MINUTES for the SECOND MEETING of the DISABILITIES CONCERNS SUBCOMMITTEE

August 25, 2016 Room 322, State Capitol Santa Fe

The second 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 August 25, 2016 at 9:17 a.m. in Room 322 at the State Capitol in Santa Fe.

Present Absent

Sen. Nancy Rodriguez, Vice Chair Rep. Tim D. Lewis, Chair

Sen. Craig W. Brandt Rep. Miguel P. Garcia Sen. Linda M. Lopez

Advisory Members

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

Sen. Ted Barela 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

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 25

Welcome and Introductions

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

Update on New Mexico's Developmental Disability Community Providers

Mark Johnson, former president and chief executive officer (CEO), Easter Seals El Mirador, testified before the subcommittee regarding the developmental disabilities (DD) waiver from a provider prospective. Mr. Johnson thanked the subcommittee for its support and its advocacy for individuals with developmental disabilities. Approximately \$331 million goes into the state DD waiver system, including the Mi Via waiver. The system serves approximately 4,400 adults. These services include case management, day support and residential treatment. Mr. Johnson noted that New Mexico is one of a handful of states that operates a totally community-based system and does not have any state institutions of care. Mr. Johnson spoke about some of the cuts that have been made to the system over the last several years. Since 2011, there has been a reduction of almost \$35 million in the DD waiver system. There was a five percent across-the-board rate reduction for providers and an eight percent reduction in the budget for recipients. In 2012, the DD waiver system for adults experienced an additional loss of \$17 million for various programs following a controversial rate study. At the same time, there has been a substantial increase in regulations, as well as mandates from the *Jackson* lawsuit.

The federal Patient Protection and Affordable Care Act has also increased health insurance premiums for more than 300 members of the Association of Developmental Disabilities Community Providers (ADDCP). As a result, several community-based programs have been closed or forced to eliminate supported-employment or supported-living programs. Additionally, some providers are experiencing staff turnover rates of 35 percent to 40 percent.

The difficulty in finding nursing personnel is becoming a real issue for providers. Mr. Johnson noted that the state is now in the twenty-ninth year of the *Jackson* lawsuit, and the state's legal fees to date total \$50 million. There are approximately 288 remaining *Jackson* class members. While the named defendants are the State of New Mexico and the Department of Health (DOH), the state has directed providers to implement the court's orders and requirements in the form of unfunded mandates. Mr. Johnson urged the subcommittee to consider a more comprehensive approach to the waiver system in the pending special session and upcoming regular session. According to Mr. Johnson, provider fees can be leveraged for Medicaid, and the New Mexico Health Care Association is working to resolve revenue enhancements for nursing homes and for intermediate care facilities for individuals with intellectual disabilities to leverage Medicaid funding.

The ADDCP's legislative platform includes: continuing to protect provider services for the most vulnerable population; a Medicaid provider act that would ensure due process for providers to address credible allegations of fraud and limit the use of extrapolation and sampling; *Jackson* lawsuit disengagement, which would require that all stipulations from the *Jackson* litigation be funded with money for compliance purposes; and a consumer and provider protection act that would safeguard providers against frivolous lawsuits.

Kathey Phoenix-Doyle, executive director, La Vida Felicidad, discussed the objectives and impact of the Family Infant Toddler Program (FIT) (please see handout for more

information). FIT serves children from birth to age three who are at risk of, or who have, a developmental disability by providing services in the child's natural setting. The program is designed to work with caregivers and children to overcome delays and maximize the potential of a child to achieve functional outcomes as close to the child's typical developing peer. Since 2009, FIT funding by the DOH for infants and toddlers at risk has been cut from 228 hours of service per year to 24 hours of service per year. That averages out to two hours per month. Currently, there are 10,693 children across the state, both in urban and rural areas, who are actively receiving services. New Mexico is the only state that includes Part C (FIT) programs in its Race to the Top grant. Ms. Phoenix-Doyle explained that this inclusion has actually been cumbersome for any home-based service system, and changes have resulted in additional costs for the providers. A 2003 rate study commissioned by the DOH determined that the rates do not cover the cost of services. For the last 13 years, providers have not been fully reimbursed for early-intervention services for children.

Ms. Phoenix-Doyle expressed concern about the need for higher rates for providers serving frontier areas. Rural areas struggle to attract early interventionists or therapists due to the remoteness of the locations, and those who are willing to travel are not compensated for travel time. In addition, the new Fair Labor Standards Act of 1938 (FLSA) rules raising the salary at which an employee is exempt will have a sweeping impact on providers. The cost of doing business will increase because overtime will now be paid to staff members who were once considered exempt. Ms. Phoenix-Doyle added that with the large amount of paperwork, the time lines and the quality initiatives being introduced, the time spent by early interventionists far exceeds a 40-hour work week. The FLSA rule change will increase the financial burden on providers. She concluded by assuring the subcommittee that all FIT providers are committed to providing high-quality services for children who are at risk of, or who have, a developmental disability. Parents want and deserve access to services for their children to succeed at the highest level possible.

Jefferson Kee, executive director, Coyote Canyon Rehabilitation Center, Inc., is a service provider in the northwest region of the state, including San Juan and McKinley counties. He addressed the subcommittee about how recent rate reductions and implementation of Supports Intensity Scale (SIS) assessments have affected the Indian reservations that his company serves. Mr. Kee explained that there are very few providers on the Navajo Nation, and individuals have no place to go after graduating from school. The staff at the center wants to help individuals with disabilities to live productive lives, but there are few opportunities available for them to remain on the reservation with limited public transportation. Mr. Kee hopes the state would consider the amount of travel some providers have to do and compensate them accordingly. The limited number of physical therapists has also been an issue, along with high turnover rates. In terms of the SIS, proponents of the assessment do not consider the limited access to medical facilities and specialized services for individuals living on the Navajo Nation. Eliminating the SIS would lower costs and allow for the restoration of some funding to direct support services. He requests that the DOH and lawmakers consider the rural areas of the state when conducting rate studies and considering any potential budget cuts.

Richard Weigle, administrative coordinator, ADDCP, agreed that the use of the SIS and the changes in reimbursement rates have affected providers and clients. Mr. Weigle recounted how the state was sued to prevent the use of the SIS in establishing a client's funding level. As a result, the state agreed to an outside review that would determine funding levels. He believes the SIS is redundant and that its elimination would save the state \$500,000 per year. Those funds could be allocated for direct services. In 2014, there were 94 agencies providing residential services. Thirteen have since closed, and several others no longer provide waiver services (please see handout). The loss of those agencies has had an impact on consumer choice, and the loss of funding for agencies has affected the ability to retain and recruit staff. Mr. Weigle echoed support for the legislative agenda outlined by Mr. Johnson, adding that the DOH needs to work closely with the ADDCP and its providers.

In response to subcommittee members' questions, the following points were discussed by the panel:

- the potential structure and channeling of a provider fee to receive matched federal funding;
- what other states are doing with respect to provider fees;
- changes to the rate structure in frontier and rural areas and reimbursement for travel time:
- incentives for individuals to work in these communities and rural areas;
- the simplification and better explanation of rates;
- the difficulty of retaining qualified staff while facing increased regulatory burdens and costs;
- support for another rate study to be conducted;
- the state's ongoing budget issues due to declining revenues;
- wasteful spending on program oversight rather than on direct services;
- various questions about the ADDCP's legislative agenda;
- the impact of the closure of many of the state's behavioral health providers due to unsubstantiated allegations of fraud and the need for provider protections;
- the impact on providers of unfunded mandates from new rules and regulations;
- an early childhood education degree as a potential requirement for the FIT;
- allocations for the DD waiver and the amount received per recipient; and
- the impact of the new federal overtime rule, which becomes effective in December 2016.

Report from Developmental Disability Case Managers

Lecie McNeese, director, Visions Case Management, Inc., provided the subcommittee with a rate sheet that was requested during the earlier presentation.

Stacy Scott, case manager (CM), Cariño Case Management, provided the subcommittee with an overview of the work done by CMs and distributed a handout describing their scope of work. CMs are advocates for the individuals they serve while creating the link to needed

medical, social, educational and other services. CMs facilitate assessments, assist with securing financial and medical eligibility and emphasize and promote the use of natural and generic supports. Ms. Scott explained that CMs are the first point of contact for individuals coming off the wait list and on to the DD waiver. CMs report to the Developmental Disabilities Supports Division (DDSD) of the DOH, but they are independent contractors who do not receive any benefits from the state, such as retirement, sick leave, annual leave or compensation for hours traveled to meet with waiver recipients. Ms. Scott added that CMs are the state's first line of defense against Medicaid fraud as they monitor services and supports to individuals and ensure that they being are administered appropriately.

Scott Newland, president, Unidas Case Management, Inc., stated that the decentralized network is the strength of the DD waiver system. Recipients have a choice of service providers. The decline in the number of service providers has been, in part, due to the relatively constant number of persons on the DD waiver. Since January 2015, there has been a serious backlog in outside reviews for justification of services. This has resulted in budgets not being approved in a timely manner and limiting access to services. Mr. Newland noted that approval of routine changes in a recipient's budget or services that used to take a few days is now taking months. In response to a question from a subcommittee member, Ron Vorhees, director, Medical Division, DDSD, explained the reason for the outside review (OR) by a third party. The DOH has received several complaints about the length of time that the ORs are taking and the lack of communication with CMs; the department is working to address these issues. Mr. Newland believes that the SIS should be eliminated and that funds should be redirected to direct services. He also recommended that the subcommittee stay informed about the status of the OR process.

Melinda Broussard, director, A Step Above Case Management, addressed the subcommittee to advocate for fair compensation for services provided by CMs. The OR process has increased the burden on CMs, yet they have not received any increases in compensation for the additional workload. Ms. Broussard suggested that the SIS be eliminated and that funds be redirected to pay for the additional work being done by CMs. She explained that the extensive amount of documentation being required by the OR for clinical justification of budgets is causing delays. Individual budget packets have gone from 20 pages to upwards of 200 pages. According to Ms. Broussard, changes to the DD waiver program were made without any input from CMs. The DD waiver serves a large range of individuals, and what works for one DD waiver recipient does not necessarily work for all of them. CMs want training on changes to the program prior to their implementation and better professional interactions with the DOH and Qualis, the third-party assessor for DD waiver services. Ms. Broussard provided the subcommittee with an email exchange to illustrate her point that requests for meetings with the DOH and Qualis have been denied.

Ms. McNeese provided an example of the workload increase and new requirements of CMs in terms of paperwork. She explained that most budget rejections and denials of services occur because of technical errors, triggering a request for information (RFI). Ms. McNeese described the RFI process and shared copies of what submissions look like with the additional

paperwork. There are 4,462 DD waiver recipients, and this process has to be done for each individual on an annual basis. Over the last 12 years, the workload for CMs has increased significantly, yet there has not been any increase in reimbursement for at least 10 years. CMs are paid a flat rate for each client and are now spending double or triple the amount of time on each client. In addition, overhead expenses continue to increase, and CMs have to deal with new rules and requirements resulting from any litigation against the state without any corresponding increase in compensation. Ms. McNeese suggested that if a rate increase is not possible, the administrative burden should be reduced. The CMs want to work with the DDSD to reduce their administrative burden and eliminate the SIS program. Ms. McNeese added that with the DD waiver currently under revision, now is the time to implement some of these changes to make the system more efficient for providers, CMs and, ultimately, program recipients.

Dr. Vorhees stated that the DOH is looking at how coordination of care can be streamlined. He acknowledged that there are a number of things that can be done to address stressors in the system. Dr. Vorhees said that the DD waiver system is fragile and complex. The department has already been considering suspending the SIS entirely. He told the subcommittee that he would take these concerns back to the DOH and look at the possibility of lengthening the time between budget submissions.

Robert Kegel, a parent and advocate for people with developmental disabilities, believes the new submission requirements are unnecessary. CMs have to submit a new packet every 12 months regardless of whether any changes have been made. Mr. Kegel believes that budget submissions should only be done to justify changes in services. He also believes that the SIS does not work efficiently and should be eliminated.

In the ensuing discussion, subcommittee members discussed the following:

- the need for annual budget submissions without service changes;
- the effectiveness and administration of the SIS;
- details about the third-party assessor, Qualis;
- concern about unnecessary levels of bureaucracy;
- concern about the collapse of the DD waiver system;
- lack of communication from the DOH and the need for addressing phone calls from CMs:
- a request for the DOH to provide the subcommittee with a synopsis of what the OR process is and justification for each level of oversight; and
- a request for the Legislative Finance Committee to provide a report on the Oregon model of supports waivers and the potential for eliminating the SIS.

Update: Special Needs Planning

Nell Graham Sale, partner, Pregenzer, Baysinger, Wideman & Sale, P.C., provided the subcommittee with an update on enabling legislation required by the federal Achieving a Better Life Experience (ABLE) Act of 2014. During the 2016 regular session, the legislature passed the

Accounts for Persons with Disabilities Act (Section 6-8A-1 NMSA 1978, et seq.). The state treasurer is responsible for promulgating rules to implement and administer this act. The act allows for the establishment of support accounts (in accordance with the federal ABLE Act) for eligible individuals with developmental disabilities. Ms. Sale clarified that all DD waiver recipients who became disabled before the age of 19 would be eligible. As provided by the ABLE Act, accounts are tax deferred and are one way to set aside funds for disability-related expenses without affecting the beneficiary's eligibility for means-tested programs like supplemental security income and Medicaid.

Four states have gone into the business of offering ABLE accounts: Florida, Nebraska, Ohio and Tennessee. All but Florida welcome applications from other states, and accounts can be rolled over from one state to another. Ms. Sale emphasized that New Mexico residents do not need to wait for the state treasurer to promulgate regulations for the Accounts for Persons with Disabilities Act to establish support accounts but can do so immediately through other states whose programs are further along. Ohio's program is already up and running, charging \$5.00 a month for nonresident account holders.

Ms. Sale explained how contributions can be made to accounts over time and used for housing and transportation expenses (please see handout regarding ABLE ACT account programs). There is a national ABLE clearing-house website that provides webinars on the different programs available through various states. Ms. Sale urged members to share this information with constituents to let them know this resource is available.

Public Comment

Melissa Coleman addressed the subcommittee as an advocate for parents of children with disabilities. Her son was born prematurely, leading to multiple disabilities, including a diagnosis of autism spectrum disorder (ASD). Her son was able to receive early intervention services from New Vistas; however, when the disruption in the behavioral health system occurred, he lost these support services. Ms. Coleman informed the subcommittee that her son had to be placed in a facility in Utah, and her family has paid nearly \$300,000 out of pocket to get him the services that he needs. She had previously been told that it would take up to 10 years to get on the DD waiver. Her son has been on the DD waiver wait list for seven years. She has seen some improvements in her son's health, but his care is costing about \$11,000 per month. Ms. Coleman stated that the only alternative for families in this situation is the juvenile justice system. Her family is desperate for her son to come home, but with limited resources in the state, it is not possible.

Nat Dean spoke about the Brain Injury Services Fund, which helps with support services for acquired brain injuries. Currently, the fund only has about \$100,000 available. To meet the needs of the approximately 275 people who require services, the fund needs \$1.2 million. Ms. Dean explained how services from the fund are administered. By law, a fee of \$5.00 to be credited to the Brain Injury Services Fund is supposed to be assessed for traffic misdemeanor moving violations. However, since more individuals are being sentenced to community service,

the fund's revenue stream has dwindled. Ms. Dean hopes the legislature will consider supporting the fund in the future.

Liz Thomson, a former state representative, addressed the recently announced five percent across-the-board budgets cuts in response to the state's declining revenues. She is concerned about the rising rates of autism, the availability of services and the impact that budget cuts will have on families of children with ASD. Her son recently had his SIS assessment, and Ms. Thomson described for the subcommittee what his designation of "C class" means in terms of service recommendations. According to the assessment, her son is in need of "mild to above average support", but she stated that her son needs extensive care seven days a week, 16 hours a day. Ms. Thomson believes this is an example of how the SIS is not an accurate assessment tool.

Mr. Kegel provided the subcommittee with a brief presentation and written material on the DD waiver. He discussed the Developmental Disabilities Act (Section 28-16A-1 NMSA 1978, et. seq), which is the enabling act for the DD waiver. According to the statute, "Support and services shall be provided based on individual support and service plans developed by an interdisciplinary team. The team is responsible for collectively evaluating the child's or adult's needs and developing an individual support and service plan to meet the needs.". (Section 28-15A-13(B) NMSA 1978). Mr. Kegel pointed out that the statute does not require or provide for outside review, the SIS or any other kind of assessment. The interdisciplinary teams, he noted, are composed of professionals specified by statute that could adequately determine the needs of an individual. He believes that the state needs to be following the law and that 30 percent of funds should not be going to pay for the SIS. Mr. Kegel directed the subcommittee to the statutory requirement for a statewide adult support and services task force charged with quality assurance. Mr. Kegel also addressed the issue of community meetings and what he argues is inadequate public notice of pending changes to the DD and Mi Via waivers. Mr. Kegel said he cannot find one person who received a mail notice for any meeting on proposed changes to the DD waiver. Some case managers and providers may have gotten a notice, but they do not have any obligation to send that information on to parents and caregivers. He asks that the DOH conduct another round of meetings to provide the opportunity for public input. He added that at the meetings he has attended in the past, public comment was limited solely to topics on the agenda. He believes that this allowed the DOH the ability to control the conversation and avoid discussing issues that the department did not want to discuss.

Senator Rodriguez expressed concern about the short notice given for the meetings. She requested an explanation from the DOH for why these notices are being mailed out so late and why the state is not meeting the statutory requirements as mentioned by Mr. Kegel. The Human Services Department (HSD) and DOH representatives at the meeting stated that they would take the concerns of the subcommittee back to their respective cabinet secretaries and the heads of those programs.

Autism Flexible Services Program

Marc Kolman, deputy director, DDSD, explained that a variety of autism services are funded by the DOH, including respite supports, and are administered through the University of New Mexico (UNM) Center for Development and Disability (CDD). The program was designed to supply up to \$2,500 a year in support services for individuals who are not Medicaid eligible.

Patricia Osborn, program operations director, UNM CDD, shared a handout with an overview of recent autism initiatives in the New Mexico Legislature. Ms. Osborn discussed some of the background of UNM CDD, noting that it has 35 medical professionals. Two new initiatives of UNM CDD are expanding bilingual services and increasing participation at Camp Rising Sun. Ms. Osborn explained that the camp has been used as a place to train individuals and to increase the awareness of living with a child with autism, providing participants with the opportunity to learn how to meet those needs. UNM CCD has long wait list, and it has seen a 38 percent increase in requests for evaluations. UNM CDD has had to cut services in the last three years due to budget constraints, which has greatly affected the services the center is able to provide. She cautioned that further cuts would jeopardize the system.

Dauna Howerton, quality and compliance manager, Behavioral Health Services Division, HSD, provided a presentation to the subcommittee on applied behavior analysis (ABA) for the last two years. ABA treatments are interventions to change behaviors for members identified with autism spectrum disorder (ASD) and for individuals considered to be at risk. ABA services are available for Centennial Care members ages one to 21. Treatment involves regular assessments for progress and involves the family. Many of the services are done at home. Ms. Howerton described the three stages for ABA and said services include an autism evaluation provider, a behavior analyst and behavioral technicians. These individuals work to develop individualized service plans (ISPs) and set goals for the client. All of the managed care organizations (MCOs) have staff with knowledge of ABA and work with providers to ensure a unified understanding of service. When the program began in May 2015, there were 30 members receiving ABA services; as of March 2016, that number has grown to 118 individuals. The number of ABA providers has also grown from six to 14, expanding each of the three stages. The network of ABA providers continues to grow statewide, making services more accessible to families.

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

- the reclassification of ASD from a developmental disability to a behavioral health issue, so it is now covered by Medicaid;
- the tendency for individuals with autism to have multiple diagnoses and additional needs for services;
- the lack of residential services available for persons with ASD;
- limitations of services through the school system and the inability to extend services beyond school age;
- efforts to create wrap-around services for individuals leaving residential care;

- the criteria for individuals with ASD to be eligible for the DD waiver and the possibility of statutory changes to expand services;
- the increasing number of ASD diagnoses throughout the country and internationally;
- the increasing number of adult ASD diagnoses;
- work by MCOs to return children to their homes from out-of-state institutions;
- the importance of educating members of the legislature and members of the public on health issues like ASD; and
- concern about potential funding cuts for programs due to the state's economic situation.

ASD Diagnosis, Assessment and Services

Rick Loewenstein, chief strategy and growth officer, Centria Healthcare Autism Services, addressed the subcommittee regarding the services his company provides for New Mexicans with ASD. Centria is a leading national provider of ABA, with operations in multiple states. It currently provides in-home and center-based ABA therapy to more than 800 children, including 41 in New Mexico. Mr. Loewenstein explained that Centria came to the state at the request of one of the Centennial Care MCOs due to the shortage of autism providers and board-certified behavior analysts (BCBAs) in the state. Part of Centria's successful growth is due to its community-based approach, which includes learning who the stakeholders are in the community, meeting with them to understand their needs and finding opportunities to work collaboratively in support of children with autism and their families. Centria currently employs 60 people in the state, and it hopes to serve another 30 children in the next few months, which will require the hiring of an additional 50 team members. Mr. Loewenstein applauded the New Mexico Legislature for adopting legislation that has paved the way for thousands of children to access ABA services, and he recognized other state initiatives to expand treatment options.

Mr. Loewenstein also noted a few areas in which the state could improve, primarily in meeting the high demand for services and addressing the lack of human resources. Additionally, there have been several system bottlenecks that have resulted in service delays (see handout). Mr. Loewenstein described some of the problems at each of the three stages of the ABA service program and made recommendations to address them. One difficulty has been the lack of stage 1 providers and that only a licensed psychologist, developmental pediatrician or pediatric neurologist can perform the assessment needed to determine if ABA will be an effective therapy under current state law. This has resulted in hundreds of children waiting to receive an assessment. Mr. Loewenstein suggested that the subcommittee consider allowing limited licensed psychologists to complete stage 1 testing on the condition that evaluations are signed off by a licensed psychologist. In closing, he emphasized the importance of early intervention and reminded the subcommittee that any barrier to services that can be erased will not only benefit a child with autism, it will affect the child's family, friends and community.

G. Richmond Mancil, executive director, New Mexico Autism Learning Partners, also noted the lack of services in the state, particularly in rural areas. Its parent company, Autism Learning Partners, is based out of California and provides services in several states. Mr. Mancil

said that another issue affecting stage 1 is the lack of available ABA services in some areas, even when assessments have been conducted. Frequently, families have to repeat an evaluation. Mr. Mancil urged the support for any funding increases for services around the state. He also recognized the work of Sarah Baca from the New Mexico Autism Society and Shawn P. Quigley, a BCBA from UNM.

Stacy M. Ertle, owner and CEO, Bridges, Inc., discussed some of the barriers to accessing ABA services. Founded in 1997, Bridges, Inc., is the state's oldest provider specializing in autism in both Santa Fe and Albuquerque. Ms. Ertle outlined some of the biggest challenges that need to be addressed, as follows, and requested the support of the subcommittee.

- 1) Autism diagnosis. UNM CDD needs increased funding in order to provide autism diagnoses in a timely manner. Currently, children are placed on a wait list before being seen for a diagnostic evaluation.
- 2) Copayments for ABA. ABA is the most recognized evidence-based treatment for children with autism. While many commercial plans provide ABA as a benefit, a copayment is charged for each date of service. ABA is an intensive service, with multiple sessions per week, resulting in multiple copayments per week. This is very cost-prohibitive for many families. Eliminating date-of-service copayments for ABA, or at least reducing them to a monthly cost-share, would be helpful.
- 3) New Mexico's limited capacity of behavioral health providers. Autism is the fastest-growing developmental disability. Providers in the state cannot meet the growing number of families affected by autism. Drastic cuts in Medicaid reimbursement rates have forced some agencies and companies to greatly reduce or eliminate behavioral health services to Medicaid recipients.

Tammie Teague, executive director, Guidance Center of Lea County, used to be a special education teacher and is a parent of a child with autism. The Guidance Center of Lea County is a nonprofit community mental health organization that added an autism clinic this past April. The clinic provides stage 2 and stage 3 services and offers support to clients in their homes, along with training for parents. Most clients receive 10 to 20 hours of therapy per week; more is available if necessary. The clinic currently has nine children on its wait list. Ms. Teague mentioned that she has contacted each school district in Lea County, and there are an estimated 120 students who have received an autism diagnosis, with the possibility of more who have not been diagnosed. UNM CDD has been a tremendous resource for the guidance center, providing diagnostic evaluations for clients.

Kathleen Karimi, co-founder and CEO, business operations, Behavior Change Institute, offers home- and community-based ABA services to clients in New Mexico. The Behavior Change Institute will be integrating individual and group psychotherapy into its service options. Ms. Karimi explained the use of telemedicine for ABA, which has been an indispensable resource in accessing rural areas. According to the U.S. Census Bureau, there are more than two million people living in New Mexico, and one in 68 will be diagnosed with autism. However,

not everyone should receive ABA treatment. Currently, there are 39 BCBAs in the state who can each oversee about 24 families; this is not enough to meet the need in the state. Ms. Karimi also thanked Dr. Quigley and representatives from the HSD for their work.

Abel Covarrubias, CEO, Aprendamos Intervention Team, shared his story of a family member in Hatch, New Mexico, with a severe seizure disorder. Mr. Covarrubias sees the importance of providing services to children in rural parts of the state. The Aprendamos Intervention Team begins screening children between the ages of 18 months and 24 months, but it is taking UNM CDD eight months to provide a diagnosis. Currently, Aprendamos is servicing 40 children with intensive therapy each week with the help of four BCBAs and one interim supervisor. Mr. Covarrubias hopes to expand to seven BCBAs and to provide services to 20 families on the wait list in Dona Ana County. Challenges that Aprendamos faces include receiving timely reimbursement from Medicaid MCOs, recruiting and retaining BCBAs and the ongoing lack of funding for autism services.

The subcommittee discussed several topics relating to the presentation, including:

- the process for getting credentialed by MCOs;
- various questions about the bottlenecks at the three stages, as outlined by Mr. Loewenstein:
- inquiries about the different certifications of medical professionals and their abilities to perform assessments and create ISPs;
- credentials and oversight of service providers;
- the need to expand the number of medical professionals in stage 1 to get necessary services to clients while maintaining quality;
- extending the authority for masters-level clinicians to do ABA at stage 2;
- current funding for UNM CDD;
- the need for more services in rural areas and expanding the use of telemedicine;
- eliminating per-visit copayments in favor of a monthly cost-share; and
- a request for an annual presentation on autism and treatment infrastructure in the state for the DCS and, possibly, the LHHS.

Motion 1

Upon a motion by Senator Ortiz y Pino, seconded by Representative Garcia, the subcommittee recommended that a letter be drafted and sent to the superintendent of insurance regarding the issue of copayments for ABA services and the financial impact on families. The motion was approved.

Public Comment

Bonnie Hardin, parent, told the subcommittee about her experience with her autistic son. Due to her age, she went to the Mayo Clinic to have a child, who was born with autism and was later diagnosed with attention deficit disorder. Upon her son's release from Texas Neuropsychiatric Institute (TNI), she was given no treatment plan or information about how to

care for her son's needs. According to Ms. Hardin, had her son received early intervention services for the eight months he was at TNI, it would have saved Medicaid a lot of money. Staff needs to be properly trained to help families, and there need to be ABA services for all ages. She believes that funds are being wasted on ineffective treatments, and individuals seeking help for their families are becoming victims of fraud.

Ms. Baca was present at last year's subcommittee hearing on autism. She mentioned that, just last year, there were limited options for ABA, but now the options are being expanded and the wait lists are being reduced. She thanked the subcommittee and the numerous advocates who have supported this issue, noting that there is still work to be done. Ms. Baca has a son with autism, and he is now getting the services that he needs and is doing great.

Zoe Migel, executive director, Bright Futures, has worked in this field for about 20 years. She was also present at last year's hearing and informed the subcommittee that every one of the families she spoke about is now receiving the services they need. Ms. Migel talked to the subcommittee about some of the work that still needs to be done, particularly in providing services to Native Americans and Spanish-speaking immigrant families. She works in rural areas north of Santa Fe; telehealth has been a great asset to these communities. Ms. Migel would like to see the Public Education Department (PED) involved in conversations about autism and to be present at subcommittee meetings. The medical community and the education community need to work collaboratively to truly help a child succeed. She noted that the main issues in the system are at stage 1. The process of becoming a stage 1 provider is arduous; there are people who are qualified to conduct the necessary evaluations, but they are not approved through Medicaid or the MCOs. The reduction in the family psychotherapy billing code has affected her practice dramatically. She added that autism has affects on the entire family as a whole, including siblings. In terms of telehealth, Medicaid recommends reimbursement, but only one of the MCOs will cover it. She believes that a number of companies and providers would expand telehealth services if they were reimbursable.

Ms. Thomson addressed the subcommittee briefly to thank members and the staff for their work and for keeping a light on autism issues. She also suggested that representatives from the PED's Special Education Bureau be routinely invited to subcommittee meetings.

Adjournment

There being no further business before the subcommittee, the second meeting of the DCS adjourned at 4:53 p.m.