

MINUTES OF THE
JOINT HEALTH AND HUMAN SERVICES APPROPRIATION SUBCOMMITTEE
Thursday, January 27, 2005, 2:00 p.m.
Room W135, West Office Building, State Capitol Complex

CORRECTED

Members Present: Sen. Sheldon L. Killpack, Committee Co-Chair
Rep. Merlynn T. Newbold, Committee Co-Chair
Sen. Chris Buttars
Sen. Allen M. Christensen
Sen. Gene Davis
Rep. Bradley G. Last
Rep. David Litvack
Rep. Steven R. Mascaro
Rep. Roz McGee
Rep. Paul Ray
Rep. Aaron Tilton

Staff Present: Spencer C. Pratt, Legislative Fiscal Analyst
Thor Nilsen, Legislative Fiscal Analyst
Norda Shepard, Secretary

Public Speakers Present: Kirk Halversen, Northern Utah Autism Program
Cheryl Smith, Parent Advocate
Catherine Conklin, Weber/Davis Autism Program
John Conklin, Weber/Davis Autism Program
Shauna O'Neil, Director, Salt Lake County Aging Services
Emily Tanner
Ken Baker, Parent Advocate
Geri Stewart
Herbert Newton
Frank Torina, Ombudsman Volunteer
Steve White, Utah County Commissioner
Eduviges (Ginger) Sigua
Ken Brown, Chairman, State Board on Aging and Adult Services
Fraser Nelson, Executive Director, Disability Law Center
Jack Tanner, Executive Director, Utah Behavioral Health Care Network
Patrick Fleming, Director, Salt Lake County Substance Abuse Services
Jane Nielsen
Dave Gessell, Utah Hospital Association
Vicky Cottrell, Executive Director, NAMI Utah
Lori Cerrar, Executive Director, Allies with Families
Lori McGinnis
Eric Mathes
Kelly Holt
Dianna Elliott
Tracy Johnson, New Frontiers for Families
Brenda Shaffer
Lisa Nichols, Executive Director, Mid-Town Community Health Center
Joyce Dolcourt, Chairman, Legislative Coalition for People with Disabilities
Carrie Roth
Sheila Wall
Rachel Loertscher

Karen Sterling
Heidi Harmon
Phil Shumway, Exe. Director, Utah Association of Community Service Providers
Pete Shingledecker, Cerebral Palsy of Utah
Amy Moore
Heidi Hamilton, Secretary, NAMI
Dawn NiSol
Cathy Searle, Director, Adoption Exchange
Kathy Hawkins
Barbara Feaster, President, Youth Foster Success
Karen Greenwell

A list of visitors and a copy of handouts are filed with the committee minutes.

The meeting was called to order by Co-Chair Killpack at 2:05 p.m.

Co-Chair Killpack welcomed those in attendance and thanked the Public Education Committee for being willing to exchange rooms for this day in order to give this committee more room. He indicated that microphones would be at the table and also someone would be available if anyone needed help to testify. He reminded those testifying of the time limits with organizations representing several people having 5 minutes and individuals 3 minutes. He stated that because there are many who wish to testify, they would hold firm to the time limits.

Kirk Halverson, a parent advocate for the Northern Utah Autism Program, distributed a booklet. He asked all the parents and children of the autism program to stand up. He said they had all come from northern Utah to express their appreciation for saving the program last year and to express a desire for additional money this year. He explained the difference in teaching method for autistic children versus regular children. The autistic program is structured and repetitive in order to teach living patterns. He gave some personal stories. Other stories are found in the booklet.

Cheryl Smith, a mother advocate for the pre-school Autism program, stated as a mother of a child with Autism she knows the value of early intervention. She said it can mean the difference between a dependant child and a functioning child who can be mainstreamed into public schools and a happy family life. It also means the difference between a dysfunctional family and a happy family. She indicated Autism has risen 172% during the 1990's, while other disabilities have only risen 16%. She distributed information and asked the committee to read about this devastating disability. She indicated there are currently 250 children on the Wasatch Front on a waiting list for Autism preschool training.

Catherine Conklin from Weber/Davis Autism Program directed attention to graphs and statistics in the booklet handed out which help to show the need for the requested funding. This high increase in incidents of Autism is consistent both in Utah and throughout the United States. She said this is turning into a large problem and what needs to be addressed is what will happen when these children start hitting elementary school where they are not set up to address these problems. She said there are huge success rates when children are able to have early intervention.. She stated that although there are many theories on the cause of Autism, it is really not known what the causes are.

John Conklin speaking also for the Weber/Davis Autism Program said he wanted to point out that Utah has pro-actively tackled this problem with vigor. He stated that as parents they were amazed to see the help available. He said teachers in the preschool are specifically trained in behavioral modification and behavioral analysis and work closely with the parents. However, the demand has outstripped the supply. He stated they were asking for funding for additional help.

Shauna O'Neil, Director, Salt Lake County Aging Services, said she was speaking as the Legislative Director for the twelve Area Agencies on Aging located in county governments throughout the state of Utah. She said the fastest growing part of Utah's population today are people turning 59 and the second largest are people turning 85. She said the typical client served by the area agencies is a woman, 85 years old, living in her own home, a tax payer since before Pearl Harbor, who has problems walking and has low to moderate income. She listed various services that are needed to allow this woman to remain in her home as long as possible. She said since this is the fastest growing part of the population, more people are calling for services than can be served and continued funding is vital.

Emily Tanner displayed pictures of Ethan and Savannah who both suffer from Autism. She said Ethan was diagnosed as profoundly autistic and they were told he would never communicate or be able to care for himself. He is currently three and talking in full sentences and progressing well above initial expectations. She said without early intervention, Ethan would not be functioning at this level today and would need additional services throughout his life. Savannah is two years old and is unable to communicate or interact socially. Mrs. Tanner said she works extremely hard to reach and teach Savannah but she is in need of early intervention. She said much valuable time is being wasted on a long waiting list due to the lack of funding. She stated this delay may create the need for more funding throughout Savannah's life.

Ken Baker a parent advocate introduced his son Brandon who is 23 years old. When Brandon was 3 years old, he was put into what was available for early intervention in Utah County. He stated his family has twenty years experience in working and basically pioneering programs for the disabled in southern Utah County. When Brandon turned 22 in May, he lost his funding through the school district. He said they knew the day was coming and had put Brandon on the waiting list at DSPD thinking that five years would be plenty of time, but they are still waiting. Before this time, Brandon was working, but because he has no funding, he sits home with nothing to do and his initial training is now being wasted.

Geri Stewart was accompanied by her mother Mary Terry who is a waiver client. She said her mother has Alzheimers and requires twenty four hour attention. She stated she is her only daughter and without the day care program, she wouldn't be able to care for her mother and she would have to be placed in a nursing home. She said since her mother has been going to day care, there has been a slight improvement. She indicated the aging programs have made a big difference in her family's and her mother's lives.

Herbert Newton said he really appreciates the meals-on-wheels. He said he lost his wife about a year ago. He said he doesn't worry about breakfast but appreciates the noon time meal. He said he will be 93 on his next birthday. He lives alone and does not drive.

Frank Tornia stated he is a volunteer for the Salt Lake County Ombudsman program. He explained that these Ombudsmen advocate for seniors in nursing homes. He said the staff is all volunteers except for one. He explained issues can run from simple diet issues to serious abuse problems. He said one of the biggest concerns is call light reaction time by the staff, which should be under two minutes, but many times takes up to one hour. He said these are just a few of the issues they deal with and he was here to ask for increased support. Rep. Mascaro said he was acquainted with Mr. Tornia and knows how much work he does in the community and he appreciates what he does.

Steve White, Utah County Commissioner, distributed a letter written to Wasatch Mental Health concerning a former client. The letter states that because of state cut backs which are really federal cutbacks, there has been a great impact on the client's family. The client has suffered from bipolar and manic depression since he was a teenager. He received a letter last year stating he no longer qualified for services at Wasatch Mental Health. He quit taking his medications. He soon started to display erratic behavior and this has caused numerous problems in his family. He became missing for awhile and now the family has been notified that he was arrested for criminal misconduct. Mr. White indicated that Utah County has sponsored with the LDS Church and IHC a Community Health Clinic for people who are not covered. He said they would be willing to sponsor something similar with the state for unfunded mental health clients.

Eduviges (Ginger) Sigua indicated she is a dialysis patient and was paying \$25 each way for a taxi to go to her treatments until she obtained help from the Salt Lake County Aging Transportation services. She said she was accepted right away and she is treated well by the drivers. She says she very much appreciates the services but she wanted to make a suggestion that they need more vehicles. She indicated that at times they have to send a Yellow Cab for her instead of their own vehicle.

Ken Brown, Chairman, State Board on Aging and Adult Services, stated that the State Board is a non-partisan policy-making board. The state is organized into twelve area agencies. He said it is projected that in 25 years the senior population will increase over 165% and will number more than school age children. He said the capacity to provide services will be overwhelmed unless support to local area agencies is improved. He indicated many seniors depend on senior services in order to maintain their independence and remain in their community and family. He said the board very strongly supports H.B. 16, Utah Commission on Aging (*Rep. P. Jones*) which will establish a commission on aging.

Fraser Nelson, Executive Director, Disability Law Center, distributed two handouts from the Disability Law Center. She indicated the law center is a private, non-profit organization designated by the governor to protect the rights of people with disabilities in Utah. She said the mission is to enforce and strengthen the laws. She updated the committee on the status of the class action lawsuit with regards to the Waiting List. The DLC sued the state in 2002 due to the fact the DSPD has maintained waiting lists for 16 years. She said the issue has been raised for the last 10 years at the legislature. She indicated the law suit is asking nothing more than the state develop a plan to address the needs of these citizens who are on the waiting list.

Jack Tanner, Executive Director, Utah Behavioral Health Care Network, said he would like to address the crisis in mental health due to the change in the Medicaid rules. He said most, including the Governor, recognize this as a challenge for the state. He said these cuts will impact 10% of the client population who have been receiving treatments in the past for their mental illness and will now lose these services. These people have diseases that interfere with normal thought processes and normal reaction and perceptions of the world they live in. This requires lifetime management. Without treatment and/or medications they will end up in emergency rooms, in trouble with the law, some will become dangerous to themselves and others and some will become suicidal.

Patrick Fleming, Director, Salt Lake County Substance Abuse Services, addressed the partnership between the state, federal and county government when it comes to mental health and substance abuse services. He said the Governor has recommended a cost of living adjustment for employees of substance abuse and mental health centers. He also said it is important the state restores funding for its federally required "Maintenance of Effort.". He said it is important that we do that. In Utah, counties are the service delivery source for these services and aging services as well. He stated that funding for DORA is critical.

Jane Nielsen stated she is currently receiving services through DSPD under the disability waiver. She indicated she was on the waiting list for three years and since receiving services, her life has greatly improved. She said without help she would be in a nursing home at this point. She said she wants to be independent and in charge of her own life. She now has a part time job and feels like she is helping and giving back. She said she hopes the funding continues.

Dave Gessell, Utah Hospital Association, stated he wanted to focus on one issue in the Human Services budget that impacts hospitals. Since the Medicaid change in funding, hospitals have seen about a 40% increase of mentally ill cases coming for emergency room visits. Without ongoing treatment, these people will go out into the community and continue to have problems and end up back in the ER or in jail. He said the Governor's recommendation of \$3 million is crucial to these individuals.

Vicky Cottrell, Executive Director, NAMI Utah, distributed two handout. She said she represents individuals and families who use the public mental health services. She indicated she has a daughter being treated for mental illness. She said she had a favorite saying, "Even in our sleep, pain that we cannot forget, falls drop by drop upon our heart

and in despair and against our will comes wisdom." She said she would like to share a little bit of wisdom that has come against her will. She said the effect to people from the Medicaid change is catastrophic. It is not their fault the rule is changed but their lives are turned upside down. She said this is not just another social program but humanitarian aid.

Lori Cerrar, Executive Director, Allies with Families, stated her organization works with families who have children with mental illness. She displayed a visual aid of cutouts of children with hearts representing the number of children in unfunded categories in the different counties who have been turned away at the door because of the Medicaid restriction. She said the total number she is reporting is 2,989 children who are at risk or have already lost the opportunity to get treatment at an early age. She indicated that some families give up custody of their children so that their children can receive mental health services through DCFS. Families should not have to be ripped apart that way. Children should be in their own homes, in their own schools and getting the treatment that they need to be productive members of society.

Lori McGinnis said she is 20 years old and the youth coordinator for Allies for Families and has also been a consumer of mental health services since she was 12. She said she wanted to testify of the importance of early identification and intervention treatments. She said without those treatments she would not have been able to be here today. She said if youth are not treated early they will turn up somewhere later in the streets, in the morgues or in the juvenile justice system where a lot of young people are receiving services.

Eric Mathes distributed a prepared letter to the committee. He indicated he has Down Syndrome. He is a member of People First and the Governor's Council for People with Disabilities. He said he was on a waiting list for services to help him with a job coach so he can get a job. He said he is currently unemployed. He said he is also on a waiting list for housing. He said his dream is to live on his own and have a job where he can pay his bills on time like other people.

Kelly Holt stated she was also a member of People First and on the Governor's Council for People with Disabilities, but she was here speaking as an individual person. She said she has been on the waiting list for services since April 2001. She has a job demonstrating products at different stores in Price but it is not enough to pay all her bills. She would like to have training so she could work in an office or in a day care. She is also on the waiting list for housing and would like to learn to cook and budget her own money.

Dianna Elliott said she sees a common denominator here in the meeting and it is the waiting list. She said she asks herself what is the top priority of the state government. Is it people or education or jobs? She indicated she is living at the Road Home shelter and even the shelter has a waiting list. She says maybe many of these homeless people are the ones who need mental health benefits. She said maybe there should be an investigation as to why there are so many on the waiting lists and what is preventing these people from getting the help they need.

Tracy Johnson said she was here to talk about the New Frontier for Families project that has been going for six years. She indicated there is a great need to continue this program, especially mental health services for children. She said the New Frontier for Families, Future Links, and Allies for Families have worked together on the project. She indicated a report from the research component had been distributed to Legislator's mail boxes.

Brenda Shaffer shared her experience as a parent of a daughter who has been diagnosed with bipolar disorder. She said her daughter is now 18 years old and scheduled to graduate from high school this spring. She said even though her illness is chronic and there are extreme highs and lows, she is quite stable now, but that was not always the case. She said until she was 14, the whole family was in turmoil. She said that without the help of the advocate from New Frontiers for Families, the outcome would have been a very bleak future. She said it was her hope that there would be an understanding of the need and value of family advocates and that funding would be continued.

Lisa Nichols, Executive Director, Mid-Town Community Health Center in Ogden, stated she was here representing Mid-Town as well as the community health centers throughout the state. She said she wanted to describe the crisis

that has occurred in community health centers relative to the discharge of patients with mental health issues from county facilities. She said her clinic is a primary care facility and the mission is to provide health care to people with no access because of insurance, language barriers, or financial issues. The clinics are not mental health specialists but have somewhat been forced to serve mental health patients since June.

Joyce Dolcourt stated she is the Chair of the Legislative Coalition for People with Disabilities. She indicated their priorities were on the fact sheet that was distributed. She said they were advocating for increased funding for the DSPD waiting list, health community providers systems and quality care at the Utah State Developmental Center. She asked committee members to read the handout for more detailed information. She said she wanted to share her time with two families who had come to testify.

Carrie Roth stated she is a single mother and introduced her son Jacob. She indicated she met Jacob when he was 12 days old and even though she was told he had Spina Bifida, she loved him and it didn't matter. She said Jacob has since had over 40 surgeries with more pending. She said she now has numerous health problems of her own and she needs help. Ten years ago, Jacob was qualified and approved for services through DSPD and five years ago she received a one time grant for respite services. She said she has kept in touch with the case worker but each time she is told there is still no funding available. She said she hoped funding could be increased for people with special needs and their families. A letter from Jacob was distributed.

Sheila Wall introduced her son Rodney and said they have been on the DSPD waiting list for eight years. During Rodney's school program he was able to work at McDonalds, All A Dollar and Dan's Foods. Since school ended, he is now home full time and is now having to be medicated for anxiety and all the work effort from the school is falling away. She said after 8 years, she is wondering when will they be helped. She said her family and others need help desperately.

Rachel Loertscher stated she has a 4 year old autistic son who had been going to the Autism pre-school in the Granite School District which contracted with the Carman Pinegree School. She said thank you so very much for the funding. She described the change in her son and the joy of having him be able to communicate his needs to her. She stated that autistic children do not learn as normal children do. They have to learn by rote and repetition. This takes intense early intervention before the brain sets and it is too late.

Karen Sterling stated she is the mother of a teenage daughter with multiple physical and mental problems. She said she regularly sees seven specialist physicians and takes thirteen medications a day. She said her mental condition severely limited the care available to her. She indicated that the day care covered by her IHC insurance was Wasatch Canyons and they refused to take her because of her medications. She said she has appealed with her insurance to try to get services elsewhere. DSPD is the only place that has the resources to help her. She said they have been on the waiting list for over three years and like so many are patiently waiting for services. She urged continued funding.

Heidi Harmon, a parent from Heber City, distributed a letter to the committee members and thanked them for their public service. She said what she had to say was close to her heart and difficult to speak about. She indicated her son Eric is 13 and has severe Autism. She said it has been a draining, emotionally challenging 11 years to deal with his demanding needs. She described Eric's behavior and limitations. She indicated that at times he has to be physically restrained because he becomes uncontrollable. She said each day they ask themselves how can we find the strength to deal with this today. She said her friend once said to her, "Your family never gets a chance to feel normal." She said they love their son and don't want him in an institution. She indicated they need respite services and all they are asking for is a chance to occasionally feel normal.

Phil Shumway, Executive Director, Utah Association of Community Services Providers, said he represents the providers contracted by DSPD to support more than 4,000 people in Utah. There are 46 small businesses which rely on Legislative appropriations to provide these services. He indicated these services are based on individual needs and can range from just a few hours per week to 24 hours a day in a residential setting. They also help people who are trying to keep their children at home. He said they are requesting a COLA this year to equal the COLA of public

employees. He thanked those who attended their open house and distributed a newsletter.

Pete Singledecker, Utah Association of Service Providers, said there was no better way to demonstrate the need for increased funding for providers than to give a story of one of their direct care staff, which is detailed in the handout. He said this staff member is just like thousands of other staff members. He said if no action is taken, this employee's bi-weekly take home pay will drop to \$470, but if the committee fully funds the requested COLA, the take home pay would be \$529.

Amy Moore distributed a letter to committee members. She said she is a parent of a 9 year old daughter with Down Syndrome. She expressed her heart felt thanks for funding the DSPD services. She said before her daughter was funded, their family spent years trying to meet the needs on their own which took a toll on their financial and emotional well being. She said that receiving the funding, including the medicaid waiver and respite care, and knowing she was not alone, has saved their family.

Heidi Hamilton, secretary, NAMI, said she was here to ask that the funding for Medicaid and funding to help alleviate the mental health crisis we are facing today be reinstated. She indicated she has witnessed some of the effects of the Medicaid cuts. She said with Wasatch Mental Health having to turn away clients, LDS Family Services and other agencies have taken the brunt of assisting those individuals but they do not have the capacity to do crisis care or to serve those with chronic mental illness.

Dawn NiSol stated that she had a childhood that few children survive followed by an abusive marriage. She said her life is painful and hard as she struggles with major depression, post traumatic stress disorder, and other learning and physical disabilities. She indicated that Wasatch Mental Health has been her lifeline and because of Wasatch, she has not only survived but had the opportunity to help others who struggle. She said that last summer, along with many others, she lost her medication, her therapist, the opportunity to service others and the feeling of being safe and valued. She indicated she has lost her lifeline.

Cathy Searle, Director, Adoption Exchange, said she was here to speak on behalf of her family and for her friends who adopted children through the foster care system. She indicated she and her husband have nine children, three born to them and six who joined the family through adoption. She indicated five of these children have special needs. She said she was grateful for the support to her family and other families throughout the state from DCFS. She said our community has set standards for safety for children and when parents are unable or unwilling to care for their children, it has been determined that it is best for these children to be placed with other families. She said adoptive families step forward because they believe that all children deserve to grow up in a family where they are safe and cherished and can grow to their potential.

Kathy Hawkins thanked the committee for being there and allowing this public testimony. She told the story of three children and their challenges leading up to adoption. She said these are the state's children. It is a partnership between the state and those families who are willing to adopt these special needs children. She said every time you allocate a dollar, you have done what America and the state of Utah needs to do.

Barbara Feaster stated she is a child abuse survivor and a former child client of DCFS and president of Youth Foster Success, which is a nonprofit organization created and run by former foster care children. She said they are working to improve the lives of children in foster care. She said that children in foster care are really important and asked that funding be made to invest in these children. She said to please make sure that funding is kept up with caseloads so that children are taken care of by their case workers. She said foster children are full of potential and can give back to society if they have a safe place to live and thrive.

Karen Greenwell displayed a picture of her family. She said she is the mother of three children, two of which have been diagnosed with bipolar disorder. She indicated that children do get mental illness. She read a statement from her children. In his letter, Taylor stated he is nine years old and has received a lot of help and his life is a lot better because of his doctor and his therapists. He said he has learned a lot about bipolar and how to control himself.

Sarah, who is 13 years old, wrote that sometimes her life is complicated and sometimes it is good but she doesn't always feel that way. She said she receives help from her parents, her doctors and her therapists. Ms. Greenwell indicated that mental health treatments are available and treatments are effective. However, access to treatment is limited and expensive and many are uninsurable.

Co-Chair Killpack stated appreciation for those who took the time to come and testify. Rep. McGee complimented the co-chairs and the staff for successfully organizing the meeting to allow so many to testify. Sen. Davis encouraged committee members if they have questions on these importance matters to ask those who are involved up front in these programs.

MOTION: Rep. Ray moved to adjourn. The motion passed unanimously with Sen. Buttars absent at the time of the vote.

Co-Chair Killpack adjourned the meeting at 4:20 p.m.

Minutes reported by Norda Shepard, Secretary.

Sen. Sheldon L. Killpack
Committee Co-Chair

Rep. Merlynn T. Newbold
Committee Co-Chair