

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

**August 3, 2017
Science and Technology Center Rotunda
University of New Mexico
801 University Boulevard SE
Albuquerque**

The second meeting for the 2017 interim of the Disabilities Concerns Subcommittee (DCS) of the Legislative Health and Human Services Committee (LHHS) was called to order on August 3, 2017 by Senator Nancy Rodriguez, chair, at 9:40 a.m. in the Science and Technology Center Rotunda at the University of New Mexico (UNM).

Present

Sen. Nancy Rodriguez, Chair
Rep. Gail Armstrong
Sen. Linda M. Lopez
Rep. Elizabeth "Liz" Thomson

Absent

Rep. Joanne J. Ferrary, Vice Chair

Advisory Members

Sen. Elizabeth "Liz" Stefanics

Rep. Deborah A. Armstrong
Rep. Miguel P. Garcia
Rep. Angelica Rubio

Staff

Michael Hely, Staff Attorney, Legislative Council Service (LCS)
Karen Wells, Contract Staff, LCS

Guests

The guest list is in the meeting file.

Handouts

Handouts and other written testimony are in the meeting file.

Thursday, August 3

Senator Rodriguez offered welcoming remarks. Members and staff introduced themselves.

Welcome to UNM

Paul Roth, M.D., chancellor for health sciences, and Patricia Osbourn, associate director, Center for Development and Disability (CDD), both of the UNM Health Sciences Center (HSC), greeted subcommittee members. Dr. Roth briefly identified the programs in the HSC that serve disabled individuals through the CDD, as well as other departments within UNM, highlighting the services they provide. Subcommittee members asked for additional information and clarification regarding Dr. Roth's presentation.

Ms. Osbourn provided an overview of the CDD, which exists to identify and serve the needs of people with disabilities in New Mexico. The CDD is part of the national network University Centers for Excellence in Developmental Disabilities. Its goals include conducting research, supporting state and local governments in implementing best practices, providing continuing education, training undergraduate and graduate students and publishing research. Its programmatic areas include services in autism spectrum disorders, early childhood and preschool services, medically fragile case management and employment for individuals with disabilities. Subcommittee members had questions regarding the source of funding for the CDD; additional information regarding Project SEARCH, an employment training program, and Healthy Workshops, an older version of employment training that is no longer considered a best practice; whether these programs lead to job placement; and the extent of family involvement in this area. Thanks were expressed for the work of the CDD, as well as concern for the perceived lack of support for and availability of these essential programs in New Mexico. Dr. Roth acknowledged that limited resources and a lack of adequate funding, particularly under Medicaid, challenge the UNM HSC every day in meeting the needs of not only this population but many others as well.

Medicaid Developmental Disabilities (DD) Waiver Update

A panel that included Jim Copeland, director, Developmental Disabilities Supports Division (DDSD), Department of Health (DOH), Jason Gordon, litigation manager, Disability Rights New Mexico (DRNM), and Peter Cubra, attorney at law, was asked to provide an update and status report on the Medicaid DD waiver program.

Mr. Copeland introduced himself and discussed his experiences and expertise in this area. He identified new staff members that have been added to the DDSD. He highlighted provisions of the DD waiver renewal that include the addition of an outside review process, a discontinuation of the Supports Intensity Scale (SIS), the addition of new language to transition *Jackson* class members to the new waiver and other language updates. New DDSD initiatives include a statewide transition plan (now in final rulemaking), rewriting standards, contract management, provider engagement and renewal of the DD waiver. He provided current statistics on the DD waiver: 6,564 people are on the central registry; 3,945 people are on the waiting list for the DD and Mi Via waivers; 4,694 are in services; and 356 allocations are on hold.

Mr. Gordon provided a brief update regarding the *Waldrop et al. vs. New Mexico Human Services Department et al. (Waldrop)* lawsuit, pursuant to which a settlement was entered to address concerns regarding the SIS. The *Waldrop* settlement establishes a process for approval

of individualized service plans (ISPs) that discontinues the use of the SIS. Team involvement and outside approval are crucial to ensuring provision of an appropriate array of services. Calls to DRNM expressing concerns about outside approval of ISPs have diminished. The budget approval process is still problematic. Mr. Gordon touched on the DD waiver waiting list. DRNM is troubled by the ongoing problems in management of the waiting list, Mr. Gordon stated, and the amount of time it still takes for a client to receive services. He reminded the subcommittee that a bill was passed by the legislature in the 2016 regular session to require reporting on the waiting list, but that bill was vetoed by the governor. He encouraged the subcommittee to continue to pursue this in the future. He noted that the federal Centers for Medicare and Medicaid Services final rule requiring integrated service settings in the community has now been delayed until 2020. The details of this rule are crucial and affect individual lives. A campaign called "Know Your Rights" is working to ensure that all people potentially affected by the final rule and other issues, including employment issues, will be well-informed.

Mr. Cubra mentioned the Ayudando Guardians case management agency, which provides guardianship for adults and is being prosecuted for fraud. Mr. Cubra contends that the Office of Guardianship in New Mexico is grossly underfunded. He also referenced the *Hatten-Gonzales* lawsuit, which contends that the Human Services Department (HSD) is terminating Medicaid benefits without proper notification and that clients affected by this are about to lose benefits. He updated the subcommittee on the status of the *Jackson* lawsuit. Mr. Cubra then commended the DOH for working hard to improve the DD waiver system while the lawsuit is ongoing. He stated that he believes that progress is now occurring and that the DOH is cooperating with national experts. Referring to a state of the states report on disabilities, he highlighted New Mexico-specific data regarding the adequacy of funding for disability services and supports. New Mexico is currently ranked nineteenth among all states in fiscal effort to fund these services.

Subcommittee members expressed concerns and asked questions regarding the following:

- a statement that DD waiver clients are not overserved; funding still needs to be increased;
- clarification regarding the need to rewrite standards for the DD waiver at this time; standards regarding guardianship, planning, human rights, transportation and more are being added;
- whether resource allocation for families will be changed; no significant change is anticipated at this time;
- clarification regarding the process for ensuring quality review in guardianship cases; the LHHS will hear more about this at an upcoming meeting;
- recognition and compliments to Mr. Copeland, Mr. Cubra and Mr. Jackson for their work;
- a concern that standards and requirements to receive DD services are very burdensome, while the Mi Via waiver requirements may be too lax;
- whether Xerox is still the fiscal agent for the DD waiver and whether serious problems are still being experienced; Shari Roanhorse-Aguilar, bureau chief, exempt

- services and programs, Medical Assistance Division, HSD, stated that she is prepared to address this issue in the Mi Via waiver presentation later in the day;
- concern that the process for recertification is very cumbersome;
 - a request for a presentation on what it would take to get out from under the *Jackson* lawsuit;
 - a request for the full LHHS to hear a presentation about the critical need for additional funding for the DD waiver and that the Legislative Finance Committee be invited to attend this presentation;
 - the importance of accommodating people with special needs and doing everything that can be done to help them;
 - whether there is high turnover among the external reviewers and whether the same reviewers are assigned to the same clients; external reviews are accomplished on a team basis; to the extent possible, members of the team remain the same;
 - the process by which information is submitted to reviewers responsible for evaluating the appropriateness of ISPs; the process is inconsistent due to inconsistencies of data submissions;
 - the critical importance of communication among and between parties; and
 - an assurance by Mr. Copeland that the DDS is committed to continued work on all of the issues raised at the meeting.

The chair announced that a letter had been received from Brent Earnest, secretary of human services, responding to concerns expressed by the LHHS at its June 16, 2017 meeting regarding Medicaid enrollment and recertification for DD waiver clients. Mr. Hely read the letter out loud at the request of the chair. The letter will be posted on the website.

Public Comment

Ira Cohen requested that the legislature not cut funding for Camp Rising Sun. Robert Bundy, Emma Ruth, Tim Brown and Miranda Patay provided personal testimony about the importance of the camp. Katie Stone, a camp employee, provided details about the training that is given to peer counselors and families. She spoke strongly about the unique and critical need for continued funding for the camp.

Mr. Copeland responded to questions regarding funding cuts. With no additional appropriations and growing expenses, difficult decisions had to be made. He affirmed that the CDD has been given flexibility to continue funding for Camp Rising Sun but that other programming is likely to be negatively affected by this. A member asserted that the legislature did not cut the funding and voiced that the member does not wish to cut funding for Camp Rising Sun and other autism services. She encouraged advocates to talk to the governor about the cuts.

Robert Kegel reviewed state law regarding authorization for providing community-based services for persons with developmental disabilities. He raised concerns about communications that are not timely or that are inaccurate and that result in disastrous outcomes for recipients, as well as delays for people on waiting lists. He also testified to the difficulty of presenting public

comment before changes are implemented. He contends that the law is not being followed, especially regarding reporting to the legislature.

Marsha Secord advocated for individuals with traumatic brain injury, who experience many of the same concerns as people with developmental disabilities. She asked the subcommittee to address brain injury more aggressively. The chair noted that brain injury is included in the work plan for the LHHS.

Tracy Perry, Direct Therapy Services, expressed concerns regarding unresolvable eligibility issues and the time it takes to begin covered services and recertifications.

Glenn Ford, Brain Injury Alliance New Mexico, spoke to the need for increased funding for brain injury services. He stated that he is eager for the DCS to hear issues related to brain injury this interim.

Wendy Cory, advocate for people with disabilities, highlighted some good work that is now being done, especially the Know Your Rights campaign. Many agencies have become involved. Ten town halls have occurred around the state with more than 600 participants this year. Many positive collaborations statewide have made this work possible.

Sarah Baca, executive director, New Mexico Autism Society, expressed thanks for all the support the legislature has given to autism services.

John Block, executive director, Developmental Disabilities Planning Council, provided additional information about Ayudando Guardians and guardianship services statewide. By court order, 166 individuals need to be transferred to other guardianship providers.

David Murley, Mi Via consultant and broker, spoke in opposition to action taken by Presbyterian Healthcare Services to provide support broker services in-house. He feels that this step will limit the ability of clients to fully self-direct their services and have their needs appropriately met. He provided written comments.

Julia Alzofon addressed a serious health problem that arises from retail grocery store security systems that hinder access by disabled individuals. Sigmund Silver noted the adverse effect of this system, which automatically locks a shopping cart's wheels if a shopper does not leave the store within a certain period of time after checkout. He described the pitfalls of Albertsons' use of timers on wheelchair carts, which creates great disadvantages for disabled individuals who depend upon these carts for shopping.

Felice Garcia identified herself as the sister of a DD waiver participant and the aunt of someone on the autism spectrum. She asked that the DCS deliver a message to the governor that Camp Rising Sun is not frivolous but an essential provider of respite services for families that are

overburdened and that it provides training and hands-on skillbuilding for camp attendees. She noted that the camp is known and studied worldwide.

Sandy Skaar, a self-directed supports worker and Mi Via consultant, identified problems for individuals with developmental disabilities who require prompting to be provided these services. She noted that benefits for individuals living with HIV and AIDS have been cut and that budgets are being decreased.

Mi Via Update

Ms. Roanhorse-Aguilar and Jennifer Rodriguez, bureau chief, community programs, DDS, DOH, gave an overview of the Mi Via waiver program. It is different from the DD waiver in that it is a self-directed program. Participants choose which services, supports and goods they need from available services and decide when and how those services will be provided. They can choose to hire their own employees or work with their choice of vendors for services. The array of services and supports available was described. Participants receive an annual budget allotment. An organizational chart was provided to better delineate responsibilities. The HSD and the DOH work in partnership to administer the program. The role of third-party assessors and financial management agents was described. *FOCoOnline* is the system for receiving and processing payments.

Lecie McNees, executive director, Self-Directed Provider Association, offered information from the provider perspective. Cheryl Durham, Consumer Direct New Mexico, and Fallon Vincell, Care Network Resource Assistance Group, stated that they were available to answer questions. Jentry Hinton, director, long term care, Presbyterian Healthcare Services, was called upon to answer questions regarding Centennial Care issues.

Subcommittee members had questions and concerns regarding the following:

- clarification regarding the role of Xerox (now Conduent) and whether Conduent is doing a good job; Conduent, a subcontractor of Xerox, processes payments for clients;
- questions regarding the accuracy of previously reported numbers of persons served by the Mi Via waiver; they are accurate;
- a breakdown of people younger than 21 and 21 and older serviced by Mi Via; the data are not broken down in that way;
- the process by which participants may lodge complaints or express dissatisfaction regarding services provided; these issues can be reported to consultants to handle;
- how participants' rights are upheld and respected; the DOH and the DDS are advocates for clients and help them understand their rights;
- clarification of the multiplicity of terms and programs and the potential for poor communication among all involved parties and agencies;
- clarification regarding the maximum amount of respite services that can be accessed; under Medicaid, there are 720 hours of respite that are available through the behavioral benefit; additional hours are available through the community benefit;

- methods by which participants learn benefits for which they are eligible; there is a variety of personal and published methods to fully inform participants about benefits; this process begins when the initial health needs assessment is performed;
- clarification regarding grievance processes; there is a formal process; grievances are filed though contractors or directly through the state;
- a sense that the program is overly bureaucratic and therefore inefficient and not user-friendly;
- clarification of how determinations are made regarding the services a client needs or receives; there is an annual review process that is different than the DD waiver process; the individual participant decides what is wanted or needed, within available services and supports, then a budget is created;
- there is a difference between the Mi Via program and Mi Via services under Centennial Care; Ms. Roanhorse-Aguilar will provide information about the differences;
- how support brokers are chosen and paid; Centennial Care has "support brokers"; Mi Via has "consultants"; and
- a request for data by diagnosis on behavioral care respite services.

Autism: Status of Camp Rising Sun

Ms. Osbourn began by discussing and clarifying how funding for Camp Rising Sun occurs. The camp is part of the overall budget for the CDD's autism programs. Funding comes from the DOH. Funding levels have gradually diminished since 2007. Over time, the CDD has identified a broad variety of needs in autism funding. Currently, funding for autism programs is at \$2.7 million. A description of autism programs within the CDD and the program cuts that have occurred was provided. Ms. Osbourn identified the ways in which the CDD has responded to cuts in funding. In fiscal year (FY) 2018, Camp Rising Sun funding is in jeopardy. She discussed the value of the camp and concluded with a request for FY 2018 to restore \$160,000, asserting that, given the dramatic rise in the prevalence of autism spectrum disorders, further cuts cannot be accommodated without a loss of services upon which families rely.

Questions and comments from subcommittee members included the following:

- the number of people served in New Mexico; the number is hard to identify, as there are many programs, and parents are served as well as participants; Ms. Osbourn estimates the number is around 350,000;
- frustration regarding the difficulty for parents of children with autism spectrum disorders to access the system of services, despite years of active advocacy; and
- a reminder that the known number of people with autism grew from one in 166 to one in 88 in the last seven years, while funding for services has declined.

Public Comment

Bill Jordan, New Mexico Voices for Children, commented that it is "morally bankrupt" to cut necessary services while awarding tax cuts.

Ms. Vincell voiced concerns that the changes to Centennial Care affecting support brokers will have a disastrous effect on clients. She is not opposed to managed care organizations utilizing their own support brokers, but she is opposed to clients not having the option to choose other support brokers as well.

Adjournment

There being no further business, the meeting was adjourned at 3:40 p.m.