

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

**October 29-30, 2009
Room 307, State Capitol**

The first meeting of the Disabilities Subcommittee (DS) of the Legislative Health and Human Services Committee (LHHS) was called to order by Senator David Ulibarri, chair, at 10:15 a.m. A subcommittee quorum was present. The chair stated that a report of this subcommittee will be made to the LHHS, along with legislative recommendations, at its meeting next week.

Present

Sen. David Ulibarri, Chair
Rep. Danice Picraux, Vice Chair
Rep. Nora Espinoza
Sen. Gerald Ortiz y Pino
Sen. Nancy Rodriguez

Staff

Michael Hely, Staff Attorney, Legislative Council Services (LCS)
Karen Wells, Researcher, LCS

Guests

The guest list is in the meeting file.

Handouts

Handouts are in the meeting file.

Thursday, October 29

Welcome and Introductions

Senator Ulibarri welcomed everyone. Members of the subcommittee introduced themselves.

Disability History 1841-1990: The 150-Year Struggle for Civil Rights and Community Living

Jim Parker, director, Governor's Commission on Disability, provided detailed information describing the long struggle to achieve civil rights and community living for disabled individuals. As early as 1892, Samuel Gridley Howe warned of the dangers of segregation based on disability. Other early champions of disability rights included Dorthea Dix, Henry H. Goddard and the

Catholic Church. In 1927, the U.S. Supreme Court, in *Buck v. Bell*, ruled that forced sterilization of people with disabilities violates their constitutional rights. President Franklin Delano Roosevelt put a personal face on disability as the first seriously, physically disabled person ever to be elected as a head of government. The federal Civil Rights Act of 1964 outlawed discrimination on the basis of race and became a model for subsequent disability rights legislation. In 1973, Congress passed the Rehabilitation Act, which served as a framework for the Americans with Disabilities Act (ADA), and in 1975, the Developmentally Disabled Assistance and Bill of Rights Act was passed. Also in 1975, Congress passed the Education for All Handicapped Children Act requiring education for children with disabilities to be integrated with fully abled children. In 1984, the U.S. Supreme Court ruled that localities cannot use zoning laws to prohibit group homes from opening in residential areas solely because their residents are disabled. In New Mexico, 1987 was a critical year in which 21 people with disabilities filed a class action lawsuit on behalf of residents of Fort Stanton and the Los Lunas Hospital and Training School. The lawsuit, *Jackson v. Ft. Stanton*, came to be known as the *Jackson* lawsuit and resulted in the de-institutionalization of those residents. The lawsuit is ongoing as the state strives to meet the terms of the agreement. On July 26, 1990, President Bush signed the ADA, which awarded people with disabilities the same civil rights as fully abled citizens.

Subcommittee members had questions and made comments as follows:

- recognition that there is still work to be done to overcome prejudice against people with disabilities;
- a description of relatively recent injustices and poor treatment at the New Mexico School for the Deaf;
- recognition of several individuals referenced in the presentation who were important figures in advancing the rights of the disabled in New Mexico; and
- expressions of thanks for the very informative presentation.

Legislation: Disabilities Task Force (Senator Eric G. Griego)

Mr. Hely, joined by disability advocates Marina Cordova, Esq., and Nannie Sanchez, presented a draft of a bill requested by Senator Eric G. Griego to create a disability concerns task force. Mr. Hely described the task force that would be created through this bill, which would be composed entirely of people with disabilities, legislators and members of the executive branch serving in an advisory capacity. The primary goal of the task force would be to study the needs of the disabled and to develop a plan to accommodate those needs in New Mexico. A report of the findings and recommendations of the task force would be required by October 1 of each year beginning in 2011.

Ms. Sanchez expressed appreciation for the development of this draft, noting that there are many areas of need that a task force such as this could address. Ms. Cordova noted the importance of a variety of different types of disabilities on the task force and stated that the task force could not only identify problems, but also highlight their strengths. She distributed some suggested changes, including a list of specific priorities for the task force to study. Jim. Jackson, director, Disability Rights New Mexico (DRNM), reported that he previously provided some comments on the draft to Mr. Hely. He pointed out that input from the full range of people with

various disabilities should be sought. The DRNM supports a combined committee of legislators and advocates and suggests that the ultimate focus of the bill might need to be narrowed, as the issues are very broad. The task force should be given the direction to identify the specific issues to address in a given year.

Subcommittee members asked questions and made comments as follows:

- the need for a central telephone number to streamline and facilitate access to services for the disabled and the need for more accountability in the service delivery system;
- a suggestion that a mother of a disabled child be a member of the task force;
- the importance of including the administration on the task force, but only as advisory members to the full committee;
- acknowledgment that Senator Eric G. Griego has not yet provided input on the bill draft;
- ways in which the proposed task force would coordinate with the Governor's Commission on Disability;
- recognition that there is a difference between a deaf person and a person who is hard-of-hearing; the needs of the two are dramatically different and should be so specified in the bill;
- recognition that the bill might not be determined germane in a short session of the legislature and a suggestion that the bill could be converted into a senate joint memorial; and
- the importance of working together to create solutions.

Report from the 2009 Southwest Conference on Disability

Ms. Wells gave a brief overview of the 2009 Southwest Conference on Disabilities. She introduced Anthony Cahill, director of the Center for Development and Disability, University of New Mexico (UNM) Health Sciences Center School of Medicine, and Mr. Parker as co-sponsors of the conference. She identified the conference as an extraordinary opportunity to learn about disability issues and solutions.

Public Comment

Ms. Cordova identified herself as a blind person with a blind daughter and spoke to the specific nature of blindness as a disability. She urged the subcommittee to ensure continued funding for the Commission for the Blind, highlighting services the commission provides. She recommended that licensure requirements for teachers of the blind require completion of the National Literary Braille Competency Test. She requested that regulations be changed to remove the provision allowing special education teachers to provide services to students who are blind or visually impaired. She would like to see an evaluation of the current system for recruiting and maintaining licensed teachers of the blind and visually impaired. Currently, some blind students are not offered the opportunity to learn braille due to the lack of available teachers. Finally, she advocated for the development of a comprehensive, statewide system to recruit and contract with qualified teachers. She provided a handout that discussed each of these issues in greater detail.

Raya Soleil identified herself as the single mother of a son with visual and physical disabilities. She spoke of the importance of the Medicaid medically fragile and developmental disabilities (DD) waivers, both of which have benefited her son. He is now enrolled in the Mi Via waiver, which allows him to independently manage his life with the help of his mother. She requested subcommittee members to protect the funding for these vital waiver programs. Subcommittee members stated that during the recent special session of the legislature, the DD waiver and the Medicaid programs were not cut; the legislature does not agree with the governor's interpretation of this issue.

Joanne Tapia Eastham identified specific problems inherent in the public school system for children with disabilities and the lasting effect of inadequate supports while they are of school age. The challenging and important role of mothers was recognized. Ms. Eastham advocated for a system of licensed Medicaid providers who could serve children in schools and assist families to link up with local resources. Ellen Pinnes noted that the federal Medicaid program has a "medically needy" option that would allow a family to "spend down" their income to qualify for Medicaid, but New Mexico has not adopted this provision. She clarified some of the numerous income eligibility categories for Medicaid.

Deb Dennison told her story as a mother of a recently deceased son who was enrolled in the Mi Via waiver. She spoke about the difficulties of navigating a very confusing and inaccessible system. Her son was denied the DD waiver five times. Ultimately, he could not be served at home and was admitted to a nursing home at the age of 26. She noted that nursing home care is an entitlement, while home and community-based services are not. She feels there is a state bias that results in people remaining in nursing homes. It was very difficult to get him discharged back to the community.

Subcommittee members requested clarification about the difference between entitlement services and waiver services, the reasons for and the numbers of people on waiting lists for waiver services and how long a person might remain on a waiting list. The community reintegration program, which allows people to receive home and community-based services following a nursing home admission, allows people who are in nursing homes to receive priority placement on waivers. Ms. Pinnes stated that this is not a state or federal law, but is state policy. The legislature was acknowledged for its generous funding of the DD waiver, even in difficult times; however, it was noted that the disabled and elderly (D&E) waiver does not benefit from additional funding as often. It was noted that funding in excess of \$9 million has been appropriated for the DD waiver, but no people have been taken off the waiting list as a result of this funding. The subcommittee expressed interest in having Secretary of Health Alfredo Vigil clarify this issue.

Jeanne Hamrick spoke in favor of the proposal for a disability task force. She described problems with finding adequate parking and asked for support for legislation regarding handicapped parking. She described an episode of discrimination that she experienced in the housing complex in which she lives.

Yvonne Horn stated that she has had chronic illness and disabilities her whole life. Despite having private insurance, out-of-pocket expenses have been overwhelming. Additionally, regulations and processes make it very difficult to access needed services. She does not qualify for public assistance, despite having medical expenses that exceed \$3,500 per month.

Susan Gray provided testimony from the Aging and Long-Term Services Department (ALTSD) regarding the lack of coordination around disability services. The ALTSD, through a federal grant, established the Aging and Disability Resource Center, which is a central location and single point of entry for information about services for the disabled. The number for the center is 1-800-432-2080 or 505-476-4846 out of state.

Anthony Alarid, Governor's Commission on Disability, gave a brief report on HM 111, which called for a study of abuses of handicapped parking. Approximately 68,000 parking placards are being issued each year, yet very few citations are issued for violations of that parking privilege. He highlighted legislative recommendations of the task force, which were also provided in a handout to subcommittee members.

Carl McKibben voiced concerns regarding the DD waiver and the inadequacy of payment for providers of group home services.

Carl Dellinger, Alegria Family Services (AFS), testified that cuts to the DD waiver program would be devastating. The needs of this population are profound. AFS teaches family members many techniques that allow their disabled loved ones to remain independent at home. A gentleman spoke as a recipient of services, stating the importance of the program.

Ernestine Morales is the parent of a 41-year-old microcephalic daughter. After years of waiting, her daughter was finally put on the DD waiver, and it has opened up her world for her. She is concerned about what will happen to her daughter in the future, as she and her husband are her primary caregivers and they are in their 70s.

Gregg Trapp, director, Commission for the Blind, provided statistics about the extent of blind and visually impaired people in New Mexico, especially those children being served at the New Mexico School for the Blind and Visually Impaired. There has been a drastic increase in the rate of children in need that will require additional resources in the future.

Marilyn Bennett spoke as an advocate for adult services representing New Vistas, an independent living center. She posed questions to the subcommittee regarding proposed cuts to the DD waiver and Medicaid. Additionally, she asked whether the number of people who have been de-institutionalized under the coordination of long-term services (CoLTS) program is known.

Eva Tafoya, a parent of a child being served through the DD waiver, spoke about her son's potential and talents and stated that the waiver has opened up employment opportunities for him and provided the necessary physical therapy services. The waiver is critical in his life and allows

him to be a contributing member of the community. She implored the subcommittee not to cut the waiver.

Rose Gonzales is a brain-injured person. She, too, implored subcommittee members not to cut the budget. Without the waiver, she could die. Even though she may not look like she is disabled, she is, and she needs the waiver services.

LaVeda Halliman spoke about the disability of mental illness. She is bipolar and has children and grandchildren with mental illness. She spoke about the prevalence of untreated mental illness in prisons and in the general society. She identified numerous types of mental illness, including depression, bipolar disease, schizophrenia, attention deficit disorder and other disorders. These disorders are difficult to treat and often go undiagnosed. A team approach of mental health providers has the greatest chance of success. Solving this problem will require many people to come together to work on it.

The chair made concluding remarks acknowledging that much work needs to be done and that legislators need much more education about disabilities. He stated that this day had been an eye-opening for him and the other subcommittee members. He thanked subcommittee members and members of the audience.

The meeting was recessed for the day at 2:20 p.m.

Friday, October 30

The meeting was reconvened by the chair at 9:15 a.m.

Housing

Gil Yildiz, executive director, Independent Living Resource Center (ILRC), highlighted the primary issues in housing for the disabled, including universal design and availability of community-based living for the elderly and disabled. Homes that do not include elements of universal design create serious access problems for people living with disabilities. The New Mexico Home Builders Association has incorporated an award in the Parade of Homes for homes that best reflect universal design. Elena Gonzales, Housing Division, ILRC, described her efforts to promote universal design statewide as a standard for the design of any home. The New Mexico Mortgage Finance Authority (MFA) supports this concept. The ILRC hopes to work with the attorney general to limit predatory lending practices by businesses outside of New Mexico offering loans to residents of the state. People with disabilities are among those with the lowest incomes in New Mexico. The ILRC is actively looking for ways to help these people become homeowners. The federal Department of Housing and Urban Development (HUD) Section 8 program is a very successful program that provides vouchers to assist those with physical and mental disabilities to purchase a home. Ms. Yildiz urged subcommittee members to encourage local housing authorities to offer this program. She added that the ILRC is a nonprofit service organization and is not a developer.

The chair noted that the attorney general has an action addressing mortgage fraud. Subcommittee members asked for clarification about which local housing authorities are and are not offering the HUD Section 8 programs and who that program can potentially benefit. The length of time for which the housing vouchers can be used was explored. Clarification was sought about the process that the ILRC uses to interact with the MFA to assist disabled people to obtain housing. The ILRC partners with the MFA to ensure the identification of appropriate financing mechanisms to assist disabled people in obtaining financing; there are multiple approaches depending on the circumstances. Subcommittee members asked what percentage of home loans obtained through the MFA go to disabled people and whether there is a waiting list. Ms. Gonzales estimates that less than 5% of MFA loans go to disabled people, but she does not have the exact percentage. She believes there is a waiting list for Section 8 vouchers available through the local housing authorities. Mr. Parker raised the issue that a number of people get "taxed out" of their homes. Previous legislation proposed a freeze on tax increases and future limits based on the consumer price index.

Job Discrimination

Nancy Koenigsberg, Esq., legal director, DRNM, gave case examples of persons with disabilities who were terminated from their positions or prevented from obtaining a position due to a disability. Despite the ADA, discrimination is still occurring. Ms. Koenigsberg estimates that the problem is widespread because pursuing legal action is very complex and time-consuming and may prevent people from seeking remedies.

Timothy White, Esq., Valdez and White Law Firm, LLC, stated that 90% of his practice is in employment law. Of those cases, approximately 30% deal with people with disabilities. He represents both employees and employers. He repeatedly sees many instances wherein a person's disability is not recognized and the required accommodations are not made. Disability carries a significant stigma. He suggested that the legislature consider an amendment to the Human Rights Act to extend to New Mexicans the same civil rights that federal law offers. Congress recently amended the federal law to clarify critical terms such as "major life impairments" and "daily life activities"; he suggested that the courts be directed to interpret New Mexico law to provide at least as much protection as that afforded by the federal law. Ms. Koenigsberg added that a change such as this would eliminate the need to litigate many cases and is simply a recommendation to align New Mexico law with federal law. The chair and Senator Rodriguez offered to sponsor such an amendment. Additionally, there are resources available to employers in New Mexico to help them understand what an accommodation is. The New Mexico Business Leadership Network has a valuable web site for both employers and workers. A more proactive stance on educating employers about this would open up employment opportunities to many disabled people in the state.

Subcommittee members asked for clarification about when federal laws apply and why the New Mexico law needs to be amended. The ADA only applies to employers of more than 15 employees. Further, the New Mexico law contains a restrictive interpretation of accommodation that the federal law has now removed. Subcommittee members are very interested in pursuing an amendment and would consider asking the governor to include it in his message to ensure it is

germane. Clarification was sought about the meaning of "at will" employment. Ms. Koenigsberg stated that if a person has been performing the essential functions of a job, the "at will" provisions should not be a factor. Mr. White stated that, when lacking a contract specifying that a person will be employed for a certain period of time, an employer can terminate a person for any reason at all, except that the employer may not terminate a person for an illegal reason. A question was asked about a written, distributed statement alleging the misuse of job coaching in the intensive supported employment program. The chair noted that the statement had been provided by Senator Clinton D. Harden, Jr.; the chair recommended that the statement be forwarded to the full LHHS for its consideration. Instances of noncompliance with the ADA were noted, such as the lack of TTY machines in many state agencies.

Brain Injury Services

Elizabeth Peterson, director, New Mexico Brain Injury Association, described her handouts, which include a CD of a brain-injury resource manual. She identified two types of brain injury: acquired brain injury and traumatic brain injury. She described the programs that are funded by the Brain Injury Services Fund and offered through the ALTSD. She provided statistics regarding the impact of brain injury in New Mexico arising from a study conducted by the Department of Health (DOH). She noted that there is no cure for brain injuries, making prevention critically important. The Mi Via program is a Medicaid waiver program that serves people with brain injuries. She would like to see an expansion of the Brain Injury Services Fund to allow use for acquired, as well as traumatic, brain injuries.

Subcommittee members requested clarification of limitations of funding. The Brain Injury Services Fund is composed entirely of state general funds and revenues from traffic tickets. Ms. Peterson noted that the Brain Injury Services Fund addresses short-term needs and provides assistance to people who may be on a waiting list for Mi Via or another Medicaid waiver. These services have less stringent eligibility requirements. The incidence and needs of veterans returning from Iraq and Afghanistan with brain injuries were noted; although the recent DOH study does not include veterans, they are known to represent a growing number of people with brain injuries. Clarification was sought about the amount of money in the Brain Injury Services Fund. Additional funding sources are needed in addition to greater flexibility in the use of those funds. Questions explored the ability of the Veterans Administration (VA) hospital to serve brain injury patients. Ms. Peterson asserted that the VA hospital might be able to provide long-term support, but that access to the short-term brain injury services funds ensures more immediate assistance to veterans. A subcommittee member identified motorcycle or bicycle license registration as a possible source for additional revenues for that fund.

Waiver Waiting Lists

Doris Husted, policy director, ARC of New Mexico, disclosed that she is the mother of a child served by the Mi Via waiver program. She began by describing basic information about the Medicaid program and Medicaid waiver basics. She noted that eligible individuals are entitled to nursing home care, but that waiver services are not an entitlement, which is why waiting lists exist. To be eligible for waiver services, an adult must meet both financial and medical eligibility requirements. Ms. Husted and Mr. Jackson identified the differences between eligibility requirements and services of the DD waiver, the medically fragile waiver, the D&E waiver and the AIDS waiver. The Mi Via waiver is not separately funded; participants enter the Mi Via program by virtue of being served by one of the other waivers. Mr. Jackson described the CoLTS waiver, which provides managed long-term care services, and how the previously described waivers interface with that program. Ms. Husted stated that there is a process for individuals to be exempted from managed care and receive services on a fee-for-service basis, but this process is only rarely approved. Mr. Jackson reiterated that Medicaid waiver services are not entitlements. Two issues emerge from this: the number of slots the state requests to be authorized under the waiver and the amount of money the legislature appropriates to fund those approved slots. Clarification was sought regarding whether the state is obligated to fund all the approved slots and whether the federal government ever refuses to authorize a requested number of slots. Mr. Jackson noted that the number of slots the state has requested closely approximates the number of funded slots. Ms. Husted stated that people on the DD waiver have been pre-screened for eligibility; for the D&E waiver, there is no pre-screening, and anyone who wants to can be put on the waiting list. Between 3,800 and 3,900 individuals are now served by the DD waiver, with approximately 4,800 individuals on the waiting list. Approximately 3,400 individuals are being served by the D&E waiver, while an estimated 16,000 are on that waiting list. The medically fragile and AIDS waivers are very small waivers and do not currently have waiting lists. It can take 10 to 12 years for a person on the waiting list to be put on a waiver. Many people will die before they receive services under the DD waiver.

A subcommittee member commented about the administrative costs that have been paid to managed care companies. Mr. Jackson noted that the decision to put Medicaid services under a managed care arrangement was made many years ago. The DD waiver is the only waiver not under a managed care arrangement at present. The original SALUD program was developed based on state law, but no law enabled the CoLTS program, which was instituted administratively.

A subcommittee member asked a question about an appropriation made in the 2008 special session for DD waiver services. Carlos Moya, director, Aging and Disability Resource Center, ALTSD, noted that the resource center and the ALTSD handle the CoLTS program, but not the DD waiver. The resource center conducts an assessment when people call in to determine whether an application should be classified as "expedited". He noted that other services are offered when a person is put on a waiting list. A question was asked about why an appropriation was not made to the DOH to reduce the DD waiver waiting list, as required by the legislature. Ms. Dennison testified that her son, who recently died, waited five months to get waiver services through the community reintegration program.

Senator Ulibarri turned the chairmanship of the subcommittee over to Senator Rodriguez, as he needed to leave. He thanked all the presenters for their testimony and the subcommittee members for their presence.

Concerns were raised about the disposition of the appropriated funds, the number of the people still on the waiting lists and why a transfer of those funds appropriated to reduce the waiting list was not transferred to the DOH for that purpose. A request was made to have all the responsible entities present at the next LHHS meeting to resolve these issues. The chair noted that a copy of a letter previously sent to LHHS members and redistributed now answers many of these questions, but not all. The outstanding unresolved question regards the appropriation made to reduce the DD waiver waiting list. Cindy Padilla, cabinet secretary, ALTSD, noted that the executive has previously presented information regarding the ways in which the three departments work together to administer the waivers. She reported that staff in all three departments feel very strongly that the people served by and in need of waiver services should be treated with the greatest attention; it is difficult for staff members to maintain waiting lists when they realize the great needs of people. The \$750,000 allocated to the ALTSD to reduce the D&E waiver waiting list is addressed in the letter; 478 additional people were served as a result of that allocation. Clarification was sought regarding which department handles which waiver. Secretary Padilla stated that the Human Services Department (HSD) is the state fiscal agent for Medicaid and holds the managed care contracts. The ALTSD manages much of the administration of the CoLTS program. The two departments are trying to develop a matrix to explain the responsibilities of all entities in managing these programs. Upon request, Mr. Jackson clarified the differences between the DD and the D&E waivers, noting that there is some overlap between the waivers. Subcommittee members expressed a desire for one streamlined program to serve people with special needs. Mr. Moya stated that the Aging and Disability Resource Center is working toward becoming a single point of entry for access to services.

Subcommittee members asked for clarification of information provided in the letter from the HSD and the ALTSD, noting apparent discrepancies in some of the figures offered. More concise and clear data would be helpful for legislators to identify how much of an appropriation is needed. Kimberly Austin-Oser, division director, Elderly and Disabled Services Division, ALTSD, clarified that the discrepancy relates to per member, per month figures that managed care companies use to describe utilization. She stated that current estimates are that it requires approximately \$33,000 (state and federal funds combined) to take one person off the DD waiver waiting list. She noted that this amount will change as the federal medical assistance percentage (FMAP) changes. Secretary Padilla noted that approximately \$7,500 is needed to serve one additional person on the D&E waiver waiting list. A subcommittee member noted that the waiver costs are approximately one-half of the cost of a nursing home. Secretary Padilla reiterated that nursing home care is an entitlement and that waiver services are not. With a waiver, a state can limit, or cap, the number of people who can receive services. A suggestion was made that the LHHS request an additional day from the New Mexico Legislative Council for the LHHS to meet and resolve these issues. An additional request was made for a chart or a matrix to be provided to describe all the different waivers, funding streams and waiting lists, and which state agency has responsibility for what. A question was asked about the number of people who have been placed

directly in a home setting without being admitted to a nursing home first. Secretary Padilla promised to deliver this information.

Wendy Basgall, staff attorney, Senior Citizens' Law Offices (SCLO), testified that people who call the office regarding waiver placement do so at the time that they need services, and not before. Ms. Austin-Oser clarified that the assessment done by the resource center helps to triage needs and identify those who have immediate needs. Many of these people can qualify for and receive personal care option services while they are on the waiting list for waiver services. A subcommittee member noted that in her personal experience, this did not happen and that steps must be taken to ensure that this does not happen again.

Mr. Jackson emphasized that from the perspective of the advocate community, state agencies have over the years not responded to legislative appropriation requests with reductions to the waiting lists. A chart was provided to demonstrate this. Finally, he drew the subcommittee's attention to provisions in state law that require state agencies to track and report to the legislature on waiting list information and information about who is served by the waivers. A request was made for information regarding projected as well as current needs for waiver services.

Autism Services for Adults

Liz Thompson, president, New Mexico Autism Society, and Pat Osbourn, deputy director, Center for Development and Disability (CDD), UNM, presented information regarding autism services for adults. Ms. Thompson identified herself as the mother of an 18-year-old son who is still in high school, but who will soon graduate to adulthood. When children with autism graduate from high school, they face a cliff; virtually no services exist for adults with autism. There are few jobs and few appropriate living situations for adults with autism. She provided as a handout the personal statement of her son, Eric Hollins, that describes the paucity of opportunities. She noted that people with autism frequently cannot get or keep jobs, not because they lack the ability to do the work, but because they lack social skills. People in general society do not understand autism. The services that do exist, for example, through the DD waiver, are not designed to meet the needs of adults with autism. Parents are developing their own solutions to problems, such as creating group homes for their adult children with autism. Ms. Thompson noted that there are no requirements in the schools for education or skill development regarding autism. Ms. Osbourn acknowledged that most of the focus has been on the diagnosis and treatment of young children with autism spectrum disorder (ASD). She provided some data and statistics regarding ASD, but noted there is very little information about adults. The largest costs of serving people with autism will come as children with ASD become adults. In addition to the fact that there are no specific services for adults with autism, there is no autism-specific training required for providers working with adults with ASD. She identified that Pennsylvania is the first state to create an autism-specific waiver. At this time, no one knows the number of people in the state with ASD or what their needs are. New Mexico would benefit from a voluntary census to provide an accurate assessment of the number of children and adults with autism in the state and their needs and development of targeted services and supports specifically designed for adults living with ASD. Ms. Thompson identified the estimated incidence of ASD, which is

approximately one in 100 in the general population and one in 56 in the military. Adults with autism are more difficult to manage, and autism is not a disease that results in early death. She spoke about the difficulty in making an application for the DD waiver, stating that it took a full year to make the application and then six years on the waiting list. Her son was able to receive some limited services, the most important of which was respite services. The depression rates of parents of children with autism are higher than that of parents of children with cancer.

Clarification was sought about the nature of services available through the gap program managed by the ALTSD; these services are primarily for environmental modifications and other one-time services and are not ongoing services. Ms. Husted noted that a small amount of funding, \$2,600 per year, is appropriated to the CDD for family support services to serve people on the waiting list for the DD waiver. Ms. Osbourn commented that provider training should require a level of competency.

Subcommittee members asked whether legislation to require provider training would be a good place to start and what elements of provider training are needed. A request regarding provider training will be presented to the full LHHS for its consideration. Ms. Thompson noted that the Development Disabilities Planning Council (DDPC) has set aside \$50,000 to develop a plan for ASD needs.

Public Comment

Ms. Dennison clarified some information provided by the ALTSD. She stated that people can apply for both the DD waiver and the D&E waiver simultaneously, and many do so to double their opportunities of receiving services under at least one waiver. She also noted that due to long waits, many people end up in nursing homes as their conditions deteriorate. Additionally, she reported that there are many nondisabled people on the D&E waiver.

Ms. Sanchez and her mother, Rosemary Sanchez, thanked the subcommittee for holding the meetings. Ms. Sanchez read a written statement that is in the meeting file. Her statement addressed the history of disability and stated that there is still a lack of such services as education, employment, transportation and recreational activities. She requested that the subcommittee be made a permanent committee. Mrs. Sanchez also read a statement for the record, which is in the meeting file. She recommended that legislation be introduced to offer a tax break to businesses that hire people with disabilities and that people with disabilities be paid at least minimum wage.

John Block with the Governor's Commission on Disability thanked the subcommittee and offered support and help.

Charles Grote with La Familia addressed the committee in sign language. He is a job developer with La Familia. He identified that there is ongoing discrimination against the deaf in employment issues. Applications for jobs are difficult because approximately 88% of deaf people do not read or write well. Online applications are a big barrier to employment for the deaf. To begin to address this issue, the Workforce Solutions Department should rewrite applications, recognizing that deaf people have their own culture and language and do not communicate well, if

at all, in the language of the hearing world. Laurel Sacks, responsible for outreach programs to the deaf at La Familia, concurred that there are many barriers for people who are deaf. She provided an example of an immigrant seeking citizenship who was not provided an interpreter for the citizenship interview. Mr. Grote asked if there are any resources dedicated in the state to ensure that deaf people on waiver programs are offered avenues to communicate that are appropriate to their disability. Mr. Block and Lisa McNiven of the Governor's Commission on Disability noted that the Governor's Commission on Disability is requesting the Workforce Solutions Department to require Walmart and other employers to have an application process that serves the deaf. The chair recommended that the subcommittee write a letter to the secretary of workforce solutions to address these concerns. Mr. Grote identified departments of state government that should be required to have services available to serve deaf people properly. He would like to see a change in the law to require "benchmarkable" services to deaf people.

Representative Picraux read a letter from Morgan White, a constituent, requesting sustained funding for the DDPC as an organization that helps people with developmental disabilities to be successful.

Ms. Cordova commented that as a parent of a blind child and as an attorney, she has had a lot of contact with parents of children with special needs. She described a lack of specialized teachers in the classroom to help children with special needs learn adaptive skills. She read three letters from three teachers of blind and visually impaired children reporting difficulties at the New Mexico School for the Blind and Visually Impaired that caused 75% of the teachers to leave in one year. The school is underfunded and cannot pay competitive salaries. A school in Oregon has a model of education that could be duplicated in New Mexico. Dismay was expressed in the letters regarding the lack of outreach services to children and in the early childhood program. The letters contend that the exodus of so many teachers in such a short period of time leaves the school unable to meet the needs of children. The cost of inaction is an uneducated, illiterate population of blind people in the future. Ms. Cordova suggested that regional cooperatives should have consultants who could work with local schools to develop strategies to serve blind children better.

There being no further business, the meeting adjourned at 3:30 p.m.

Medicaid waivers

1) **\$9.4 million appropriation for DD waiver waitlist** – Not a single person has been added to the DD waiver from the waitlist using these appropriations.

- \$4 million from 2008 special session
 - Money from nonrecurring funds, but clearly intended by Legislature to be used for recurring expenditures to serve people on DD waiver waitlist. *(Jim Jackson will be part of the panel on waiver issues. You can ask him to clarify this as needed.)*
 - Appropriated to HSD, which should have transferred the money to DOH to be used for the DD waiver. According to DOH Secretary Vigil, HSD has not transferred the money to his department.
 - ◆ *If Secretary Vigil is in attendance, you might ask him if he's asked HSD to give DOH this money. If not, why not?*
 - ◆ *If someone from HSD is present, ask what HSD has done (or intends to do) with this money.*
- \$5.4 million in HB 2 in 2009 regular session
 - Appropriated directly to DOH.
 - Recurring funds, but Secretary Vigil has taken the position that he does not want to expand the program when the state is facing a budget shortfall.
 - ◆ *Possible questions for Secretary Vigil: Isn't it up to the Legislature to decide whether to expand the program? Didn't the Legislature make that decision when it appropriated the money for the DD waiver, at a time when it recognized that money was tight?*

2) **Disabled & Elderly waiver**

- The D&E waiver is now part of the Coordinated Long-Term Services (CLTS) program. Although the stated goal of CLTS is to serve people in the community rather than in nursing homes, the number of people receiving waiver services has fallen.
- Allocations to the D&E waiver are controlled by HSD, not by the CLTS managed care organizations.
- At the present time, the only people getting slots on the D&E waiver are individuals in nursing homes who want to return to the community. That means the only way to get on the waiver is to go into a nursing home (which is an entitlement in Medicaid) and then be transitioned to the waiver.
 - This is not required by federal or state law. It is policy set by HSD.
- \$750,000 was appropriated by the Legislature in the 2008 regular session for the D&E waiver waitlist but the number of people has the waiver has decreased.