in the first major expansion of existing waiver services to people with physical disabilities and brain injury since the inception of the program in the early 1980's.

The members of this particular Committee will be especially familiar with this history because of your individual and collective leadership in the disability arena. You are familiar with these programs because you proposed and fought for them.... with these assurances because your insistence made them happen. You have always been and continue to be the voice of people with disabilities when they have no other. You are the one constant in their struggles and often their only hope.

Now legislators have been presented a new challenge.... implementation of a comprehensive plan developed by people with disabilities, for people with disabilities. A plan designed to address their primary needs, the needs of their peers and of their families. A plan which, I might add is also the result of legislative initiative.

Paul, Bob, Mary and John Chambers, Chairman of the State Developmental Disabilities Council, will discuss the benefits of creating the Committee proposed by SB 137 in coordinating, evaluating and tracking the impacts of disability need and service. It is the hope of the groups I represent today that you will view the new oversight committee as the natural, logical outgrowth of what is now going on three decades of legislative leadership.