

**MINUTES
of the
SECOND MEETING
of the
DISABILITIES CONCERNS SUBCOMMITTEE
of the
LEGISLATIVE HEALTH AND HUMAN SERVICES COMMITTEE**

**October 7, 2011
Albuquerque Convention Center**

The second meeting of the Disabilities Concerns Subcommittee of the Legislative Health and Human Services Committee for the 2011 interim was called to order by Representative Antonio Lujan, chair, on Friday, October 7, 2011, at 9:18 a.m. at the Albuquerque Convention Center.

Present

Rep. Antonio Lujan, Chair
Sen. Nancy Rodriguez, Vice Chair
Sen. Rod Adair

Absent

Rep. Nora Espinoza
Sen. Mary Kay Papen
Rep. Danice Picraux

Temporarily Appointed Members

Sen. Dede Feldman for Sen. Mary Kay Papen
Rep. Miguel P. Garcia for Rep. Nora Espinoza

Guest Legislator

Sen. Cisco McSorley

Staff

Michael Hely, Staff Attorney, Legislative Council Service (LCS)
Lisa Sullivan, Staff Attorney, LCS
Rebecca Griego, Records Officer, LCS
Abenicio Baldonado, Intern, LCS

Guests

The guest list is in the meeting file.

Handouts

Copies of all handouts and written testimony are in the meeting file.

Friday, October 7

Call to Order

Representative Lujan welcomed presenters, members of the subcommittee and the public to the second meeting of the Disabilities Concerns Subcommittee of the Legislative Health and Human Services Committee for the 2011 interim.

Long-Term Services: Status of Coordinated Long-Term Services; Hilltop Institute Report

Julie Weinberg, director of the Medical Assistance Division of the Human Services Department (HSD), began her presentation by distributing a handout titled "Coordination of Long Term Services Program Fall 2011". Ms. Weinberg referred subcommittee members to the statistics in her handout about the Coordination of Long-Term Services (CoLTS) program. Ms. Weinberg also discussed the CoLTS program fact sheet prepared by the Hilltop Institute (Hilltop Survey). (See handout.) Subcommittee members asked her whether the Hilltop Survey addressed payments. She was asked how many claims were rejected as "clean" claims (submitted without errors by providers) and what are the time frames for paying formerly rejected, but successfully appealed, claims. Another subcommittee member asked whether those percentages were unique to New Mexico and how these figures compare to other states. Ms. Weinberg agreed to get that information to the subcommittee.

Subcommittee members stated that they are frequently contacted by providers who are not promptly paid, particularly in the Native American community. Ms. Weinberg stated that the latter problem stems from confusion in managed-care organizations' (MCOs) claims processing systems. These problems tend to be technical issues that take a while to work out. The HSD worked on it for a year to fix it. Both CoLTS MCOs over the summer finally figured out how to get those payments out.

Subcommittee members asked how CoLTS will fit into the HSD's proposed Medicaid modernization. Ms. Weinberg said that MCOs are siloed under the current system. Modernization aims to reduce the number of silos, so it is anticipated that fewer MCOs will be selected as "health plans", as these fewer MCOs will be charged with taking care of the various programs such as CoLTS and the other waiver and non-waiver programs, including behavioral health. She stated that the separation of behavioral health from other CoLTS services was a "big issue" for CoLTS participants. Ms. Weinberg stated that the secretary of human services has said that services might be reduced, but not as a result of modernization; any cuts would be the result of mounting health care costs. Subcommittee members mentioned that providers need continued funding to continue providing necessary services.

Subcommittee members reiterated the request that the legislature review the HSD's Medicaid redesign concept paper before the 1115 waiver application is submitted. Ms. Weinberg stated that the legislature would be provided an opportunity to see the concept paper.

Gil Yildiz, executive director of the Independent Living Resource Center (ILRC), told the subcommittee that the ILRC has been providing services and advocacy for people with disabilities in 10 counties for 20 years. From an independent living perspective on the Hilltop Survey report, the ILRC believes that there are strategies in the report that can improve independent living services and encourage the state to investigate implementing those strategies, particularly the money follows the person concept. The ILRC advocates for full implementation of money follows the person. Community reintegration is not money follows the person. It is more costly to put someone in a nursing home than to allow the individual to live in the community. New Mexico has a history with this: in 2006, a money follows the person statute was passed, but the prior administration never fully implemented this state law.

Ms. Yildiz stated that the ILRC supports the Community First Choice Option set forth in the federal Patient Protection and Affordable Care Act of 2010 (ACA) to replace the Personal Care Option (PCO) program and thereby reduce disparity in income eligibility. She pointed out that this strategy is recommended in the Hilltop Survey report.

Jimmy Maldonado testified before the subcommittee about his receipt of services. He has been in a wheelchair for 27 years. The PCO program started somewhere around the year 2000, he stated. Before that, it was difficult to get help. The PCO program's appearance in 2000 changed his life. Before that, he had his large extended family help him to avoid getting bedsores. Every year for the last 10 years, he has had to fight for maintenance of the PCO hours he gets. He emphasized that he is not asking for more. He has to go in front of a hearing officer to fight to get the same number of hours. It is scary for him to think that he could end up in a nursing home. This program gives him the opportunity to be independent and be cared for out in the community. He told the subcommittee about a friend who was forced to enter a nursing facility after her PCO hours were cut from 40 hours per week to 20 hours per week. Going to a nursing home is a heartbreaking experience. Mr. Maldonado stated that he has been able to keep up his health because of the PCO and contributions to his community by coaching YAFL (Young America Football League) football.

Subcommittee members commented that if the state keeps reducing PCO hours, the medical costs (e.g., for bedsores) will be higher than just paying for PCO hours. Agreement was expressed with Mr. Maldonado's contention that putting him into a nursing home is not as beneficial as keeping him in the community in the PCO program. Subcommittee members stated that community reintegration gives first priority for already funded slots. When someone moves from a nursing home into the community, that person displaces another person on the waiver waiting list by taking up a waiver slot. The money follows the person concept is where Medicaid dollars flow to the community on PCO hours rather than using waiver dollars. One subcommittee member stated that this concept is really hard to understand. Ms. Yildiz stated that there are members of the disability community who would be happy to meet with members of the subcommittee to explain the concept.

Subcommittee members asked for more explanation about Medicaid rules that require participants to "lose everything" if they go into a nursing home. Mr. Maldonado stated that he lives in an "accessible" apartment in which, for example, the light switches are low and everything is wheelchair accessible. If he had to go into a nursing home, he would have to give up the apartment and might not have accessible housing to go back to.

His mother's house is difficult to be in, he said. Mr. Maldonado told the subcommittee that he prefers to be able to come and go as he pleases as opposed to being in a nursing home with restricted hours and restrictions on coming and going. Being in your own home and the little bit of independence that disabled individuals have would be lost, according to Mr. Maldonado. Without PCO services, people with disabilities feel that they are imposing on their friends and family when they have to ask for help. A paid PCO attendant is seen as being there for the individual and is not being imposed on; this gives the individual more control over that individual's life. He stated that he did not know where he would go if he lost those services.

Public Comment

Ellen Pinnes, consultant for the Disability Coalition, explained the money follows the person concept and the difference between it and community reintegration. In community reintegration, any slots that open up in the home- and community-based CoLTS-C (formerly disabled and elderly) waiver are reserved for people leaving nursing homes to return to the community. Only individuals leaving nursing homes can get a waiver slot, which means no one from the waiver waiting list is ever taken off the list to receive services, and the total number of people receiving waiver services does not go up. In money follows the person, a new waiver slot is created for the person leaving the nursing home, using the money that Medicaid has been paying for nursing facility care to pay for community services instead. Because any vacancies that arise in existing slots do not have to be saved for people leaving nursing homes, those vacancies can be given to people on the waiting list. By filling vacancies in this manner while adding new slots through money follows the person, the total number of people served on the waiver goes up. Ms. Pinnes stressed that the state's policy has been that ONLY individuals leaving nursing homes can get waiver slots, so the time spent on the waiting list before receiving services has essentially become infinite, as no one is ever taken off the list to receive services. She also noted that the total number of people served on the waiver has been falling because not all vacant slots have been filled.

Subcommittee members asked whether it would take more money to add people to money follows the person. Ms. Pinnes stated that it would not take any more money; the idea of money follows the person is that money the Medicaid program is already paying for nursing home care is used instead to pay for services in the community. Ms. Weinberg said that it is the HSD's position that the way integration works is not fair for individuals awaiting placement on the CoLTS-C waiver. The HSD did apply for money follows the person under the ACA, but Ms. Weinberg's office is short-staffed. The federal government says it will allow the state to implement money follows the person in addition to the waiver. Ms. Pinnes informed the subcommittee that there is an increased federal match for people who move from a nursing home

to the community through money follows the person. Ms. Weinberg also said that the grant pays for planning.

Lisa Schatz-Vance, executive director for the Senior Citizens' Law Office in Albuquerque, encouraged stakeholder participation in the money follows the person discussion. The perception in the community is that people who fall off the CoLTS-C waiver, due to death or improper transfer of a family home, are not having their vacancies filled.

Jim Jackson, Disability Rights New Mexico, stated that the policy that only people coming out of nursing homes get the slots is a state policy, not a federal policy. Therefore, the legislature has some control over that. Ms. Schatz-Vance stated that the total number of people served has dropped significantly. Mr. Jackson also addressed the design of the CoLTS program. There are still silos among the component services. Also, the eligibility requirements have not changed. He stated that many participants would lose Medicaid eligibility if they leave the nursing home to return to the community. Thus, the state has to keep people in more expensive care, i.e., nursing homes, so that people do not lose coverage because there is no mechanism to fund them for community services other than through the waiver program. This is because income eligibility is much higher for nursing home or waiver services than it is for other Medicaid programs such as the PCO. He stated his concern about Medicaid modernization because the state intends to have all Medicaid MCOs handle the full range of services for all populations, which means that MCOs with no experience working with the disabled community would manage long-term services.

Long-Term Services: Status of the Medicaid PCO

Charles Sallee, deputy director of the Legislative Finance Committee (LFC), addressed the subcommittee regarding the PCO program. He distributed LFC Report #11-04. He discussed the CoLTS program's goals (see handout). He endorsed the concept of a bill introduced in 2011 that would have required that any changes to the state's Medicaid plan, or any waiver changes, be accompanied by a fiscal impact report. The bill was passed by the legislature and pocket-vetoed by the governor. The costs of CoLTS have exploded. He explained that the state is paying a lot of money to MCOs to manage a continuum of care, but state policies do not allow an actual continuum of care. Now, there is an incentive to use lower-cost community services versus nursing homes. Many CoLTS enrollees start out not using many services as "healthy dual eligibles" (individuals enrolled in both Medicaid and Medicare). Yet, they usually graduate to using more services. Once they use even five hours of state waiver services, costs to the state balloon. Before the transition to CoLTS, the state created the PCO entitlement program. Full implementation of CoLTS has meant that in fiscal year 2010, \$800 million went to CoLTS, which is \$235.5 million, or a 40% increase, over fiscal year 2007. The HSD built in 10.5% in administrative costs for management by MCOs, assuming that would keep costs down.

The Hilltop Survey reported that community reintegration that keeps people in the community will save money, but community-based services that do not prevent eventual nursing home enrollment will not save money.

Projections from the HSD to fund the CoLTS program fluctuated wildly. For example, healthy dual eligible participants cost the state \$180 per month per individual. Meanwhile, nursing home client projections were too low, resulting in an unanticipated \$14.5 million cost.

Ms. Weinberg distributed a handout titled "The Personal Care Option Program Update" and directed the subcommittee to slide 7. She said it was the federal government that was at fault; most CoLTS-C services used are the homemaker services. Skilled workers are not used as much as the PCO-style (homemaker) services. She stated that the HSD agrees with the LFC in that the PCO program is driving a lot of the costs in CoLTS. Last year, the HSD started identifying natural supports when assessing PCO participants to try to save money when multiple PCO participants live together because chores such as cooking and laundry could be done at the same time. New budgeting does not allow for duplicative services when individuals are already receiving services from other places, such as family. They talked about efforts to reduce the number of fair hearings and thus reduce costs and the burden on members. The HSD has seen some reductions in PCO hours, mostly based on determinations of natural supports, such as when a member lives in a family where there is an able-bodied parent making meals. However, for the services that a household member would not otherwise be doing, they should be assessed as not a natural support. Ms. Weinberg stated that the HSD has no plans for regulation changes. She reported that she heard that the number of activities of daily living (ADLs) with which the average nursing home resident requires assistance is now four. The threshold to become nursing home-eligible is two ADLs. She told the subcommittee that she had heard that the nursing home occupancy rate has not changed. To her, it seems that the community is well-balanced in terms of people with long-term support needs in the community because those in nursing homes are clearly those who need more assistance than those in the community.

Ms. Pinnes distributed a handout titled "The Personal Care Option: A Vital Part of New Mexico's Long-Term Services System". In order to receive PCO services, one must be assessed as needing a nursing home level of care and be covered by Medicaid. The PCO allows people to receive services at home. It is cheaper than institutional care and improves recipients' quality of life. For those who qualify, the PCO, as an entitled program, is available without a waiting list — unlike the disabled and elderly (now CoLTS-C) waiver, whose waiting list is infinite because, pursuant to state policy, no one is taken off the waiting list to receive services. Ms. Pinnes reviewed the history of the PCO program to show that the program is not "out of control" as is often claimed. She stated that the program was poorly designed and administered in its early days. However, since changes were made in 2004, the rate of growth to the PCO program (52%) has been considerably lower than that of the Medicaid program overall (65%). Payment rates and the average cost per person have dropped dramatically. The HSD has continued to make regulatory changes that reduce the numbers of hours of PCO services received by individuals. Ms. Pinnes noted that the latest revision changes the assessment instrument in a way that reduces the number of hours of service by 30% to 40%.

Significant reductions to PCOs may run afoul of the federal Americans with Disabilities Act of 1990 (ADA), which is about allowing people with disabilities to live, as much as possible,

like people without disabilities. The Disability Coalition does not object to relying on natural supports when they are available. However, Ms. Pinnes told the subcommittee that caution is needed to ensure that the state is not pushing family members into things that they are not willing and able to perform, as that can lead to abuse and/or neglect of the person who needs services. She pointed out that families already bear a significant portion of the burden of providing long-term services, both paid and unpaid, and that this imposes financial, emotional and physical stresses that usually fall disproportionately on women.

Ms. Pinnes also distributed a handout on the Community First Choice option that she and Ms. Yildiz encourage the state to consider. This option would help to equalize income eligibility for long-term services programs. Also, because there would be an enhanced federal match, the state could serve more people in the community without increasing state expenditures. Finally, she distributed the Disability Coalition's recommendations for Medicaid redesign, which have been provided to the state's contractor, Alicia Smith.

In response to subcommittee members' questions, Ms. Weinberg said that she does not necessarily agree that the regulations will reduce PCO hours by 30% to 40%, and not everyone will suffer a reduction. She stated that the HSD is looking at household services that can be done simultaneously. She believes that pre-hearing conferences will help PCO recipients before a hearing on the reduction in hours. Ms. Weinberg stated that she does not know how people who cannot advocate on their own behalf and have no one to do it for them can do an appeal.

Public Comment

Venita Goor, peer support mentor with the San Juan Center for Independence in San Juan County, inquired why PCO hours are being decreased. When someone transitions from a nursing home to that person's own home, that person is given 38 hours, then MCOs do an assessment and decrease the hours to seven. These people will wind up back in hospitals and back in the nursing home as a result of reduction in PCO hours.

Sarah Grace, advocate and co-chair of the legislative action team for the New Vistas Independent Living Center informed the subcommittee that her group had met with Secretary of Human Services Sidonie Squier and Governor Susana Martinez. She expressed her wish that the HSD continue to support the Disability Coalition's recommendations for redesign and to continue to solicit stakeholder input throughout the process and not just at public hearings.

Yvonne Hart stated that she has helped a few people with disability fair hearings. She reported that she has a "real problem" with the assessment instrument; that it misses the mark. The level of care assessment by social workers and caregivers is a one-hour assessment not involving observation of functioning — only involving questions. Many people are unable to communicate their needs. She stated that she has a lot of experience regarding natural supports, which provides a shifting of resources, not "free" services, by family members. It is not realistic to consider them otherwise.

Penny McMallon identified herself as living with autism. She stated that when people usually think of accessibility, they think about physical impairment. As a person living with autism, she told the subcommittee that she has seizures from flickering fluorescent lights; ceiling fans, especially if they have lights, too; perfumed soap in restrooms; and screeching brakes by public buses. If employers speak too fast, she cannot understand.

Independent advocate Nat Dean stated that she had been on a waiver waiting list for seven years to receive services for traumatic brain injury. As a brain injury survivor, she really appreciates the subcommittee's hard work and the formation of the subcommittee as well as the members' willingness to serve on it.

Diane Lucero told the subcommittee that she is the mother of a disabled quadriplegic son. He has had three brain strokes and lost his vision. He has been told that he does not qualify for Medicaid because he receives Social Security Disability Insurance (SSDI), which was not his choice. He cannot receive the PCO seven days a week. He receives help three days a week through Medicare. There are people who are not getting the care they need. For the last two years, the person giving his care seven days a week has been his girlfriend. He will not go to a nursing home to qualify for the waiver. His girlfriend hurt her back last spring. He cannot get out of bed himself. He still needs help even though he gets \$708 a month through SSDI, which makes him ineligible on the basis of income for the PCO.

Lisa Rossignol, a graduate student at the University of New Mexico (UNM), identified herself as the mother of a four-year-old girl living with epilepsy. She wants her daughter to be on the developmental disabilities waiver. She was put on the CoLTS medically fragile waiver waiting list. When her daughter got to the top of the list in September 2008, the funds were then frozen. Ms. Rossignol explained that she had to walk away from a career with \$1,000 copayments a month on private insurance so that she could qualify on the basis of income for Medicaid. She asked the subcommittee to consider what would it look like to extend the Medicaid waiver portion to people on a wait list just to help with private insurance copayments.

Business Opportunities for Individuals Living with Developmental Disabilities

Nannie Sanchez stated that she wants the disabled population to be empowered and self-sufficient through creative employment opportunities. She has had her own business, assisting the movie industry, for the last three years. A subcommittee member credited Ms. Sanchez with creating the subcommittee. Rosemarie Sanchez, Nannie's mother and herself an advocate, reiterated what her daughter said about people with cognitive disabilities being the real minority. Rosemarie's and Nannie's group wants to see more people with cognitive disabilities own their own businesses. The Sanchez's are requesting legislation to serve as an incubator to five businesses, providing each with \$25,000 with a five-year loan. "There are no jobs for people with developmental disabilities", Rosemarie Sanchez stated. If they have access to the means to earn a living, these individuals will be removed from dependence.

Ruthie Marie Beckwith, Tennessee Microboards Association, Inc., has been appointed by the courts to look for employment opportunities for people coming out of the state facilities at

Los Lunas and Fort Stanton. Ms. Beckwith discussed the benefits of, and impediments to, furthering the employment opportunities of the cognitively disabled. Her favorite example of a job that can be carved out is at the airport, grabbing gray bins from the conveyor belt to free up Transportation Security Administration officers. The purpose of incubating corporations is to nurture businesses owned by people with developmental disabilities. She distributed a proposal for incubating small businesses owned by the cognitively disabled titled "New Employment Options for Individuals with Developmental Disabilities".

The subcommittee then made and passed a motion that it endorse in concept the Sanchez-Beckwith proposal.

Developmental Disabilities Self-Advocacy

James Maes, parent of a 14-year-old son living with Down syndrome, wanted to bring the subcommittee up to date. As a parent of a child with developmental disabilities, one of his greatest concerns is what will happen to children when their parents are gone and how will they be received in the community. He stated that the New Mexico Center for Self-Advocacy (CSA) at the Developmental Disabilities Planning Council provides training to individuals for coping and self-advocacy and to schools to make others more aware and tolerant of people with disabilities. It also does training modules to prevent bullying and on how to be treated as an adult and not as a child. It has been working with UNM and New Mexico Highlands University (NMHU) students, who work alongside the CSA as participants or "members".

Connie DeHerrera, director of the CSA, distributed a handout about what the CSA does. The mission of the CSA, she stated, is to support people to advocate for themselves and to create awareness in the community. She reported that CSA participants' opinions are very important. They develop the training modules and they learn from each other as they learn new skills. UNM graduate students are studying special education. They work with the members to develop PowerPoint presentations. The UNM students learn the importance of student-driven teaching. NMHU students also are learning to be special education teachers. CSA members also work with dental students, behavioral health students and insurance agents. The U.S. Army Corps of Engineers just hired someone with autism. The center will do sensitivity training. The CSA recognizes and celebrates the dignity and struggles of people with developmental disabilities. This year, the CSA conducted 168 trainings and trained 3,524 people. The CSA was invited to do training in the Northern Mariana Islands because people there with developmental disabilities were not out in the community, and they got to see the CSA's self-advocates out in the community, speaking at conferences. The CSA made a big difference. The CSA also has a sign language class and a computer literacy class. Some members have moved from group homes into the community. Many have the confidence to start post-secondary education. Some have sought employment.

Daniel Ekman identified himself as being personally and professionally involved at the CSA. He is living with autism. He began his work with the CSA as a graduate student. He stated that he had not known that advocacy was an option for anybody, including himself. He had few role models. He graduated with honors as an undergraduate and with a 4.0 grade point

average from graduate school; but he always felt like a failure, was depressed and had low self-esteem. At the CSA, he was working with people who saw his disability as part of the whole picture, not as faults to be criticized. The CSA gave everyone a support network. Mr. Ekman saw many people facing the same challenges who were successful. He has seen self-advocates improve their confidence, social skills and sense of self-worth. They experience an improvement in the opportunities they encounter.

Minutes

Minutes for the June 24 Disabilities Concerns Subcommittee meeting were approved.

Disabilities Services and the Disability Trust Fund

Jim Parker, director of the Governor's Commission on Disability, told the subcommittee that his office registered more than 1,000 people at the Southwest Conference on Disabilities at the Albuquerque Convention Center going on today. Last year, the subcommittee endorsed SB 65, sponsored by Senator Phil A. Griego, to assist in funding disabilities programs. During the 2011 regular session, the bill was tabled in the Senate Finance Committee. It would have called for a \$5.00 per vehicle add-on fee at registration. The goals of the bill would have assisted organizations throughout the state in such endeavors as the one just discussed by people from the CSA. Subcommittee members urged Mr. Parker to not give up. Subcommittee members also acknowledged John Block for his work. Mr. Parker said there are a lot of other organizations and advocates in the state for the disabled who help make a difference in how the disabled are seen as people and how legislation is pursued to help break barriers to bring that community into the greater community.

Public Comment

Liz Thompson, who is involved with the New Mexico Autism Society, thanked the subcommittee for its work.

Rachel Riboni is a stakeholder in the Mi Via self-directed waiver program. She said that HSD regulations need to be changed to ensure adequate care. She said that the UNM Hospital does not accept Evercare Health Plans and that the other medical centers from which she sought wound care similarly refused to treat her. Senator Rodriguez said she would talk to the director of Evercare.

Nancy Bearce of New Mexico Abilities just completed her second week as its chief operating officer. She said her organization is trying to employ the disabled under state contracts.

Sally Fox, who calls her organization "Equality for New Mexicans with Service Dogs/People on Medicaid", advocates equality for Medicaid recipients with service dogs. Since 2008, state regulations will not permit veterinary or grooming services for therapeutic assistance animals. She won a human rights hearing, but she has been discriminated against based on that ruling. The regulation violates the ADA, which requires equal services for disabled and

nondisabled individuals. Enrolling in the Mi Via program was a blessing. She wants an executive order or a memorial saying that the ADA must be followed in this respect.

Adjournment

There being no further business before the subcommittee, the second meeting of the Disabilities Concerns Subcommittee of the Legislative Health and Human Services Committee for the 2011 interim adjourned at 3:25 p.m.