

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

**August 30, 2010
Room 307, State Capitol
Santa Fe**

The first meeting of the Disabilities Concerns Subcommittee of the Legislative Health and Human Services Committee (LHHS) for the 2010 interim was called to order by Senator Nancy Rodriguez, chair, on Monday, August 30, 2010, at 9:15 a.m. in Room 307 of the State Capitol in Santa Fe. She announced that the meeting would be webcast (audio only) on the internet.

Present

Sen. Nancy Rodriguez, Chair
Sen. Rod Adair
Rep. Keith J. Gardner
Rep. Antonio Lujan
Sen. Gerald Ortiz y Pino (for
Sen. Mary Kay Papen)
Rep. Danice Picraux

Absent

Sen. Mary Kay Papen

Staff

Michael Hely, Staff Attorney, Legislative Council Service (LCS)
Karen Wells, Researcher, LCS
Zelda Abeita, LCS

Guests

The guest list is in the meeting file.

Handouts

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

Monday, August 30

Welcome and Introductions

Senator Rodriguez reminded committee members that the subcommittee was created pursuant to a bill that she sponsored. She recognized Nannie Sanchez and Rosemary Sanchez, who were instrumental in passage of the bill, and introduced members of the committee and staff.

Evaluation of the Developmental Disabilities (DD) Waiver Program: Report of the Legislative Finance Committee (LFC)

Pamela Galbraith, LFC program evaluator, provided background information regarding the DD waiver program report and noted that it was originally presented to the LFC in June 2010. Following that LFC presentation, the Department of Health (DOH) has taken actions that will be reported by Secretary of Health Alfredo Vigil. Ms. Galbraith provided historical background on the establishment of the DD waiver and identified appropriations from 2006 to the present. At the time the study was conducted, the DD waiver was serving 3,792 individuals, with 4,555 individuals on a waiting list. She highlighted issues and recommendations from the report. First was the issue of unsustainable funding due to a critical budget situation in the state, declining federal funding and the rising cost of services per individual. Key to this finding is a determination that the DOH lacks an adequate assessment tool to evaluate properly the needs of clients. Additionally, the DOH has poor access to real-time information. Compared to other states, New Mexico's distribution of client acuity is skewed, with New Mexico participants receiving assessments that recommend a far higher level of care and support than the levels of care and support indicated in other states. The number of individuals being added to the waiting list far outpaces allocations to the DD waiver. The LFC recommended that the DOH complete a cost-benefit analysis of the purchase of an evidence-based assessment tool, integrated information system and rate validation study. The staff at the DOH and LFC are working together to address these issues and recommendations. Ms. Galbraith noted that the report found that increased program oversight, improved cost management and benefit redesign will be necessary to maintain or expand the DD waiver. The report identified certain provider outliers whose services exceed national norms. In general, New Mexico provides therapy services to approximately 70% of its clients, while other states, on average, provide 25% of their clients with therapy services. A possible conflict of interest exists between case management agencies and service provider agencies in some situations, suggesting a need for closer surveillance of these arrangements. The LFC also recommends a closer look at the provision of support services, home modifications and goods and services, all of which have seen dramatic cost increases in recent years. Ms. Galbraith commented on the cost of the *Jackson v. Ft. Stanton* lawsuit and the work by the DOH to resolve the lawsuit. She noted that it is a complicated process. Finally, she noted that the DOH has a highly structured quality monitoring system and has received very favorable national rankings for outcome performance. Enhanced reporting to the legislature and the public could help build on positive benefits of the program.

Secretary Vigil testified that the DOH is trying very hard to increase quality and access and to resolve the *Jackson* lawsuit in the face of budget constraints. He commented that the program is dynamic, changing all the time. Realistically, the cost of the program cannot be reduced all at once, but efficiencies can be put in place that will have a positive effect over time. The DOH is making in an aggressive effort to disengage itself from the *Jackson* lawsuit and has made significant progress toward completing a settlement.

Subcommittee members had questions and made comments in the following areas:

- clarification regarding the waiver options available to potential clients;

- clarification regarding Mi Via, a self-directed waiver program that is jointly managed by the DOH and the Aging and Long-Term Services Department (ALTSD);
- clarification regarding who makes the care decisions if clients cannot make their own decisions;
- ways in which the waiting list is managed; each region has a separate waiting list that is managed on a first-come, first-served basis; this is done to ensure that rural areas have reasonable access to the waiver;
- clarification regarding the Money Follows the Person in New Mexico Act, which is an approach to ensuring access to home and community-based services that is not, in itself, a waiver program;
- whether clients are at risk of being thrown off the waiver if the cost is too high; CMS could intervene with the department, but individual clients are not at risk;
- clarification regarding family-based versus agency-based services; services are available through family-living, community-living and supported-living settings; all services are available to any client who is on the DD waiver;
- whether there is any indication of which setting is the most expensive; supported living is more expensive than independent or family living, but the figures do not include other services that a client receives;
- whether the LFC report suggests that services that are not needed are being approved in care plans; the complexity of the program makes the question difficult to answer; addressing any one component of the program would make only a small difference; multiple factors must be addressed;
- the extent to which administrative expenses and bureaucracy are factors; fragmentation and duplication do contribute to the overall cost of the program;
- clarification regarding the role of Molina Healthcare; it is contracted to develop initial care plans for clients, which plans are then intended to be approved by the client's case manager;
- clarification regarding the role of Affiliated Computer Services (ACS); ACS is the fiscal agent that processes claims for payments;
- clarification regarding the process for writing the new DD waiver, which is being written jointly by the DOH and the Human Services Department (HSD);
- clarification regarding the roles and responsibilities for resolving the *Jackson* lawsuit; an observation that the addition of a community monitor seems to have resulted in a vastly increased cost to the suit;
- an observation that the cost of the *Jackson* lawsuit is unsustainable, and the lawsuit is composed of many elements that have little or nothing to do with ensuring quality care to clients;
- a request for a list of remaining elements of the lawsuit that still require disengagement; the DOH will provide the list;
- an observation that this lawsuit has lasted for 23 years, while other states in similar situations saw resolution in an average of eight years;
- a request for monthly, detailed reporting on this topic; a list of components to be resolved can be provided monthly, the request was made for this report to be provided by the November meeting of the LHHS;

- whether people on the DD waiting list are receiving any services; Secretary Vigil indicated that the answer is yes, but these are not DD waiver services; there is a process by which a person with critical needs can get on the waiver quickly;
- recognition that some individuals on the waiting list may have dire needs of which there is no public knowledge; and
- clarification regarding the process of reporting of abuse, neglect and exploitation of individuals on a waiting list.

Nannie Sanchez and Rosemary Sanchez, advocates; Larry Maxey, director of Alegria Family Services; and Carol Romero, executive director, Advocacy Partners, LLC, made remarks regarding the DD waiver program. Nannie Sanchez testified that, as an advocate for developmentally disabled individuals, she is interested in maintaining quality of life and support for individuals to remain in the community. She fears that the DD waiver program will sustain cuts and that the DOH will require waiver recipients to live in group-home settings, which she said would be an abrogation of the recipients' freedom to live as they choose. She voiced further concerns that the rewrite of the waiver will reduce access to needed services. The DD waiver is a good program and should be maintained. She supports continued availability of community services, group services and other elements of the waiver. Although not everyone needs all services, each of the services is important for some people and helps people to remain as independent as possible.

Rosemary Sanchez expressed the concerns of many regarding anticipated cuts in the DD waiver, describing the impact should such cuts be made. She testified that the DOH is reluctant to share information and questioned the education and training of staff. Plans of care should be developed with individual needs in mind and with the assistance of service providers. She feels extensive monitoring of the program and more accountability for outcomes should be accomplished.

Mr. Maxey noted that he is the director of a small agency in Albuquerque. He shared the concerns of Ms. Galbraith regarding family living and supportive living. He believes that the state is receiving value from family-living services being provided. Of the 1,600 people receiving family services, 600 to 700 people are at the highest acuity level. He believes that the family services they are receiving save the state a significant amount of money. If these recipients did not receive family-living services, they would need residential services. He described "family living" as services provided in a small group-home setting where a caregiver, usually a parent, lives with the individual in need. Supported-living services serve a larger number of individuals, and the caregivers work on a shift basis. The services are very similar; however, family living is more cost-effective. Proposed and actual cuts disproportionately affect family-living providers. Cuts should be equitable and across the board. He identified case management as a core service. He advocates for in-state accomplishment of system monitoring rather than outsourcing such activities.

Ms. Romero identified herself as a mother and a guardian of adults who receive services from the DD waiver and whose needs are unique. She described the value of the DD waiver and

the successes each recipient has experienced due to the support services that the waiver provides. Intensive support is needed for clients who are able to live independently. She summarized her remarks by noting that clients and their families are strong advocates, and they desire a voice to be heard as the waiver is rewritten.

Subcommittee members made comments and asked questions in the following areas:

- whether any recommendations could be offered regarding the Molina and ACS contracts; both are recognized as additional administrative layers, but they may be providing necessary services; delays in payment can be significant through ACS, especially when a client is in transition from one agency to another; and
- recognition that managed care organization capitation rates over time appear to have cost the state more than \$91 million in reimbursement for services that were never rendered.

HM 56: Consolidated Caregiver Training

Secretary Vigil provided an update on HM 56, relating to consolidated training of caregivers. Jennifer Thorne-Lehman, deputy director, Developmental Disabilities Supports Division, DOH, explained that the DOH does not have the resources to create a task force as requested in the memorial, but it does work closely with experts in developing a training system for caregivers. She described the statewide system of training that the DOH conducts. The curriculum in colleges does not at this time meet the requirements of disengagement required by the *Jackson* lawsuit.

Subcommittee members had questions and comments in the following areas:

- whether the sponsor of the memorial is satisfied with the DOH contention that the DOH cannot meet the requests of the memorial; the DOH met with the sponsor and the advocate behind the memorial and answered their concerns; and
- clarification regarding the extent and nature of DOH caregiver training; the DOH has researched national trends and best practices for curricula; training is personalized and tailored to the needs of the client.

Governor's Commission on Disability (GCD) — Recommendations and Funding Issues

Jim Parker, director, GCD, testified that the GCD is requesting the establishment of a disability fund to be funded with a \$5.00 add-on to the motor vehicle registration fee. The fund could be used for a variety of purposes, including home modifications, service and support personnel, accessible rural transportation, an adaptive driving program, reasonable accommodations in employment settings, guardianships, sign language interpreters, the New Mexico Conference on Aging, the Southwest Conference on Disability, Freedom Day (to promote disability awareness), centers for independent living, the state Independent Living Council, base funding for the GCD and the New Mexico disability history project. Subcommittee members reviewed bill drafts amending sections of the Motor Vehicle Code to establish the disability fund and to implement various fees, including initial applications and applications for replacement of handicapped parking placards, that would be distributed to the disability fund. A portion of the funding would cover the administrative costs of manufacturing the placards.

Committee members had questions and made comments in the following areas:

- whether the Commission for the Deaf and the Commission for the Blind are equally treated in these requests; Mr. Parker answered that the Commission for the Blind is eligible for a federal match for which the Commission for the Deaf is not eligible;
- recognition of the importance of independent living centers; a number of these centers are beginning to enter the housing market;
- clarification regarding the GCD; it is a statutory commission;
- whether efforts have been made in the past to obtain direct appropriations to the GCD; the request for the establishment of a fund is for unmet needs that have not received appropriations through general funds or that have received only limited funds;
- clarification regarding the amount the fund would generate; Mr. Parker indicated that he expected that the fund would generate a little over \$10 million per year;
- a concern about requiring a fee for placards and the potential negative impact of the fee on those needing placards; Mr. Parker replied that the amount proposed is only \$5.00 over a four-year period and that the fee would benefit the disability community; and
- a suggestion that informational materials provide more comprehensive information about the potential uses of the funding.

The chair noted that the bill draft regarding the placard would need an opinion of the attorney general before proceeding. Senator Ortiz y Pino made a motion, seconded by Representative Lujan, for the subcommittee to endorse the bill recommendations brought to the subcommittee, to be presented to the full LHHS for consideration.

Public Comment

Anna Otero Hatanaka, executive director, Association of Developmental Disability Community Providers (ADDCP), spoke to the issue of government restructuring. She stated her opposition to consolidating the DD waiver into the HSD or the ALTSD. The waiver should remain in the DOH, Ms. Otero Hatanaka said, to ensure cooperation between all the programs that serve the DD population. Additionally, she commented that the ADDCP supports the tiering of clients based on need and that funding should be based on acuity. The ADDCP is working very closely with the DOH and the HSD to identify efficiencies and cost-cutting measures.

Disability Provisions of the Patient Protection and Affordable Care Act (PPACA)

Ms. Wells offered a presentation summarizing the provisions in the PPACA that affect or benefit the disability populations. Provisions include the Community First Choice option, a new approach to waiver services for targeted populations, the Money Follows the Person Rebalancing Demonstration and the Community Living Assistance Services and Support (CLASS) Act. She described expansions to insurance and Medicaid coverage. The PPACA contains a "sense of the senate" statement exhorting Congress to address long-term services in a comprehensive way that promotes community-based care and guarantees that disabled and elderly individuals get the care they need.

Entities Related to Disabilities in New Mexico State Government

Mr. Hely reviewed state agencies and agency subdivisions that house various activities and services related to disabilities. These agencies include the Department of Finance and Administration, the HSD, the DOH, the Veterans' Services Department, the ALTSD, the Children, Youth and Families Department, the Public Education Department and the Higher Education Department. Additionally, the Interagency Behavioral Health Purchasing Collaborative and the Interagency Committee on Long-Term Care are statutory entities with responsibilities to address disabilities. Numerous commissions, boards and councils address disabilities, and various state educational institutions target persons with disabilities. Areas of overlapping responsibilities and functions were highlighted. Business support for disabilities was identified. Mr. Hely focused briefly on agencies and programs that specifically provide employment services, health and home care and business support services to persons with disabilities. Finally, he described the transportation services and housing and support services by which the state provides support to persons with disabilities.

Committee members sought clarification regarding the New Mexico Council on Purchasing from Persons with Disabilities. Attorney Marina Cordova, Cordova Law Firm, stated that the council provides first right of refusal to persons with disabilities seeking contracts with the state. No further discussion occurred; the committee members stated a preference to discuss restructuring with the full LHHS.

Public Comment

Deborah Dennison, an advocate for the New Vistas program, testified about transitional services that assist a person to leave a nursing home and be reintegrated into the community. There is an inadequate number of community services to meet the needs of people who transition in this way. She contends that the Money Follows the Person in New Mexico Act, which would make a wider array of services available in the community, is not being followed.

A request was made that additional testimony regarding the Mi Via program be presented to the full LHHS. Ms. Dennison provided personal testimony regarding emergency placement of her son on the DD waiver. She told the committee that her son "fell through the cracks" due to a discrepancy between state and federal regulations regarding emergency placements.

Ken Cable of La Vida Felicidad in Albuquerque stated that the DD waiver program generates money for the state due to the federal match and, with the multiplier effect, actually serves as an economic engine for the state. He further noted that 9.5% of all the clients on the developmental disabilities waiver consume 65% of the developmental disability resources. It costs less to have clients in family living than in independent living.

Doris Husted, a parent and guardian of an adult daughter with developmental disabilities and the public policy director for the ARC of New Mexico, stated that family-based services, though critical for some, are not appropriate for everyone. The state needs to conduct an accurate assessment of need and make an appropriate allocation of resources for all levels of need.

Ms. Cordova contended that the DOH is violating the federal Medicaid Act by not giving public notice of changes in reimbursement and rates. She has had numerous clients express concern about this. She also believes that the DOH is violating a requirement for a public process regarding the rewriting of the DD waiver.

Bernard and Lorraine McArdle presented themselves as a successful family-living unit. They are fearful for the life of their son, Bernard, Jr., should anything happen to them. They believe that it has been demonstrated that group homes do not support independence or safety for clients. Their son has been to New York and the Grand Canyon, has ridden on a motorcycle, has held a job and, in general, has thrived in the home environment. Mr. and Ms. McArdle expressed the opinion that the DOH is unresponsive to the needs of family caregivers like them. They voiced concern that the DOH is trying to promote the group home model of care.

A question was asked about whether a person with cerebral palsy is generally cared for in a group home. Ms. Husted answered that a group home is the most common environment for such a person if a family environment is unavailable.

A subcommittee member asked that the subcommittee take note of the lack of responsiveness of the DOH and report back to the full LHHS.

Marie Garcia introduced Valerie, a person with a developmental disability. Ms. Garcia is a surrogate provider. She is concerned that small providers are being closed down due to poor payment practices, and she contends that the Mi Via program is out of control. Some providers have gone without pay for three months. Small family-based providers are contracted to an agency; when that agency closes down, the small provider is left without income. If more clients could be taken out of a group home and cared for by a family-based provider, the state would save money and the clients would gain a home. Mr. Cable added that the attorney general closed the agency being described due to alleged Medicaid fraud and that money is being held in the Attorney General's Office pending further litigation. The subcontractors were given no notice, and many lost at least a month's pay.

The chair assured all those making public comment that their concerns would be examined further.

There being no further business, the subcommittee was adjourned at 4:10 p.m.