MINUTES
for the
FOURTH MEETING
of the
DISABILITIES CONCERNS SUBCOMMITTEE

October 7, 2016
Picuris Room, Albuquerque Convention Center
Southwest Conference on Disability
Albuquerque

The fourth meeting of the Disabilities Concerns Subcommittee (DCS) of the Legislative Health and Human Services Committee (LHHS) was called to order by Senator Nancy Rodriguez, vice chair, on October 7, 2016 at 9:18 a.m. in the Picuris Room at the Albuquerque Convention Center in Albuquerque.

Present	**Absent**
Sen. Nancy Rodriguez, Vice Chair	Rep. Tim D. Lewis, Chair
Rep. Miguel P. Garcia	Sen. Craig W. Brandt
Sen. Linda M. Lopez	

Advisory Members	
Rep. Deborah A. Armstrong	Sen. Ted Barela
Sen. Gerald Ortiz y Pino	Rep. Nora Espinoza

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

Minutes Approval

Because the subcommittee will not meet again this year, the minutes for this meeting have not been officially approved by the subcommittee.

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.

Friday, October 7

Welcome and Introductions

Senator Rodriguez welcomed members to the fourth meeting of the DCS, which was hosted by the 2016 Southwest Conference on Disability. Members of the subcommittee and staff introduced themselves. The subcommittee was welcomed to the Albuquerque Convention Center by conference director Anthony Cahill, Ph.D., director, Division of Disability and Health Policy, Center for Development and Disability, University of New Mexico (UNM). Dr. Cahill informed the subcommittee that the keynote address for the conference would be given by Lorri Unumb, vice president of state government affairs, Autism Speaks.

Update on State Budget Impacts on Services for Persons with Disabilities

Eric Chenier, fiscal analyst, Legislative Finance Committee (LFC), addressed the subcommittee with a post-special-session recap of state revenue projections, Department of Health (DOH) budget and the developmental disabilities (DD) waiver (please see handout for more information). Mr. Chenier explained the impact of legislation passed during the special session that resulted in a $169.4 million reduction to appropriations in addition to previous fund sweeps, capital outlay cuts, closure of tax loopholes and changes to public fund distributions. For adjustments to fiscal year (FY) 2017 General Fund appropriations, all state agencies and programs received appropriation reductions and were directed to implement those reductions within their respective departments. The exceptions to these reductions included the DOH's Developmental Disabilities Supports Division (DDSD) and Facilities Division; the Human Services Department's (HSD's) Medicaid and Medicaid behavioral health programs; the Children, Youth and Families Department (CYFD); and the Department of Public Safety. Overall, the FY 2017 operating budget for the DOH was reduced by $4.7 million during the 2016 special session.

Mr. Chenier discussed intellectual and developmental disabilities (IDD) services in the state. New Mexico is one of only 12 states not operating IDD institutions. In FY 2013, New Mexico ranked sixteenth in the nation on per capita federal home and community-based services (HCBS) waiver spending. The DDSD budget request for FY 2018 is in line with the FY 2017 request. The current budget includes $800,000 for 40 DD waiver slots and nonreverting language; while no reductions were taken, the measures are still insufficient to reduce the wait list for the waiver. The DD waiver wait list is over 10 years long and the need continues to outpace slot availability, growing at a rate of 5.5% per year. As requested at a previous DCS meeting, Mr. Chenier shared some information about how other states administer their DD waiver programs. It was noted that a state-by-state cost comparison is problematic because each state offers different services and extends services to different groups, and some states have separate supports waivers. Nationally, about one-half of the states offer a waiver for individuals with autism, and almost all of the states have a separate waiver specifically for children with IDD. Colorado has five waiver programs for individuals with IDD: a children's autism waiver; children's extensive support waiver; children's habilitation waiver for those in foster care;

supported living services waiver for adults; and a persons with DD adult waiver. Colorado also offers six other waivers, including ones for the elderly and for persons with brain injuries.

Cathy Stevenson, director, DDSD, noted that New Mexico has a waiver for the medically fragile, which is no longer limited to children. Ms. Stevenson provided the subcommittee with a spreadsheet detailing the DDSD's contracts for FY 2016 and FY 2017. Because budget cuts were restored during the special session, the DDSD will be revising the spreadsheet, and it will be provided to the subcommittee at a later date.

Members of the subcommittee and the presenters discussed several topics, including:

- interest expressed over the interim for a supports services waiver in New Mexico;
- limitations and coverage of existing waivers;
- the pros and cons of diversifying services under new waivers;
- the potential customizing of waivers to fit needs;
- limitations under the current state budget;
- the DD waiver renewal process and status;
- the possibility of setting up a supports services waiver for future implementation;
- the number of elderly in HCBS;
- concern about cuts made during the special session to public health and other health services; and
- inquiries about Colorado's waiver programs.

Supports Waiver and Renewal of State Waivers

Ms. Stevenson addressed the subcommittee regarding the current status of the renewal process of the DD waiver. Under the current DD waiver, participants are required to demonstrate need for a level of care every year with the help of an interdisciplinary team. Ms. Stevenson provided an overview of the outside review process (see handout for full details). The state is required to comply with rules from the Centers for Medicare and Medicaid Services (CMS) in order to draw down federal matching funds. The DD waiver is up for renewal by the CMS, and the state now has the opportunity to make any changes to the process for participants. New Mexico received an extension until February 2017 to submit the DD waiver for approval. The DDSD will be releasing a draft of the renewal soon; there will be a period for individuals to provide feedback on the changes. Ms. Stevenson noted that the draft has eliminated the requirement of the Supports Intensity Scale (SIS), which has drawn much criticism. The approach behind the draft renewal is that once a participant has been clinically approved for services, there is no need for reapproval of those services unless the condition has changed. The DDSD is working to reduce the administrative burden of the process. These changes are in response to the feedback from advocates and providers. In closing, Ms. Stevenson thanked DDSD staff for their work on the DD waiver renewal.

Robert Kegel, advocate, expressed appreciation for the efforts of the subcommittee in addressing issues regarding the DD waiver. Mr. Kegel believes that the state needs to do a better job during the appropriation process to ensure proper funding of programs such as DD. A member of the subcommittee noted that part of the challenge of a part-time legislature is the issue that not all legislators are fully informed on every program and service, creating a disconnect during the appropriations process. Mr. Kegel also expressed the need to keep public input at the forefront of changes regarding the DD waiver and DD services. According to Mr. Kegel, there were several issues with the DDSD's public hearing period. Many advocates, caregivers and case managers did not receive any information or notice about upcoming public hearings; a total of only 16 comments were documented. Ms. Stevenson acknowledged that no letters were sent out and notice about the meetings was only sent via email. The DDSD typically does not send out any correspondence by mail because it has been ineffective. The division does not maintain a database of addressees. Ms. Stevenson added that the DDSD is working on this issue and is seeking better methods of outreach for future use.

In response to questions raised during the August 4 meeting of the DCS, Mr. Kegel prepared two presentations for the subcommittee: 1) a survey and comparison of disability waivers that provide services to children with autism; and 2) a survey and comparison of Medicaid disability supports waivers. The presentations included detailed information about waivers and services provided in several states. Mr. Kegel is advocating for a separate autism waiver for New Mexicans, positing that if individuals get early intervention therapy, their care costs in the long-run are substantially reduced. Currently, 14 states offer waivers specifically for autism services. Total program costs range from $337,000 to $33 million, and the number of participants ranges from 47 to 1,500. The costs do not reflect the respective state's share of these costs, which can range from 50% to around 70% depending on the relative wealth of the state and the federal match rate; New Mexico's share is about 30%.

While the DD waiver has a component specifically for children, the time on the wait list is at least 10 years. In addition to comprehensive waivers, most states offer a supports waiver with an average cost of $15,000 per person in both federal and state funds. With approximately 6,000 individuals on the wait list, a supports waiver in New Mexico could tremendously benefit those on the wait list, specifically children, until they are approved for the DD waiver. Mr. Kegel would like to see three waivers in place — a children's, a supports and a comprehensive. With the implementation of separate waivers, the state could better leverage federal dollars and stimulate job creation. Leveraging funds for autism services alone would reduce General Fund costs to $53 million. Mr. Kegel urged the members to address the issue of the wait list during the upcoming session and to begin reassessing the needs of the state through the budgeting process.

On questioning, Mr. Kegel and Ms. Stevenson discussed the following topics with the subcommittee:

- the need to follow current law to avoid future litigation;
- the impact of state budget cuts during the special session, specifically cuts to the DOH;
- the likelihood of additional cuts during the 2017 regular session;

- a need to better leverage federal funds;
- a comparison of the renewal process for the Mi Via waiver;
- services being provided by non-Medicaid programs;
- the potential for individuals being excluded from services with the expansion of the waiver program;
- existing programs for children, including the Family, Infant, Toddler Program;
- eligibility for the medically fragile waiver;
- inquiries about funding for particular services and administrative costs;
- lack of coverage for autism services under the Children's Medical Services Program;
- a comparison of services provided in other states;
- a current DD waiver wait list age breakdown; and
- a request that Mr. Kegel draft a public input plan to share with the DOH.

Public Comment

Elisheva Levin is a self-advocate with autism. Ms. Levin addressed the subcommittee to voice the needs of adults with autism who do not qualify for the DD waiver or for Medicaid services. These individuals have the potential to be great contributing members to society, but they need specific services. For example, Ms. Levin stated that assistance in the development of soft skills is crucial to not only acquire a job, but to be successful in the job. Another issue facing adults with autism is the lack of providers for diagnosis — many individuals end up self-diagnosing. Ms. Levin shared that she was diagnosed out of state. She acknowledged the importance of early intervention for children, but wants to bring attention to those adults that were not diagnosed at an early age.

Gay Finlayson told the subcommittee that advocates have been seeking an autism wavier for several years. The most recent attempt, last year, sought early and periodic screening, diagnosis and treatment (EPSDT) services for children. New Mexico's current Medicaid program for children with autism who do not need specialty care is adequate. Ms. Finlayson would like to see an autism waiver that would cover a basic package for families. She also expressed concern about insurance copays, noting that some families cannot afford to pay multiple copays for services that are provided several times a week or month, and that some families terminate services for this reason. There is a need for an estimated $10 million for autism services in the state; about $3 million is currently being spent. Ms. Finlayson wondered how much the managed care organizations (MCOs) are spending on children's autism services and how much is being spent on out-of-state residential treatment. A member of the subcommittee expressed interest in receiving more information on this matter.

Wendy Corry works with individuals with disabilities and believes that a closer look at how much money MCOs are spending on out-of-state services needs to be taken. There are huge advantages for families to receive services within the state, including keeping spending in New Mexico, better support networks for families and job creation. Ms. Corry echoed the statements made by Ms. Finlayson and Mr. Kegel. She noted the importance of keeping the needs and wants of the individual with a disability at the forefront when providing services. In looking at the potential for additional waivers, the state needs to consider the tremendous cost of building infrastructure, capacity and the provider network. Ms. Corry believes that more attention needs to be given to independent living and to helping individuals develop skills to live on their own.

Sandra Fortier is the mother of a child with a developmental disability and has been denied waiver services. Her child has fetal alcohol spectrum disorder (FASD), a lifelong neurodevelopmental condition that prevents individuals from being able to live independently (a handout was provided to the DCS). Ms. Fortier questioned why New Mexico residents with FASD are being denied the services and supports they need that are provided by the DD waiver. New Mexico's DD waiver eligibility determinations currently utilize an antiquated list of diagnoses that are the only specific related conditions eligible for the waiver, even if the person has a diagnosed syndrome or disorder and meets the adaptive functioning criteria. This list from 1992 was not intended to be used as a comprehensive list. FASD was on the list but was left out of the New Mexico Administrative Code. A member of the subcommittee asked Ms. Stevenson if FASD could be included in the DD waiver renewal. Due to a pending lawsuit, Ms. Stevenson was unable to comment but noted that there is a functional eligibility requirement that would qualify an individual with FASD for the DD waiver. Ms. Fortier added that FASD is not considered an intellectual disability because individuals have IQs of at least 70. A member requested that LCS staff look at current statutes and draft potential legislation for consideration by the LHHS.

Cathy Salazar, parent, informed the subcommittee that adopted children are getting services through the DD waiver and the medically fragile waiver. Ms. Salazar wanted the subcommittee to know that the medically fragile waiver works very well but it only serves 350 children statewide. She urged the subcommittee's continued support for the waiver. Medical interventions help improve the quality of life for these children, while extending their lives and keeping them out of institutional care. The medically fragile waiver supports families by providing nursing care from home health aides. Ms. Salazar stated that there has been a movement to transfer the medically fragile waiver to the purview of Centennial Care with HCBS. She believes this would be a negative move because the program is geared more for adults. The medically fragile waiver needs to stay intact as a separate waiver.

Lisa Rosignol, parent and advocate, thanked the subcommittee for its work and attention to issues relating to disabilities. Ms. Rosignol believes that all parties that work with children with special needs have good intentions but frequently lack the resources they need. Ms. Rosignol supports Mr. Kegel's views on Medicaid 1915(c) HCBS waivers. She shared a story about a young girl in the 1980s who contracted viral encephalitis while in Iowa and was unable to return home due to the extensive care costs she required. Under President Ronald Reagan, the 1915(c) waiver was signed into law. The Section 1115 demonstration waiver of the Social Security Act was later implemented in attempts to unify MCOs and services. This waiver has done a phenomenal job meeting the needs of adults, but, Ms. Rosignol cautioned, good people make bad choices due to lack of information. Centennial Care could fill the need by providing more respite hours with an exemption from the waiver through the Aging and Long-Term Services Department.

Carol Maestas shared a handout with the subcommittee requesting the DOH and HSD to add Rett syndrome to the list of qualifying conditions for the DD waiver and Medicaid supports and services. Ms. Maestas addressed the LHHS during its September meeting regarding this issue. Until 2013, Rett syndrome was included under the autism umbrella and therefore qualified for services. Senate Memorial 81 from the 2016 regular session was introduced to look at this matter but was not passed. The sponsor has agreed to reintroduce the memorial during the 2017 legislative session. A member requested that Rett syndrome be added to the draft legislation regarding FASD for LHHS consideration.

Peter Cubra recalled the issues surrounding the SIS going back several years. He believes that there are so many elaborate mechanisms built into the system to prevent individuals from accessing the services and supports that they need by requiring them to justify services. The notion that the state was overspending on services was a false narrative. The SIS is expensive and ineffective. Mr. Cubra expressed frustration at the additional work burden being placed on case managers, leading to burnout. He acknowledged Mr. Kegel for his work and contributions as an advocate and urged the subcommittee to continue working with him. In reference to the HCBS rule presentation scheduled on the agenda, Mr. Cubra requested an end to the segregation of people with disabilities in the state. This program is still a form of segregation and is illegal. Mr. Cubra also encouraged the expansion of supportive employment, adding that more needs to be done for individuals with severe disabilities.

Dan and Barbara Taggart shared their experience with the transition planning process for bringing their son back into the state from out-of-state services. The Taggarts are 30 days away from their son's discharge, and no transition plan is currently in place. This process does not consider that New Mexico's adult placement might not meet the level of care needed by a person who ages out of adolescent placement. There is a court order for a three-year transition plan, and the family has been rejected by Molina Healthcare. The Taggarts stated that their son remains a danger to himself and others and cannot be placed in a group home. There is no place in New Mexico to care for their son. They added that just because an individual ages out of services does not mean that their needs or diagnoses have changed.

Selene Alverio has a hearing disability and is the parent of a child with autism. Ms. Alverio has had her child taken from her by the CYFD twice and is being investigated by the police. She has a bachelor's degree in social work from UNM. Ms. Alverio lost her job twice in a period of nine months because of unsubstantiated allegations by the CYFD. She believes there needs to be a change in the system to protect parents with disabilities. There should be services for parents if they are overwhelmed or if they need respite care. She would like to see a program created by the CYFD for parents and children with special needs and also a process for working with parents with disabilities.

Approval of Minutes

Upon proper motion made and seconded, the minutes for the second meeting of the DCS were approved by the subcommittee.

Final CMS Rule on HCBS

Rachel Morgan, senior committee director, Health and Human Services, State and Federal Relations Department, National Conference of State Legislatures (NCSL), addressed the subcommittee via teleconference regarding the final CMS rule on HCBS. Ms. Morgan provided some background on the rule and the long-term services and supports (LTSS) program. Medicaid is the single largest payer of LTSS, and the program provides a broad range of supports. LTSS accounts for one-third of all Medicaid spending, even though only 6.2% of the Medicaid population is receiving these services. The purpose of the final rule on HCBS was to ensure access for individuals, and it supports the United States Supreme Court ruling on *Olmstead* — a shift from the institutional setting to community-based programming. Under the new rule, Medicaid recipients receive full access to community living opportunities. The final rule provides the option to combine three different groups under the waiver. Ms. Morgan outlined the key provisions of the final rule, noting the five-year approval window and the provider payment reassignment provision. Under this provision, states are allowed to make third party payments for employee benefits; previously, states were only allowed to make payments to a practitioner. Ms. Morgan added that this is an opportunity for the state to work with some providers.

The new rule establishes criteria for qualities of HCBS settings with an emphasis on person-centered planning. Qualities for settings include: integrated settings, setting choice, individual rights, personal independence, service and provider choice. These requirements allow individuals greater access to the community, as well as more independence and control over their own lives. Individual rights must be ensured by the setting. Ms. Morgan noted that the new CMS rule does present a few challenges for the state and, with so many changes going on with Medicaid, timing may be an issue. The onus is on state agencies to implement the final rule, and CMS did not clearly define the role of MCOs. The NCSL is working with states on network adequacy as the final rule takes effect.

Jennifer Rodriguez, Community Programs Bureau chief, DDSD, mentioned that the DOH was participating at the conference and had already given two presentations. Ms. Rodriguez shared a portion of the presentation that was relevant to the CMS final rule, which included a short video. The new rule frames disability rights as both human rights and civil rights. The DDSD, DOH and HSD have collaborated to launch the "Know Your Rights" campaign — a statewide initiative to reaffirm values and get communities involved. The campaign seeks to act as a catalyst by changing how people think about individuals with disabilities. Ms. Rodriguez stated that the best way to learn how to be in the community is to live in the community; that is why the CMS rule is so pertinent. The DDSD is promoting best practices and supporting inclusion and integration into communities. New Mexico's three waivers — the DD waiver, Mi Via waiver and medically fragile waiver — and Centennial Care are subject to the final rule from

CMS. The state must be fully compliant with the final rule by March 2019. Ms. Rodriguez shared a final video, *How Do You See Me?*, demonstrating the importance of people with IDD having the same rights and opportunities as everyone else.

Melanie Buenviaje, deputy bureau chief, Exempt Services and Programs Bureau, HSD, provided a brief update on the statewide transition plan. In March 2016, the CMS asked for more details and the state opened up a public comment period, which ended on September 20. The CMS issued more guidance and extended New Mexico's submission date to October 20, 2016. The draft transition plan is available on the HSD website. The state has completed a systemic assessment of all waivers, the code governing the waivers, provider agreements and all documents that control the waivers at the state level. Through this process, several areas have been identified as needing updates to become compliant. The HSD will begin meeting with participants in these settings to make sure that they are getting their needs met in line with the final rule. To date, only Indiana and Idaho have met all of the requirements of the final rule. CMS has invited New Mexico to participate with a five-state group to discuss these transition plans.

Tallie Tolen, bureau chief, Long-Term Services and Supports Bureau, HSD, oversees the long-term care program under Centennial Care. Ms. Tolen noted that there are also long-term care services under Centennial Care's 1115 demonstration waiver. The two departments are working to integrate all of these various programs together.

In response to questions from subcommittee members, the panel addressed the following:

- further inquiries regarding the scope of the final rule;
- the impact of the final rule on the elderly in long-term care;
- the impact on providers, particularly in rural areas;
- implementation of *Olmstead* plan principles into the final rule;
- the absence of an *Olmstead* plan in New Mexico;
- efforts by the HSD and DOH to seek input from advocacy groups and the public;
- the CMS's request for the inclusion of assisted living, home health aides and the medically fragile waiver into Centennial Care;
- concern about requiring integration and limiting association;
- the availability of technical assistance to help existing programs with compliance;
- hiring efforts at the HSD for staff with disabilities and family members; and
- the scope of the HSD's Exempt Services and Programs Bureau.

Intellectual and Developmental Disabilities Employment Services Supports

Carrie Roberts, DDSD supported employment lead, DOH, provided the subcommittee with an update on employment services in New Mexico for IDD and DD. Ms. Roberts noted that the timing is optimal for promoting employment in light of the CMS final rule; she is also a member of the Know Your Rights campaign. Many different departments, divisions and organizations are collaborating in a partnership with a vision to increase capacity for employment of New Mexicans with IDD and DD. Focus is being placed on training and technical assistance for employers. Ms. Roberts shared information about recent events held to promote employment, including a symposium and webinar. The training for partners for employment had a total of 1,736 participants. Ms. Roberts highlighted the following key initiatives.

Sell Teams. Sell teams conduct outreach to meet people where they are and provide networking opportunities for local leaders and job developers.

Certified Employment Professional Exam. The certified employment professional exam is an effort to evaluate employment supports professionals. In the initial testing, 14 of the 16 people who took the examination passed, which is better than the national average. The voluntary exam will be back in 2017, and the DDSD will offer 24 scholarships for individuals wanting to take the exam.

Employment First Plan. The DDSD is taking the lead on the "employment first" plan. This process asked individuals with IDD leading questions relating to informed choice. The intent of this policy and procedure is to give some guidance and direction in determining good employment options. Ms. Roberts will participate in a statewide tour to meet with providers and answer questions about this process.

Informed Choice Project. This project is being piloted in Los Lunas and is related to the *Jackson* lawsuit. The DDSD has identified 119 individuals who are *Jackson* clients and is working with them to conduct "discovery activities".

Office Worker's Program. The existing office worker's program has been revamped to give people more experience in the community. This program will fund trial work experiences and the opportunity for a person to have the person's own business. Of the 18 participants in this program, eight have started new businesses and three have been hired by others. This program also helps individuals write their resumes.

Central Registry Unit. An additional grant is being introduced to help individuals in the registry between ages 18 and 25 with employment supports on the job. This includes additional options for transportation and other nontraditional supports.

Data Project. The most recent national data for individuals in services with an employment goal is from 2014 (data are from 2013). Approximately 18.6% of individuals with DD are employed nationally; in New Mexico, that number is closer to 36%. Currently, billed services are being tracked but not outcomes. The project seeks to track outcomes on a quarterly basis by looking at how long people have been in their jobs and how they are spending their days.

Community Life Engagement Pilot. This pilot, done through a competitive grant bid process, partners with ARCA to help people engage in community life. Out of 11 states that applied, New Mexico and the District of Columbia were awarded the grant. The "Tool Kit" pilot consists of four guideposts: individualized supports, promoting community membership and contribution, using human and social capital instead of paid supports and ensuring that supports are outcome oriented and regularly monitored. The national team will be coming to New Mexico in October.

Following Ms. Roberts' presentation, members of the subcommittee asked questions about some of the outlined projects and initiatives. A member noted that a lot of places do not know what "employment first" means and more needs to be done to promote employment over other supports and to encourage work as part of community life. Ms. Stevenson added that there is no fiscal or resource commitment from the CMS with the final rule other than technical support. All of the states are getting a slow start at implementing the final rule, and Ms. Stevenson anticipates a corrective action plan for those that are not in compliance. There is concern with the overall state budget situation and the impact it will have on programs and CMS compliance. The likelihood of limited financial resources would mean fewer services to fewer people.

Insurance Coverage for Autism: Aligning State and Federal Law

Mr. Hely addressed the subcommittee with an overview of different federal and state laws relating to autism spectrum disorder (ASD) insurance coverage (please see handout). Mr. Hely discussed the various federal and state laws, noting that there are multiple layers of law in effect. Under the federal Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA), autism is classified as a mental condition and, therefore, must be covered. Mental health parity also applies to the federal Employee Retirement Income Security Act of 1974 plans and Medicaid. Under the federal Patient Protection and Affordable Care Act (ACA), preventive service has to be provided, including ASD screening and diagnosis. Essential health benefits under the ACA include rehabilitative and habilitative services. Under the Social Security Act, states must cover ASD screenings, diagnosis and treatment under the EPSDT program for individuals under the age of 21. States may elect to include ASD services on state plans for individuals over the age of 21 or provide services through an HCBS waiver.

New Mexico currently has a mental health parity law. Under the New Mexico Insurance Code, private plans must provide coverage for diagnosis, speech therapy, occupational therapy and applied behavior analysis (ABA) therapy. State law allows state private plans to limit ASD benefits and services to individuals age 18 and under, or under age 22 if enrolled in high school. Annual and lifetime caps on the dollar value of benefits and services are also permitted. Additionally, private plans are allowed to establish copays for ASD screenings of children. New Mexico Medicaid does not provide ABA services for persons over the age of 21, which is in violation of the federal mental health parity law.

In March 2015, the Office of Superintendent of Insurance (OSI) issued a bulletin clarifying that commercial, individual and small group plans may not have limits in autism coverage pursuant to the ACA. This bulletin informs insurers that large group plans may not have limits pursuant to the MHPAEA and also indicates that the OSI will seek to change the state law "at the earliest opportunity". The OSI has the authority to enforce federal law. Some other portions of state law violate federal law, but are preempted by federal law.

Senator Rodriguez mentioned the letter (in the meeting file) to the OSI regarding multiple copays for services requested at the last meeting of the DCS. The letter is requesting the OSI to see if anything can be done to address the additional hardship on families. Senator Rodriguez hopes to receive a response prior to the 2017 legislative session in case legislation is necessary to address the issue. Members of the subcommittee discussed the presentation by Mr. Hely, noting the need for addressing existing statutes to come into compliance with federal law.

Ms. Unumb, keynote speaker, agreed with the information presented and added that adults on Medicaid cannot access ABA. If the state is able to change statute, Ms. Unumb urged the members not to codify the Diagnostic and Statistical Manual of a Mental Disorders V (DSM), but recommends language that refers to the DSM that was in effect at the time of diagnosis. This approach has been taken by other states and does not negatively affect children.

Public Comment

Nat Dean and Lindsey Sloan addressed the subcommittee regarding the abuse of service and emotional support animals usage. According to Ms. Dean, the incidence of individuals claiming pets as service animals is very high, creating problems and dangers for individuals with actual service animals. Ms. Dean thanked Senator Rodriguez for sponsoring Senate Bill 320 (2013), which made it a misdemeanor to falsely pass off a pet as a service animal. However, this misdemeanor is not being enforced by law and may require additional legislation and education about the issue. Under the federal Americans with Disabilities Act of 1990, no certification or vest is required for service animals. Ms. Sloan stated that she was forced to retire her service dog because it was attacked on a bus by another dog that was being falsely identified as a service animal. Ms. Sloan noted that bus drivers are unaware of their right to ask owners to leave. Properly trained service dogs cost between $30,000 to $70,000, making it extremely expensive to replace them. Ms. Dean and Ms. Sloan want to bring attention to the issue and are advocating for the education of businesses and transportation to better distinguish service animals from pets.

Cindy Padilla, consultant, Mi Via waiver program, wanted to share some positive feedback with the subcommittee about some of her clients. One of her clients obtains services from Very Special Arts in Albuquerque. This client, who is confined to a wheelchair, receives person-centered planning and has demonstrated major improvements and growth through his participation. Ms. Padilla wants legislators to be mindful that some beneficial programs are not considered integrated services and, therefore, would not comply with the new CMS rule. These are valuable programs that are very important to clients and the community. Ms. Padilla hopes these programs do not get left out or eliminated by the CMS final rule.

MaryBeth Weeks has six children, three of whom are waiver participants — two on the medically fragile waiver and one on the DD waiver. Ms. Weeks emphasized that the majority of participants on the two waivers are unable to self-advocate. Many of the medically fragile waiver participants get incorporated into rules without consultation of the family members or caregivers. Under the CMS final rule, Ms. Weeks and her household will be considered a "provider". Taking her children into the community creates a lot of logistical issues, and no programs will come into the home to provide services. Ms. Weeks shared that her medically fragile daughter recently caught a cold and passed away a few days later. She noted that this is a very fragile group of people who really cannot participate in a lot of the programs that are required under the CMS final rule. This population needs to be considered in any decisions and rule changes.

Ms. Stevenson, responding to a question from the subcommittee, clarified that the CMS final rule applies to all HCBS. The CMS is asking states to do validation and verification of services. The DOH is arguing that services in the home of a child are not subject to these rules; however, if the state is receiving Medicaid funding, the state must comply with the rules set forth by Medicaid. Members offered their condolences to the Weeks family and expressed the need for more advocates for the medically fragile. It was noted that gathering feedback from medically fragile caregivers and family is more difficult and must go beyond simple invitation to meetings.

Ms. Finlayson stated that she had met with the OSI over the summer regarding age limits in insurance plans. According to Ms. Finlayson, some families with children in private plans are being informed that they are "aging out" of services. She has talked to Medicaid about expanding ABA therapy for adults and the importance of expanding these services. The use of ABA has made significant impacts on individuals' progress and ability to succeed.

Elizabeth Thomson, former state representative, thanked the members of the DCS for their dedication to these issues and acknowledged Ms. Stevenson's attendance and participation in meetings. Ms. Thomson questioned the methods being used to gather public input and to advertise notice of meetings and program changes. She believes the DOH could make better use of existing listservs for autism and Down syndrome, as well as social media, to get information to stakeholders. Ms. Thomson expressed concern with the continual practice of putting money into programs that sound good but do not have any real impact on individuals' well-being; saying "employment first" does nothing if people are not actually employed. Ms. Thomson shared some of the issues she is having with private insurance covering services for her son. The state needs to look at the families that are trying to help the system by buying private insurance and not overburdening Medicaid.

Mr. Kegel stressed the importance of looking at how the state builds the budget. The budgets were built by a consultant who captured every cent of the large providers' budgets. This will have a big impact on small and rural providers. He believes the state's rate structure is a disaster; adding these additional requirements without giving providers an appropriate rate structure will result in serious problems. Mr. Kegel reiterated his concern about the lack of public comment and the need for the DDSD to compile a thorough mailing list.

Adjournment

There being no further business before the subcommittee, the final meeting of the DCS for the 2016 interim adjourned at 5:01 p.m.