

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

**June 24, 2011
Room 322, State Capitol**

The first 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, June 24, 2011, at 10:35 a.m. at the State Capitol in Santa Fe.

Present

Rep. Antonio Lujan, Chair
Sen. Nancy Rodriguez, Vice Chair
Rep. Nora Espinoza
Sen. Mary Kay Papen
Rep. Danice Picraux

Absent

Sen. Rod Adair

Guest Legislators

Sen. Dede Feldman
Sen. Gerald Ortiz y Pino

Staff

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

Guests

The guest list is in the meeting file.

Handouts

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

Friday, June 24

Call to Order

Representative Lujan asked Mr. Hely to read a June 1, 2011 letter (see attached), submitted by Nannie and Rosemarie Sanchez, but containing no signature, regarding the state's developmental disabilities waiver (DDW). The unnamed parties to the letter: (1) praised the legislature for supporting the DDW; (2) urged transparency and input into the DDW renewal process; (3) raised concerns about the collaborative-consultive model of delivering therapeutic services; (4) suggested that clients and caregivers have greater control over individual budgets;

(5) asked the Department of Health (DOH) to provide information about how the DOH support intensity scale (SIS) would affect benefit levels and to provide clients with due process guaranties; and (6) recommended that the DOH conduct audits on standards and quality of care.

New Mexico DDW Overview and Proposed Changes

Cathy Stevenson, deputy director, Developmental Disabilities Supports Division (DDSD), DOH, explained that administration of the DDW program is shared by the DOH and the Human Services Department (HSD) under a joint powers agreement. The DDSD acts as the general manager for the program.

Bob Beardsley, deputy director, Medical Assistance Division (MAD), HSD, explained that people in the DDW program, in contrast to those in the other Medicaid waiver programs, need assistance with two or more activities of daily living. Mr. Beardsley presented: (1) a general overview of the state DDW; and (2) an overview of proposed changes to the state DDW program. In the general overview, Mr. Beardsley touched upon the history, services, medical and financial eligibility requirements and enrollment and expenditures figures for and administration of the DDW program. In the overview of proposed changes to the DDW program, Mr. Beardsley discussed the proposed changes.

Subcommittee members expressed concerns that there have been no public hearings on the proposed changes to the DDW program. Ms. Stevenson replied that there was no procedure or authority for public hearings, and Mr. Beardsley added that there will be public hearings on proposed regulations after the HSD publishes the proposed regulations for the DDW renewal.

DDW Renewal

Ms. Stevenson stated that the current DDW expires on June 30, 2011. Ms. Stevenson said that an explanation of the specifics of the renewal application would take two hours.

DDW Program Costs

Ms. Stevenson stated that the DDW program currently costs an average of \$78,000 per person per year. Last year, the DDW program cost \$288 million, of which the state pays one-third (about \$96 million), while the federal government pays the rest. She asserted that the DDW program needs to be restructured: (1) to achieve cost neutrality; and (2) to include more people from the waiting list. Achieving either or both of those goals requires cost reductions.

Ms. Stevenson listed several cost-reduction measures to be implemented, including: (1) streamlined administration of the DDW program; (2) more accurate assessment tools; (3) tying budget amounts to established need; (4) identifying resources beyond waiver funding; (5) promoting the DDW program members' self-sufficiency and community inclusion; and (6) structuring paid services to supplement other sources of support.

Needs and Costs Assessments

Ms. Stevenson stated that the assumption is that one-fourth of the people on the waiver are receiving more DDW services than they need. Subcommittee members asked whether that

assumption was based on the perception that faulty assessments were performed or that DDW enrollees lied about their needs. Ms. Stevenson responded that the assessment system is "broken". In response to the subcommittee's request for a clarification, Ms. Stevenson stated that maybe the assessments were not faulty but that maybe New Mexico has more DDW enrollees than other states do.

SIS Assessments

Ms. Stevenson stated that the DOH and HSD already have begun studying ways to change the DDW program to reduce costs. The first method of study is a pilot project in which 500 adults currently are being assessed, through 2011, on an SIS. Ms. Stevenson stated that, in contrast to traditional assessments that measure developmental disabilities by the skills that individuals lack, the SIS assessments: (1) measure the DDW member's support needs in the areas of home living, community living, lifelong learning, employment, health, safety and social activities; (2) examine how DDW members protect and advocate for themselves; and (3) determine the nature and extent of extra support needed to deal with DDW members' medical and behavioral needs. The SIS assessments will be performed by a third party — the National Association of State Directors of Developmental Disabilities Services. The pilot program will be used to determine if the SIS may be used to assess the needs of all adults in the DDW program.

Service Rates Changes

The second method of study matches assessed service needs to service rates. This rate study is being conducted by the Human Services Research Institute through subcontractor Peter Burns and Associates. In response to the subcommittee's request, Ms. Stevenson stated that she would arrange for the contract with the institute and Peter Burns and Associates to be posted on the HSD's web site.

Ms. Stevenson identified the following DDW program goals to be completed in 2011:

1. work with the federal Centers for Medicare and Medicaid Services to have the DDW renewal application approved by July 1, 2011;
2. complete the SIS pilot project;
3. start assessing the remaining DDW program enrollees with the SIS;
4. use the information from the SIS assessments to establish a baseline and to develop a prototype for budget methodology;
5. complete work to finalize rates to be used after the DDW is renewed;
6. use the rates and SIS assessment data to finalize a resource allocation model; and
7. transition DDW program enrollees to the restructured DDW program.

Reduction of Therapy Time and Levels of Care

Additional cost-saving measures will include reducing the amount of time that therapists spend with each enrollee and reducing the total amount of therapy allowed per year.

DDW Program Waiting List

Ms. Stevenson said that there are more than 5,000 people on the waiting list who qualify for the DDW program. In response to a question about whether the DDW wait list categorizes

persons based on severity of need for purposes of enrolling people in the DDW program based on severity of need, Ms. Stevenson explained that there are no categories of need and that the federal district court's decision in *Lewis v. New Mexico Department of Health*, 275 F. Supp. 2d 1319 (2003) requires the DOH and HSD to admit applicants to the DDW program according to the oldest date of application and certain exigent circumstances having nothing to do with the severity of the developmental disabilities of the applicant.

In contrast, Oregon is able to enroll all qualified applicants in its DDW program, resulting in no waiting list, but each enrollee receives less services than would be received in New Mexico, according to Ms. Stevenson.

Communication and Review

In response to subcommittee concerns, Ms. Stevenson agreed to share with the subcommittee, as well as an independent reviewer, the data being collected and the results of the pilot project.

Public Comments

Gregory Bundrick, a behavioral health consultant, is concerned that SIS assessments may not be performed in a way that is sensitive to New Mexicans' culture or specific care needs.

Albert Montoya, executive director of the Ability Center, hopes to see a reduction of the waiting list and improvement in the services provided.

Peter Cubra, plaintiffs' counsel in the *Jackson v. Los Lunas Center for Persons with Developmental Disabilities* case, hopes to see more service providers, not fewer, such as more nurses, more case managers and more health care coordination for people with complex medical needs, to avoid preventable deaths.

Robert Sterns's son is in the DDW program, and he wanted to thank the subcommittee for its continuing support of the program and to express his happiness with the services received.

Fritzy Hardy, whose daughter is in the DDW program, agreed that the system needs to be changed, but cautioned, "don't drop lives".

Nannie Sanchez, who is in the DDW program, informed the subcommittee about a group called "Family Providers" that meets every Monday to discuss DDW issues.

Rosemarie Sanchez, mother of Nannie Sanchez, suggested that the DOH conduct annual audits on service providers, many of whom, she believes, fail to provide adequate services.

Mary Sciumbato's son is on the Mi Via waiver, which costs \$12,000 per year less than the DDW program. She is concerned about the renewal application for enrollees, which is confusing and was sent out with very little turnaround time. She also requested at least two weeks' notice before the public hearings so that stakeholders can participate.

Doris Husted, who is employed by the Arc of New Mexico and has a son who changed enrollment from the DDW program to the Mi Via program, thanked the legislature for its time and funding. She pointed out that the current rate of taking 50 people off the waiting list each year means that it would take 100 years to get all 5,000 people off the waiting list. Some people on the waiting list get old and die while waiting to get into the DDW program, and their needs are never addressed while waiting.

Ellen Pinnes, lobbyist for the Disability Coalition, praised some aspects of the proposed restructuring of the DDW, including recognizing the need for a more reliable and focused assessment process, support of meaningful employment opportunities and better matching of needs with services. She also pointed out that New Mexico's DDW costs may differ from other states' costs because fewer DDW program enrollees are institutionalized. Finally, she suggested that the HSD create a task force to study reorganizing the waivers, as the DOH has.

Anna Otero-Hatanaka, executive director of the Association of Developmental Disabilities Community Providers, stated that home- and community-based waivers should not be included in any global waiver and that the best way to get people off of the wait list is to end the *Jackson* lawsuit and stop paying legal fees for that case.

Shelly de Abreu has been a special education teacher for the Albuquerque Public School District and a DDW teacher for 13 years. She stated that she is an advocate of home-based living versus the institutionalization and group homes that cost much more than waiver programs.

1 June 2011

Legislative Health and Human Services Committee
Sub-Committee on Disabilities
c/o Mr. Michael Hely
New Mexico Legislative Council Service
State Capitol
Santa Fe, New Mexico 87501

Dear Mr. Hely:

We would like to thank the Committee for their continued attention to issues impacting the state's Developmental Disabilities waiver (DDW) during the legislative interim. As family based caregivers, we would also like to thank the legislature for its sustained backing of the DDW-a program that provides critical life and wellbeing services to thousands of New Mexico's most vulnerable residents.

As New Mexico continues to face budget challenges and also begins to consider a redesign of the state Medicaid program, we ask that the legislature remain committed to ensuring that the DDW be a 'person centered' program that adequately meets the unique needs and exceptionalities of those who depend upon it to lead fuller and more rewarding lives.

To that end, we ask the Legislative Health and Human Services Committee, Sub-committee on Disabilities to consider the following topics during the legislative interim.

DDW Re-Application process should be transparent and inclusive of client and caregiver input New Mexico is currently submitting a re-application for a DDW to the federal Centers for Medicare and Medicaid Services (CMS) as required by federal regulation. While the Department of Health (DOH) has solicited written comments on the proposed re-application, the department should also conduct public hearings so as to provide a broader range of DDW clients and caregivers the opportunity to comment. As DDW caregivers must generally secure substitute care to attend such meetings, the DOH should provide advance notice of at least two-weeks to better ensure stakeholder participation.

Implementation of the Collaborative-Consultative model of therapy raises concerns regarding quality of care and client safety The DOH is moving towards implementing a collaborative-consultative model for delivering therapeutic services. This model would require therapists to train individual DDW clients and their caregivers to either self-administer or provide therapies. Family caregivers remain unclear of the rationale for adopting this service delivery model, and are concerned that it may negatively impact the quality of therapeutic care that clients receive. Further, this model also raises issues regarding client safety, as some therapies will no longer be directly provided by a trained and licensed therapist.

Clients and their caregivers should have greater control over individual budgets Currently, how much a client can spend on a given therapy or service is capped. In practice, this limits the ability of clients and their caregivers to direct resources in a way that best supports the client's individual needs. Inevitably, clients and their caregivers are the best decision-makers when it

comes to identifying and meeting the client's individual needs. As such, the department should consider ways to increase the role that clients and their caregivers play in allocating resources within annual individual budgets.

The DOH should provide information regarding how implementation of the AAIDD Support Intensity Scale (SIS) may impact benefit levels, and provide clients with due-process guarantees

The DOH is currently piloting use of the SIS as a new tool for identifying the level of benefits, and thus care, that clients receive. To date, the department has provided clients and caregivers with little information on how benefits levels may change as a result of a SIS analysis, nor how new benefit levels compare to existing tiers. The DOH should provide this information to clients and caregivers as soon as practicable.

Further, it is conceivable that a SIS analysis may recommend a reduction in benefits for some clients. In order to protect client interests in the benefits they currently receive, the DOH should provide clients with due-process protections. These could include, but are not limited to, the right to appeal a SIS benefits-level determination, and to have the issue decided by an impartial decision maker.

The DOH should also ensure that persons conducting the SIS are experienced in working with the exceptionality of the clients whom they are evaluating. Additionally, in order to ensure a transparent and client-centered evaluation process, the DOH should include caregivers in the selection of potential SIS evaluators.

Quality audits on standards and quality of care should be conducted by the department

Caregivers are concerned about the quality of care that clients receive in some program settings. Specifically, we ask the DOH to conduct quality audits of residential and day-habilitation facilities, as well as rehabilitation services. If the department is already engaged in this activity, then reports should be made available to the legislature and the public. This level of oversight is essential to ensuring the effective and efficient use of public funds, and to protecting client safety.

We are committed to working with the LHHS and the Sub-committee on these and other issues during the interim. If the Sub-committee's schedule allows, we would request the opportunity to make a presentation at the June 24th meeting on these issues and how they impact both DDW caregivers and clients.

Please do not hesitate to contact Jacob Candelaria (jacob.candelaria@gmail.com) with any questions, comments or concerns; or to arrange our presenting before the sub-committee.

Sincerely, Families who Care.