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Good afternoon and thank you for the opportunity to testify on behalf of establishing a legislative committee for persons with disabilities. My name is Bob Hogan. I am the Program Director for the Nevada Community Enrichment Program, the state's only non profit program for persons with brain injury and stroke. I have been in the field of rehabilitation for over twenty years, the last eleven of those in Nevada. I had the privilege of serving on the recent Disability Task Force that produced state's strategic plan. With more than one in every six Nevadans living with a disability, those on the task force felt it was surly time well spent. I would like to applaud all those who participated in that monumental effort, made possible by a forward thinking governor and several key legislators from the 2001 session. In the forward, our chairman, Brian Lehrn wrote of the plan,

“it provides the reader with a consumer validated perspective of how Nevada must ultimately build an integrated system of care”

I would like to take a moment to provide my perspective on the importance of the committee that would ultimately be charged with the coordination and oversight of this plan. There is a story that has been told about a wonderful thing that happened at a Special Olympics event in Seattle a few years ago.

There were ten young men and women, proudly representing their respective states at this meet. They were all qualifiers for the 100 yard dash. They had all won many earlier events to qualify. As the starting gun fired, each one full of adrenaline and excitement left the starting line with all their might, hoping against hope that they might be the one to cross the finish line first and capture the gold metal. One young man stumbled shortly after the start and went down hard with a cry of pain. The others, one by one, realizing what had happened, stopped racing and turned to see the fallen boy laying on the track and all began to walk back to where he lay. One girl bent down, took the boy by the arm and helping him to his feet, kissed him and said "don't worry you'll be O.K." Then the most amazing thing happened. All ten competitors, each who had come to fulfill the dream of winning a gold metal Locked arms and to the thunderous roar of the crowd walked arm in arm together to the finish line.

The strategic plan is a beautiful document, but it is only a document. It describes in detail a wonderful vision of a truly integrated system of care. Today many professionals, service providers, agencies and organizations are hoping, through this plan, to reach the same goal. However, unless someone with real authority guides the implementation and coordination of this plan and assures that we all walk together arm

in arm, many individuals with disabilities will be left behind.

For
Example

There is a 21 year old young man, who currently resides, here in Nv. in a locked mental health facility, on heavy psychotropic medications because, following his automobile wreck and subsequent brain injury, there was no mechanism to triage him into the right system.

We have committees on many important things, education, taxation, transportation, finance, natural resources and the like. Of course we should have a committee on issues concerning people with disabilities. Remember we in Nv. are rapidly approaching a population of 400,000 individuals with disabilities. Each of us, if we live long enough, will face disability at some point in our lives.

this important program
would not exist
without the legislature

We at NCEP have administered the Nevada Personal Assistance Program (PAS) for several years, Since my full time job is running our Brain Injury Program, my contact with the PAS program consumers is usually minimal. One Saturday night while my wife Jane was filling in for the PAS program manager, she got a call. Due to a sick attendant, and no back up available, there was no one to provide services to a gentleman named Richard. As luck would have it,

Richard lives only a few miles from our home, so Jane and I offered to act as fill-in's. As late evening approached and Richard was faced with the prospect of continuing to sit in his wheelchair while we tried to find an attendant, he good heartedly agreed to let us come to his home and to instruct us on his personal cares. Little did I know that I was in for one of the richest learning experiences of my life. Richard is a quadriplegic. We all know what that means, right? He has no use of his body below his neck. Richard is also a college educated marriage and family therapist with a thriving practice. In fact, he needed to get to bed, so, with a clear mind, he could see his clients the next day. Before Richard's injury, he, like most of us, held a steady job, but also like most of us, did not have the kind of insurance needed to provide personal assistance services should he require them. Because of his work history, once disabled, Richard received too much SSDI to allow him access to Medicaid. Thank God for the PAS program, aye Richard? So, here we were in Richard's home, to help him go to bed. How hard could that be? And who better to do it than us? I have worked with individuals with brain injuries for over 20 years, as has Jane for over 15. We have at least average intelligence and have graduate degrees, and there are two of us. How hard could this be? Well Bob and Jane, Thank God for Richard, aye? He patiently walked us, step by step through the

process: undressing, emptying leg bags, peri-care, hygiene, preparation, medication, transfers, positioning, water bottles, phones, blankets and on and on. More detailed than you can imagine, everything had to be done just right. If the phone was out of position he could not call 911, if the water bottle was one inch too far away he could not drink, without towels rolled and placed just so under his arms he would experience skin breakdown, and pressure sores that might lead to hospitalization. You see when we left Richard, he would be completely alone until someone from the PAS program came in the morning to help him start his day. I was especially struck by the experience of transferring Richard from his wheel chair to his bed. I have transferred hundreds of people with disabilities. How hard can this be? We got ready, I counted one ..two... three and here we go.- we didn't go. In the past, I have fought against tone and spacticity, I have had folks go left when I went right, I've had wheelchairs slide away and gait belts break. But never have I transferred an individual whose only ability to assist in any way was to verbally instruct me. I was momentarily awestruck by how totally dependent this gentleman was on my ability to do for him what he was physically unable to do for himself. We all think we know but I suspect many of us do not. The experience caused me to have a much deeper sense of how important Personal assistance can be, how

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important assistive technology can be, how important all of those things and services can be that allow people like Richard to live life, with a disability, outside of an institution. Without those services, Richard, with all of his heart and patience and education and intelligence and skills would be in a nursing home costing "the system" huge amounts of money. Instead, Richard, works, pays taxes, pays a co pay to the program that allows more individuals to be served, all while providing an invaluable service to persons with family and marital problems. Jane will be reading a statement that Richard sent her, because he could not attend today's hearing. You see, Richard would love to be here today in person, but ironically, he chose not to let down or inconvenience those people who depend on him for the help that they need. On behalf of Richard and all those who have fallen somewhere in the race to the finish line, I urge you to pass this legislation to establish a committee that provides the coordination needed to insure that we do all that we can to lift up those who can not lift up themselves.

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