

**MINUTES
for the
FIRST MEETING
of the
DISABILITIES CONCERNS SUBCOMMITTEE**

**August 4, 2016
Room 307, State Capitol
Santa Fe**

The first meeting of the Disabilities Concerns Subcommittee (DCS) of the Legislative Health and Human Services Committee was called to order by Senator Nancy Rodriguez, vice chair, on August 4, 2016 at 9:22 a.m. in Room 307 at the State Capitol in Santa Fe.

Present

Sen. Nancy Rodriguez, Vice Chair
Sen. Craig W. Brandt
Rep. Miguel P. Garcia
Sen. Linda M. Lopez

Absent

Rep. Tim D. Lewis, Chair

Advisory Members

Rep. Deborah A. Armstrong
Sen. Ted Barela
Sen. Gerald Ortiz y Pino

Rep. Nora Espinoza

Guest Legislators

Sen. Cisco McSorley
Sen. Howie C. Morales

Staff

Shawn Mathis, Staff Attorney, Legislative Council Service (LCS)
Rebecca Griego, LCS
Alexandria L. Tapia, Contractor, LCS

Guests

The guest list is in the meeting file.

Handouts

Handouts and other written testimony are in the meeting file. Handouts can also be found at https://www.nmlegis.gov/Committee/Interim_Committee?CommitteeCode=DISC.

Thursday, August 4

Welcome and Introductions

Senator Rodriguez welcomed members to the first meeting of the DCS. Members of the subcommittee and staff were asked to introduce themselves.

Fiscal Issues Facing the Department of Health (DOH) and the Developmental Disabilities (DD) Waiver

Charles Sallee, deputy director for program evaluation, Legislative Finance Committee (LFC), provided the subcommittee with a post-session recap, overall DOH budget update and details about the DD waiver. The state budget for fiscal year (FY) 2017 was built on an estimated \$5.9 billion; however, based upon projections done in May 2016, actual revenues are estimated at \$5.74 billion. Falling revenue projections are forcing the prioritization of departments. Medicaid and public safety remain at the top: Medicaid makes up 15% of the recurring General Fund appropriation. With few options for making up the shortfall, the legislature is looking at drawing funds from the Tobacco Settlement Permanent Fund.

Eric Chenier, senior fiscal analyst, LFC, noted that in terms of the DOH FY 2017 budget, facilities and the DD waiver have been prioritized. DD support makes up \$160.7 million of the DOH's total appropriations. The federal Patient Protection and Affordable Care Act (ACA) and Medicaid expansion improved the financing of rural primary health, public health and facilities. The FY 2017 appropriation included 40 new DD waiver slots and nonreverting language that retains unexpended funds. These new measures are still insufficient to reduce the DD waiver wait list. Mr. Chenier explained the *Waldrop* and *Jackson* lawsuits and their outcomes on the state's financial picture. The subcommittee was provided with an update of ongoing litigation expenses.

Federal regulations require that the cost of community-based services be less than institutional care costs. In 2010, the state's per enrollee costs were on track to equal, and potentially exceed, institutional care costs. At that time, the LFC recommended a needs-based assessment tool; the DOH subsequently implemented the Supports Intensity Scale (SIS). Mr. Chenier informed the subcommittee that the DD waiver application rate has grown at almost twice the number of annually available slots; the wait list is outpacing available slots at about 5% per year. To reduce waiver wait times, New Mexico can look to other states for options in terms of leveraging local funding. Six other states use local funds for the Medicaid match, while 10 states use local funds for other DD programs and services. In FY 2014, New Mexico counties held \$30.4 million in county indigent fund balances. Mr. Chenier suggested that statutory changes could be made to require counties to contribute indigent funds for the needed Medicaid match.

In addition to the DD waiver, the State of New Mexico offers the Mi Via Self-Directed Waiver Program (Mi Via). Mi Via is designed for participants who have disabilities to manage their own services and supports. Individuals can choose the program from which they want to

receive benefits. The average cost per client on Mi Via is \$44,100 a year. In comparison, the average cost per client on the DD waiver is \$70,000 per year; however, Mr. Sallee stressed that these are only averages. In some cases, annual cost per recipient may exceed \$200,000, while other individuals requiring fewer services cost less. Encouraging more people to use Mi Via would help decrease costs and reduce the number of individuals on the DD waiver wait list. The LFC will be working with the DOH to determine what can be done to reduce costs and maximize efficiency.

In response to the LFC's presentation, members of the DCS inquired about the following issues:

- the potential special session and falling revenue projections, including the need for addressing budget expenditures, not just using other funds to cover the budget deficit;
- the wisdom of using the Tobacco Settlement Permanent Fund to address the budget shortfall;
- the need to identify sustainable revenue sources;
- the LFC's updated General Fund financial summary, due out at the end of August;
- the progress of efforts to "disengage" from the *Jackson* lawsuit;
- the status of the *Jackson* and *Waldrop* lawsuits;
- use of county indigent funds to reduce the DD waiver wait list;
- leveraging of local funding and premium taxes;
- tracking of funds from the ACA for the improvement of rural primary health, public health and facilities;
- LFC report cards for state agencies;
- the impact of budget cuts on programs; and
- the lack of additional funding for the DD waiver in FY 2017.

Public Comment

Robert Kegel, advocate and father of a son with severe disabilities, spoke of his four years of research into the state's DD waiver. Mr. Kegel recently met with LFC analysts to present findings that he alleges contradict long-standing claims that New Mexico has the most expensive DD waiver program in the country. According to Mr. Kegel, in 2009, New Mexico was the first state in the nation to replace institutionalization of people with DD with community services. According to Mr. Kegel, if the cost of New Mexico's DD waiver is compared to the spending for community services in other states that institutionalize their severely disabled populations instead of maintaining them in the community, New Mexico's waiver would, of course, be more expensive. Mr. Kegel explained that, in his opinion, a report prepared by a consultant retained years ago to evaluate New Mexico's DD waiver program was misleading because it did not take this into account. Based on research that he has provided to the subcommittee, Mr. Kegel has urged the state, and particularly the LFC, to revisit the consultant's conclusions that the state's DD waiver spending was excessive and thus needed trimming back. Mr. Kegel argued that misplaced reliance on the consultant's report led to the implementation of the SIS. He provided the subcommittee with examples of other states' services and costs, noting how New Mexico is

different. In providing services, the waiver is secondary to schools. Institutional care is done by group homes that provide more services to individuals; the waiver can never exceed the cost of institutionalization.

Texas spends around \$2 billion on 4,000 people, approximately the same number of people on New Mexico's DD waiver. Mr. Kegel explained the funding behind the DD waiver, adding that there is a misconception of what the waiver is actually costing the state. Mr. Kegel noted that New Mexico's DD waiver budget has declined over the last several years. He also criticized the lack of analysis of the state's population of waiver applicants, stating, "We don't know who is on the waiting list, what types of cases are on the list or the extent of services needed for those on the list...yet, we know that the wait list for the waiver is growing faster than our population with an up to 10-year wait.". Other states are using support service waivers, something New Mexico should consider.

Since the state is facing financial difficulties, Mr. Kegel recommended prioritizing Medicaid spending by identifying where money is going and how funds are being used. He noted that Mi Via may have a lower per person cost, but it has an additional Medicaid cost. Mr. Kegel reminded subcommittee members that the *Jackson* lawsuit has saved the state hundreds of millions of dollars because it required the state to close institutions that other states have kept using. Mr. Kegel also expressed concern regarding the billing and lack of cost containment on the part of Medicaid managed care organizations.

Mr. Kegel shared a few examples of DD waiver recipients who had died or had serious medical complications that he claims were due to delays in the approval of individual budgets. He also recommended requiring that anyone conducting audits of waiver programs be a certified public accountant and providing compensation for caregivers who have to stay with DD waiver clients in the event of a client's hospitalization. He also urged adoption of a supports waiver, which would require federal approval but result in an overall cost savings. A supports waiver could provide respite care, case management, nursing for those that need it and potentially a daycare program. If there were a supports waiver, people could be started on services much earlier and they might not end up on the comprehensive DD waiver. Members questioned why some of these services were not being covered under Centennial Care's long-term care services.

Lecie McNeese, DD waiver case manager (CM), spoke to the subcommittee about the vital role of case management in the DD waiver program and provided a handout to members. Case management is the only required service under the waiver program. CMs create individual service plans for program recipients and monitor implementation by service providers through home visits. Ms. McNeese explained that CMs are the conduit for communication among the recipient of services, individual team members, state agencies, families and other community members. In 2007, there was a rate decrease of 10% and that amount was never restored, despite the increases in caseloads, administrative requirements and rising costs in providing services. Ms. McNeese recognized that asking for a rate increase is difficult, given the current financial

climate of the state; however, she did request that CMs be given an opportunity to be included in future discussions related to changes in the DD waiver.

Scott Yuland, CM, addressed an earlier question from a member stating that money spent on the SIS is not necessary. According to Mr. Yuland, an SIS assessment is not required to clinically justify services. The money that is being spent on about 1,000 recipients of the SIS each year, which is not federally matched, could be used for service rate increases or taking people off the wait list, which would be matched with federal Medicaid funds. He suggested that there is money to be "found" within the current system.

Jim Copeland, executive director, Alta Mira Services, informed the subcommittee that his company is one of the few that provides DD waiver, Mi Via, state waiver and early intervention services. He offered a provider's perspective to the subcommittee. Mr. Copeland reminded the subcommittee of a Centers for Medicare and Medicaid Services (CMS) final rule that will restrict the types of programs for persons with disabilities that will be eligible for Medicaid reimbursement. According to Mr. Copeland, the judge presiding over the *Jackson* lawsuit is not satisfied with the consistency of care for the *Jackson* plaintiffs. Providers face many challenges that affect the quality of services, such as large staff turnover rates, mostly due to noncompetitive wages. Providers are often overloaded with requirements from state and federal agencies without corresponding rate increases; most providers are in financial distress. Mr. Copeland would like to see providers included in the decision-making process. He noted that, in 14 years, there have been seven directors in the Developmental Disabilities Supports Division (DDSD) of the DOH and nearly as many secretaries at the DOH.

Lisa Rosenthal, Parents Reaching Out, is an advocate who works to help parents find resources for recently diagnosed children with DD. She shared her personal experience with her daughter who has severe disabilities. She highlighted some of the challenges that families face and what her organization does to help them. She is concerned with systematic dismantling of services and budget cuts to critical programs. Centennial Care has done great work in this area, but it has not been enough for children. Ms. Rosenthal believes that there needs to be a separate waiver exclusively for children. Centennial Care removed community supports and replaced them with care coordination. According to her, care mapping for children with special care needs consists of 35 professional contacts that are involved in a child's care; the system is very complicated and cumbersome. Because Medicaid does not cover it, respite care has been cut down to 100 hours per year. Families are finding ways to reinstitutionalize their children because they are overburdened. She warns that the issue is dire and that it will only get worse.

Report on DD Supports and Services

Sharilyn Roanhorse, bureau chief, Exempt Services and Programs Bureau, Medical Assistance Division (MAD), Human Services Department (HSD), presented with Angela Medrano, deputy director, MAD, HSD, a report on the DD waiver. The current DD waiver expired on June 30, 2016 but received CMS extensions to continue operating through the end of the year, at which time the renewal application will be submitted. Ms. Roanhorse stated that the

waiver renewal time line was significantly impacted by the *Waldrop* litigation and the new CMS rule on home- and community-based services (HCBS) settings. Ms. Roanhorse explained some of the changes to the DD waiver program, including changes required by the CMS to quality measures and reporting and enrollment counts (please see handout for more information).

She explained that every rule and renewal requires stakeholder input. The department began announcements regarding the DD waiver renewal in 2015. She advised that statewide community outreach and informational meetings were held in June 2016 and that the HSD received input from providers, advocacy groups and other interested parties. The DDS has a page on the Access Community Together New Mexico website dedicated to information and submitting comments and ideas to the DDS, which can be found at: <http://actnewmexico.org/ddw-renewal.html>. A complete draft application will be posted on the HSD website in mid-September. Ms. Roanhorse provided information regarding formal public notification, detailing time lines for both tribal notification and general public comment periods. The CMS has a 90-day review period with an opportunity to request additional information, both formal and informal. It is anticipated that the CMS will approve the application by April 2017.

Ms. Roanhorse provided the subcommittee with an update on the CMS rule on HCBS that went into effect on March 17, 2014. The rule is designed to enhance the quality of HCBS, provide additional protections and ensure full access to the benefits of community living. Several changes for HCBS are included in this rule, such as the requirement of comprehensive assessments of all HCBS settings to ensure that services are provided in an integrated setting. The rule applies to all waiver programs and requires formal public input. Approval of a statewide transition plan (STP) is required by the CMS, and all states must be in compliance with the rule by 2019. Ms. Roanhorse shared the status of New Mexico's STP, which encompasses the DD waiver, Mi Via, medically fragile waiver and the Centennial Care waiver. After the period for public and tribal input, the amended STP will be submitted to the CMS by September 30, 2016. Ms. Roanhorse outlined the key components of the STP for the state and the next steps for STP approval. According to her, Tennessee is the only state that has received full approval for its STP; New Mexico is on track for approval.

In response to the presentation, members of the subcommittee inquired about the following issues:

- the definition of "integrated setting", which is the most significant change for the state;
- congregate services that will not be funded under the CMS rule;
- whether the STP is intended to bring all waivers into compliance with the new CMS rule;
- the department's plans to promote provider compliance, rather than termination of providers;
- content changes to the DD waiver and the requirement for third-party clinical review;
- consideration of the supports waiver;

- how *Olmstead* requirements impact the STP;
- the consequences of noncompliance with the CMS rule for providers and the state;
- plans for tribal consultation and public hearings; and
- whether statewide community outreach meetings have been well-attended by consumers and members of the public.

Renewal of New Mexico's DD Waiver

Cathy Stevenson, director, DDS, DOH, noted that there are many other services and supports provided to people in addition to the DD waiver, and she highlighted them briefly (see handout). The DOH has operational oversight of the DD waiver program. Ms. Stevenson drew the subcommittee's attention to the flexible supports program, which provides those on the DD waiver waiting list with \$3,500 per year to purchase services or goods to accommodate their needs related to their disability. This program only has \$500,000 available and is a pilot for what the supports waiver would be; the supports waiver would require a higher level of funding.

Ms. Stevenson also talked about the Family Infant Toddler Program (FIT), which provides individualized early intervention and developmental services to children (birth to age three) who have or are at risk for a developmental delay and their families. New Mexico is one of the few states that funds a program like this. In FY 2016, the FIT served 14,050 children, which was an increase of 762 from the previous year. The number of children served per month is 6,938, with the average cost per child totaling \$3,652 per year. The total amount of federal Medicaid matching funds expended in FY 2016 for the FIT was \$29,194,679; this does not include the state's share, which is in the DOH budget.

The DDS Medicaid waivers provide an array of HCBS to support individuals with DD, of all ages, to live successfully in their homes and in communities of their choice as an alternative to institutional or facility-based care. These waivers include the traditional DD, Mi Via and medically fragile waivers. The FY 2017 operating budget for all of these waivers is over \$105 million. During FY 2016, 4,673 individuals were served by the DD waiver and Mi Via — with 6,402 on the DD waiver wait list. It was noted that the cost numbers in the charts do not include the cost of Medicaid services that persons also receive. Those who qualify for Medicaid get it, regardless of what waiver they have.

Ms. Stevenson explained that the SIS is only for those who are on the DD waiver and is used to help identify service needs for participants. The SIS contract is with the University of New Mexico's Center for Development and Disability. In December 2016, the DD waiver will move from the current three-year assessment cycle to a five-year assessment cycle. In FY 2018, the DOH plans to make the SIS available to a limited number of DD waiver applicants who are next in line for allocation. This will speed up entry into services when funds become available.

The subcommittee was given an overview of the outside review process that ended in June. The outside review process is the additional clinical review as a result of the *Waldrop* case. An initial backlog in clinical reviews required a system-level adjustment to authorize plans on an

interim basis so that providers could bill for services. There have been significant issues on the state side, the case management side and the provider side, but the backlog for annual budgets has been addressed. Plan and budget submissions are often incomplete, and if so, the submissions cannot go on to clinical review without CMs correcting errors or providing supplemental documents. Ms. Stevenson explained how the systems fix was implemented by the state to address issues with the clinical review to ensure that services remain available and providers get paid. She commended the providers and CMs for their work, noting that some agencies have continued to serve people while waiting for their funding. The DOH continues to meet monthly with providers, CMs and the outside reviewer to solve problems.

Following the presentation from Ms. Stevenson, the subcommittee had comments and questions regarding:

- improvement in the approval rate of budgets and the number of budgets returned for additional information;
- qualifying criteria for each waiver program;
- notification of the availability of flexible supports for the DD waiver;
- the fair hearings process since the *Waldrop* settlement agreement;
- concerns about the SIS;
- how the SIS is used to determine a waiver recipient's budget;
- a request for additional information containing a breakout of waiver cost by age group;
- criteria allowing for individuals with critical needs to move from the waiting list to the waiver;
- clarification and details about the medically fragile waiver program; and
- specific constituent cases for DOH follow-up.

Motion 1

After discussion of a potential supports waiver, a motion was made and passed without objection to request a presentation from the LFC on the different support waivers being used throughout the country to be given at an upcoming DCS meeting. The presentation is also to include a report by the LCS on the model being used in Oregon.

Fritzi Hardy, B.S., M.A., chair, Association of New Mexico Family Providers, told the subcommittee about her daughter, who is on the DD waiver. Her daughter is able to attend VSA Arts of New Mexico (VSA), where she gets the help she needs to deal with her seizures. With the new CMS rule, VSA will be eliminated. Under the new rule, individuals cannot be isolated from their peers and are required to be out in the community for 15 hours a week. Ms. Hardy believes that the DD waiver requirement to be out in public interferes with a person's right of association and is unconstitutional. She was in support of the SIS until she started hearing feedback on the system. She wishes the department and programs would listen to input from people dealing with these problems firsthand — the parents, families, caregivers and providers.

Ms. Hardy shared a letter with members from an individual going through the fair hearing process. She added that family living saves the state money, but families need respite.

Ms. Stevenson acknowledged that programs like the VSA model do not fit in with the CMS final rule. The DOH is looking into what can be done for these programs. The CMS is not saying that states cannot have these programs, but the CMS is saying that it will not pay for them. VSA provides services to many clients, but the CMS has stated that reverse integration would not comply with the final rule. Ms. Stevenson added that these issues will be addressed as part of the transition plan.

Report on Issuance and Renewal of Registry Identification Cards for Qualified Medical Cannabis Patients

Senator Rodriguez expressed disappointment as she informed members of the subcommittee and the public that despite an invitation from the subcommittee, representatives from the DOH would not be present to address this issue. Instead, the department sent a letter to the subcommittee with information about the medical cannabis program. Senator Rodriguez stated that a list of questions would be directed to the DOH prior to the Legislative Health and Human Services Committee's upcoming meeting in Taos, which the secretary of health has indicated that she will attend.

Duke Rodriguez, president and chief executive officer, Ultra Health, stated that as a former cabinet secretary for the HSD, he knows the importance of these hearings and meetings to address questions from patients who cannot obtain their medication and manage their chronic illnesses due to problems in renewing their medical cannabis registry cards. According to Mr. Rodriguez, submitting an application on time for renewals should be adequate. Using information from the DOH, he stated that there are 27,980 active patient cards and 6,033 current personal production licenses. Mr. Rodriguez informed the subcommittee that 32% of forms are not processed by the department within the 30-day statutory time limit. In his opinion, in comparison to other states, the 30-day time frame is a generous standard, with New Mexico ranking last among states with medical cannabis programs in getting cards out to patients in a timely manner. He shared information from some neighboring states' programs. In Colorado, there are 106,000 medical cannabis cardholders in the system; as of July, Colorado is running 14 days behind for processing applications. Arizona's program has 98,000 cardholders and is able to issue cards within 10 to 12 calendar days using an online automated system. The fastest-growing program, in Nevada, has processed 20,000 new cards in its first 12 months of creation. On a more global scale, Israel is able to deliver medicine to a patient's door within 24 hours of diagnosis and card request. He suggested working with the Motor Vehicle Division of the Taxation and Revenue Department to get patients a temporary approval for purchase while the DOH processes their cards.

He pointed out that the DOH website fails to mention licensed medical cannabis producers as its partners, despite payments of nearly \$3 million in licensing fees to the department; thus, the patients are paying for 100% of this program. Mr. Rodriguez criticized the

DOH's current limit on the number of plants that can be cultivated, which would only produce one-half of a plant per patient per year, assuming full statewide production. Accordingly, he argued that the department is not meeting its statutory requirement to provide for an adequate supply for New Mexico's medical cannabis patients.

Leigh Jenke, president and chair, Licensed Non-Profit Producers, used to work for Molina Healthcare, where she was charged with serving high-priority members in Medicaid. She sees the same population in the medical cannabis industry. These people are extremely sick, and their registry cards are their lifeline in order to function in the activities of daily living. Patients with cancer want to use cannabis instead of opioids or narcotics because those medications make them sick. Ms. Jenke noted several conditions and diseases that are managed, treated and even halted by medical cannabis. She stated that her organization just went through its renewal process as a producer and had difficulty. The DOH has provided it with a "work around", which she suggested could be done for patients. The medical cannabis industry continues to expand all over the country. Ms. Jenke stressed that patients are the primary concern. The majority of these patients are low-income Medicaid recipients, and they still have to pay out of pocket for medical cannabis because it is not covered under Medicaid.

Nicole V. Morales, executive director, New Mexico E.M.P.A.C.T., thanked the subcommittee for the opportunity to present and weigh in on this issue. The renewal card delay and backlog started in April of this year and is only compounding. So many patients are being affected by this. Ms. Morales raised concern over individuals desperately turning to illegal sources to get the medicine they need to treat their illnesses but who are not getting the quality strains they need for treatment. She was appalled by the suggestions of DOH employees that patients return to opioids and other pharmaceuticals; many have worked hard to get away from these drugs. She thanked the subcommittee for its attention and help in this matter.

Anita Briscoe, psychiatric nurse practitioner, stated that psychiatrists have been referring patients into the program for the last seven years. Ms. Briscoe shared information about the range of conditions of the patients with whom she works, particularly those living with posttraumatic stress disorder (PTSD). Irritability is one hallmark of PTSD and can be manifested in violent outbursts. Ms. Briscoe said it is not a crime to have this condition, but it is a crime to deny access to medicine after doctors and patients have gone through the appropriate measures to get registry cards. She echoed the comments of a previous presenter, reminding subcommittee members that many patients have worked hard to recover from opioid dependence and have been aided by the use of medical cannabis. Ms. Briscoe commented on the risks that patients are taking to get their medicine, which is medicine they have been properly prescribed. She suggested that if New Mexico could pass legislation allowing for the production of massive amounts of cannabidiol, the state could become a major supplier of cannabis oil.

Garth Wilson, personal production license holder, echoed some of the comments from the other presenters. He shared his experience in getting his registry card and producer's license. After waiting 40 days for his card, he called, only to find out that the DOH had mailed the card to

the wrong address. He claims he was "victim-shamed" by the department and blamed for its mistakes. Mr. Wilson told the subcommittee about his care provider being charged \$50.00 for a replacement card after the department mailed it to the wrong address. A veteran and cancer patient had a similar experience. He feels these "mistakes" are criminal negligence on the part of the DOH.

Timothy Keller, state auditor, explained what his office can do to rectify the situation. The Office of the State Auditor (OSA) believes this is a public health emergency, while the DOH is treating it as an administrative challenge. Auditor Keller noted that when this administration thought there was a behavioral health emergency in mid-2013, resources were found immediately to address the problem. The OSA found out about problems in issuing registry cards in mid-June through the fraud hotline and other constituent calls. The OSA gave the DOH 60 days to fix the problem and there are 30 days remaining. The OSA has determined that the DOH is violating the law and needs to address the matter immediately. Auditor Keller does not believe that the department lacks funding to administer the program properly. The program had \$90,000 prior to the most recent payment from the producers. Temporary or emergency personnel could be hired "if this was a priority" for the secretary of health. According to Auditor Keller, the growth of this program was foreseeable and should have been planned for accordingly.

The OSA has looked at the potential of card outsourcing and is concerned that even if registry cards are issued in a timely manner, there may not be sufficient production of medical cannabis to meet the demand, as indicated to Auditor Keller by reports of frequent product shortages. He suggested that caps on production and limits on the amounts that a patient can possess should add up to what constitutes an adequate supply. Nevertheless, the OSA is limited in terms of what it can do. Auditor Keller explained that his office can conduct financial audits but not performance audits. His office is confident that alleged resource constraints do not exist; this program is financially self-sustaining. He noted further that department employees who are recommending that medical cannabis patients "go back to prescription medication" may be breaking other laws.

The OSA has included this issue in its annual audit of the DOH. December will be the earliest the OSA will get those results. If the DOH continues to break the law, it could receive an "at risk" designation from the OSA and subject the state to potential lawsuits. Auditor Keller noted that there have been many options suggested by other members of the panel, and the OSA wants to see an immediate solution.

Several members of the subcommittee stated their displeasure with the DOH for not sending a representative to the meeting. Members discussed the following matters:

- the fee for replacement cards;
- the program's revenues as more than sufficient to pay for the cost of administration;
- various suggestions for addressing the delay in getting medical cannabis to patients, including temporary extensions for cardholders under an emergency rule;

- details about the application process and document requirements;
- whether program requirements are regulatory or statutory;
- the wisdom of annual renewal requirements for chronic conditions;
- the need to treat delays in patient access to medical cannabis as a public health issue;
- the source of "bottlenecks" in the approval and processing of medical cannabis registry cards;
- the likelihood of litigation against the state for violating medical cannabis laws; and
- whether regulations and statutes need to be revisited to guarantee an adequate supply of medical cannabis for patients statewide.

Public Comment

Nat Dean has been a medical cannabis patient for seven years and suffers from chronic pain due to a traumatic brain injury. The usage of medical cannabis allowed her to go from 27 different prescriptions, including narcotics, to about six, thus increasing her ability to be more active. She shared statements from Cathy Smith and Joel White. Ms. Smith is an arthritis patient who has been waiting two months for her registry card and cannot get prescription narcotics for fear of losing her Section 8 housing voucher. Mr. White has multiple sclerosis, a permanent condition. Ms. Dean does not understand why patients have to renew cards every year for conditions that are not going to improve. It is expensive to be required to see a physician for annual reviews. In her opinion, the DOH has sufficient funds from the program alone to address staffing needs.

Mr. Kegel spoke to the subcommittee on behalf of Danny DePalma, who is a DD waiver service provider. Mr. DePalma wanted the members to note that, even if DD waivers were being automatically approved to catch up on the backlog of outside review, in such cases, the client is unable to make any changes. Of the 400 provider budgets, 90 are overdue; two-thirds of the year has gone by, and only one-half of the budgets have been approved. In the meantime, providers have to provide services paid for out of their own pockets. Mr. DePalma has a daughter on the waiver and did not receive any notifications regarding community meetings for DD waiver renewal. Mr. Kegel did not receive any notifications either, and he does not believe that the DOH and HSD are sending out the proper notices.

Richard Talley shared a letter he had sent to the secretary of health and the governor about the difficulty of getting a medical cannabis card. Mr. Talley has been trying to acquire a medical cannabis card for a family member suffering from chronic pain. According to Mr. Talley, it is taking 45 days to 55 days or longer for the DOH to issue medical cannabis registry cards. Because some medical conditions do not change from year to year, he does not understand why a yearly renewal is required. He does not understand how it is easier to obtain prescription opioids than it is to get medical cannabis. He added that Hawaii started its program last year, and it takes 10 business days to issue cards to patients.

James Rivera, tribal member, Pueblo of Pojoaque, raised the issue of tribes being excluded from the medical cannabis industry. If a tribe wants to grow and dispense medical

cannabis, will the DOH be willing to explore this to advance the medical cannabis program in the state? Due to sovereignty status, Mr. Rivera questioned if a tribe would be able to move product after cultivation to a processing plant. He believes the tribes could be a huge asset to the state in terms of the medical cannabis program, as they would not be subject to state law and could produce more efficiently, thus getting patients the medicine they need. Mr. Rivera requests legislation that would allow tribes the ability to move product off tribal land.

Larry Love, patient activist and licensed grower, said the DOH has put the health of patients at risk by delaying renewals and taking too long for initial applications. Mr. Love stated that the last two secretaries of health have not been physicians, and he believes a physician should be involved in the department. According to him, "the governor has done everything to try to kill this program, including hiring the right people to stall it". He added that he has heard a lot of complaints from patients about the rudeness of DOH employees. Mr. Love pleaded with members to ensure that the medical cannabis program survives.

Ms. McNeese stated that level of care is the only requirement for Mi Via. The DD waiver also has this requirement, and she questioned the continued need for the SIS. Both waivers are excellent programs, but Mi Via requires less to qualify. She believes that there is too much red tape and that the system is overburdened. The renewal of the DD waiver is the right time to reduce the burden and streamline the system to make it more sustainable.

Sarah Martinez, CM, talked about resource allocation and explained that both the DD waiver and Mi Via use level-of-care assessments. For non-*Jackson* class members, level of care is used but the money attached to those categories is not the same as for *Jackson* class members — their budgets are tied to SIS categories. If one moves to Mi Via, the budget has nothing to do with disability but is instead based on age. A suggested service may not be offered with the SIS category to which a person is assigned. The use of the SIS is an arbitrary process that is ingrained in the system. Ms. Martinez added that the SIS is never used for planning services; it is wasted money that could be used for something else.

David Valdez, medical cannabis patient, runs a clinic to help patients get enrolled in the program. He said that patients have been dealing with this problem for a long time, and he shared some examples of issues he has experienced with other patients. According to Mr. Valdez, the DOH has a problem with misplacing applications: one out of every five is misplaced. The requirements to resubmit applications cause strain on the patients. He claimed that the DOH will not accept any diagnosis over a year old, even if a physician signs off on it. The DOH is making it difficult for both new applications and renewals. Mr. Valdez has begun hand-delivering applications to ensure that applications are arriving to the DOH. According to Mr. Valdez, DOH employees are rude and have told patients that if they were not answering calls from patients, the employees would have more time to process applications. Mr. Valdez also believes that the caps on tetrahydrocannabinol (THC) levels are ridiculous, and doctors can override that to 100% pure THC if the patient needs it. Some patients are so discouraged that they want to give up, while others are deciding to grow their own for personal use.

Tori Moorman stated that she was not surprised that DOH representatives were not present at the meeting. She told the subcommittee that Families ASAP has been very successful helping families with children suffering from seizures and brain disorders. She wishes that the PTSD diagnosis could be extended to children. She talked about her personal experience with getting a card and the costs associated with it: \$250 for certification by a physician and \$50.00 to replace a registry card that the DOH sent to the wrong address. The THC limit is also a big issue for the department. She was previously on over \$3,500 worth of medication per month paid for by Medicaid. The medical cannabis program is a huge savings to the state. There needs to be accountability on this issue.

Christopher Castillo, patient and licensed producer, told the subcommittee that it took 61 days to get his card renewed. He shared that he had experienced childhood trauma, and as a result, he has trouble sleeping. In the days he was without his card, he was unable to function normally, and he lost his job. He was deeply affected by this delay, and he is only one person out of 30,000 dealing with the same issue.

Adjournment

There being no further business before the subcommittee, the first meeting of the DCS adjourned at 5:48 p.m.