

MINUTES OF THE  
JOINT HEALTH AND HUMAN SERVICES APPROPRIATION SUBCOMMITTEE  
Wednesday, January 25, 2006, 2:00 p.m.  
Room W135, West Office Building, State Capitol Complex

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

Members Excused: Sen. Chris Buttars  
Sen. Gene Davis

Staff Present: William Greer, Legislative Fiscal Analyst  
Debbie Headden, Legislative Fiscal Analyst  
Norda Shepard, Secretary

Public Speakers Present: Lisa-Michele Church, Executive Director, Department of Human Services  
Mary Bennett, President, Utah Adult Day Services Providers Association  
Mary Velasquez  
Karmen Sanone, Salt Lake County Aging Services  
Laura Polacheck, Associate State Director, AARP  
Shirley Kelly  
Sherri Wittwer, Executive Director, NAMI of Utah  
Christie Kropf  
Andrew Riggle, Disability Community Alliance  
Pat and Ryan Allen  
Justin Olsen  
Sara Lomair  
Donna Adams  
Joyce Skidmore  
Joyce Dolcourt, Legislative Coalition for People with Disabilities  
Ann Gonzales  
Rebecca Hyde  
Kathy Jaspersen  
Kathy Costanzo  
Kris Fawson, Utah State Independent Living Council  
Aaron Hollingsworth  
Debra Mair, Director, Utah Independent Living Center of Salt Lake  
Jean Pfoutz  
Cheryl Smith  
Christine Jones  
Tom Brownlee, Co-chair, State People First  
Trudy Johnson  
Emilie Tanner  
Johnny Osborn  
Kelly Holt  
Vickie L. Radl  
Jerry Costely, Disabled Rights Action Committee

Tami Diaz  
Teri Stock  
Lori Cerar, Executive Director, Allies for Families  
Melanie Lahman  
Terry Hawkes  
Heidi Hawbacker

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 2:10 p.m.

### **1. Update of Federal Legislation**

Lisa-Michele Church, Executive Director, Department of Human Services, said she had been asked to report on the impact of the purposed federal legislation on services provided by the Department. She distributed two handouts, a drawing showing the impact of cutting caseworkers for in-home services and a typed analysis of the federal changes impact. She said it is anticipated that when this proposal is heard again there will be no changes. The handout for in-home cases shows that one caseworker serves 27 families with children who are eligible for foster care but are being given services in order to enable the family to remain together. If that one case worker was eliminated, those 27 families, representing 64 children, would no longer be served and would save \$97,929 in General Fund. However, if 33 of these children go into foster care, the services would cost \$595,584 in General Funds, thus costing the state \$497,655 for each in home case eliminated.

Ms. Church stated that \$11 million will be needed for FY 2006 for the retroactive cuts and approximately \$20 million to restore the budget for FY 2007. Other programs in addition to the in-home services would be the medical and mental health services to foster children and children in care. These are critical services. She indicated it is difficult to build a budget around Medicaid when the state is left with the programs but our federal partner is changing their investment policy.

Mr. Church said the subcommittee had ask her to make a priority list but she finds this difficult, as every one of the requested building blocks are critical needs, not a luxury item or a "wish list" for new programs. She said restoration of the federal cuts would have to be number one to protect exiting programs and those people already in service. Other programs to look at would be additional waiver services for people with disabilities, services to the mentally ill and aging waivers for seniors to remain in their own homes. There are also those programs which have experienced actual increases in costs , such as meals-on-wheels, transportation, and adoption subsidies. She said there were three areas where the Department wanted to put new people into services, the Drug Courts, the waiting list and the adult beds at the State Hospital.

### **2. Approval of Minutes**

**MOTION:** Rep. Last moved to approve the minutes of 1-19-06. The motion passed unanimously.

### **3. Public Testimony**

Mary Bennett, President, Utah Adult Day Services, said there is one thing we all have in common and that is we are aging. Most people if polled would say they want to be "successful agers" and don't want to spend their last few years needing help. We want to stay in our homes and be in good health. Unfortunately, not all have that opportunity and will need help. This is when the AAA's come into play. The AAA's do two major things very successfully. They provide a safe environment for clients and time off for care givers. She said seniors are our treasures. She distributed a brochure entitled "Adult Day Centers in Utah."

Mary Velasquez said she had the opportunity to have her mother receive meals-on-wheels. Her mother looked forward to those volunteers coming each day to bring her the meals and talking with her. This is sometimes the only

meal and the only outside contact homebound people receive. She indicated that she became a volunteer with the Heritage Center in Clearfield after her mother's death. She said most of the work done in the centers and meals-on-wheels is done by wonderful volunteers. These services need to be continued.

Karmen Sanone, Salt Lake County Aging Services, indicated there is a waiting list in several counties for meals-on-wheels and these are critical needs.

Laura Polacheck, Associate State Director AARP, said that AARP represents people age fifty and over. She said after looking around the room today she agrees with Ms. Church that the subcommittee has heartbreaking decisions. She said they would like to see more money put into human services as there is clearly a need. She said that a lot of people look at Utah as a very young state, but actually it is also a very old state. People tend to stay near their families here and there is a huge need to provide services for the older population. She said she would plead with legislators to consider ways to funding without diminishing services.

Shirley Kelly said the Autumn Grove Senior Center in Kaysville is a gathering place for people over 60 to eat lunch and enjoy each other's company. It keeps many from just sitting at home 24 hours a day in a boring, lonely situation. Many can only get there because of the bus which comes to their door to pick them. She said the drivers kindly help if anyone has difficulty getting on the bus. When needed, the bus will also take people to their physicians. A reasonable fee is charged for these services.

Sherri Wittwer, Executive Director, NAMI Utah, stated that the mission of NAMI Utah is to insure the dignity and improve the lives of people affected with mental illness through support, advocacy, and education. They have a four pronged message: (1) treatment works; (2) recovery is possible; (3) there is hope; and (4) you are not alone. She stated these are not just words to make people feel better. They have hope and believe in recovery because they see it every day. Recovery does not always mean a cure, but that people can manage their mental illness and live meaningful, productive lives with healthy relationships and achieve their own personal goals. She said this requires treatment and asked for support for funding the 30 new adult beds at the State Hospital.

Christie Kropf stated she lives in Provo and receives in-home services from Mountain Land and Central Nursing. She said she has several disabilities: partial blindness, hearing problems, and a broken neck and without these services she could not be independent. She said she would be in a rest home and a burden to Utah because she could not afford to pay.

Andrew Riggle, Disability Community Alliance, distributed a letter and brochure from DCA to the subcommittee. He stated he would echo the wisdom of investing early for services in an effort to prevent more serious and costly needs later on. He said he wanted to concentrate on one word today and that word is "opportunity." He said he has cerebral palsy but is lucky to be otherwise healthy. He stated he had supportive parents who taught him to be independent. He graduated from the University of California at Berkeley. After returning home, he wanted to do work that would make a positive difference in the lives of people. He stated that without adequate funding, some families are forced to make a choice between caring for a disabled child or their marriage, or between keeping the child at home and their career. He said individuals with disabilities can and want to live independently if they get the help and training needed.

Ryan Allen said when he was 11 years old he was run over by a truck and received a traumatic brain injury resulting in a coma for three months. He left the hospital after three months but life was different for the rest of his life, with a wheelchair for his legs and a computer for his voice. He returned to school and graduated with honors. He said because of the services he receives he is able to go to a day program where he continues to learn and receive physical therapy. The day program helps to keep his legs as strong as can be. He said he is grateful for these services that allow him to be in the community with others instead of just staying at home.

Pat Allen, Ryan's mother, said that as a care giver she hoped that funding can be found for people with disabilities no matter what the disability may be. Each needs help and support. She thanked the subcommittee for the opportunity to be heard and said she hoped they could make decisions appropriately.

Justin Olsen said he has been on the waiting list for DSPD since he was six years old. He is now twenty three. He asked when are we going to get the help we need. He asked, " When are we going to give our parents a break." He said his mother has cared for him for twenty three years. She never worries about herself but always worries about him. He said taking care of a disabled child is full time, seven days a week, with no time off for self or vacations. He said it is time to find funding to help those in need.

Sara Lomair stated she is twenty seven years old and has a form of Muscular Dystrophy which causes her muscles to weaken and atrophy. She said she wanted to come to the meeting today to put a face on the tax dollars that are spent on the DSPD personal attendant waiver. With funding for a personal attendant, she was able to move out of her parent's home and live independently in an apartment. She is attending school. She said she wanted to say thanks for the money given to DSPD for this particular waiver and encouraged subcommittee members to do their best to continue this funding so more people can have the opportunity that she has to be independent.

Donna Adams stated she is eighty two years old and has two sons; Ron, who is fifty-six, and Brian, who is fifty-four. Both sons have cerebral palsy and mental retardation. She said Ron has financial help assuring that he has programs such as workshop placement for work and instructor or mentor who comes into the home teaching him living skills. Brian, on the other hand, has been on the waiting list for eighteen years. She said if Brian had this same kind of help he could get employment and have a job coach and have a mentor come into the home to help him learn living skills to manage basic needs. She said she worries about his future.

Ms. Sanone read a letter from Laura Drew who was unable to attend today. Ms. Drew's mother is a recipient of the Aging Alternative In-home Care Program. This program has allowed her mother to remain living in her home. The services received include someone who comes in to bathe her three times a week and some one to clean. A volunteer provides once a week respite care. Ms. Drew stated in the letter that because of her own health concerns, she would not be able to keep her mother at home without the help received from the Alternatives Program.

Joyce Skidmore stated she is a care giver for a husband with dementia and a brother with lung cancer and heart disease. She said she is a care giver 24/7. She said this has completely changed her life. She said she has thought about what her husband really needs and what would be the most cost effective. He needs emotional support and support that would give him an incentive to be as normal as possible. She said this is where aging services has come to their aid and hopefully will continue to do so.

Joyce Dolcourt, Legislative Coalition for People with Disabilities, indicated that rather than taking too much time, she had prepared written testimony which was being distributed. She asked subcommittee members to please read it. She asked those in attendance who were there in support of the waiting list to stand. Many in the audience stood.

Ann Gonzales stated she has twin daughters who have had services for eight years. Currently they are in a day training program. She said they feel very fortunate for the benefits which have enabled their family to stay together and have the girls at home for them to enjoy a quality of life. She said she hoped the funding could be found to help the families on the waiting list to enjoy their children and keep them at home.

Rebecca Hyde said she was privileged to be here today. She said she wanted to paint in words a snap shot of the crisis her family struggles with everyday in trying to care for a child with disabilities. Her eighteen year old daughter has had uncontrolled epileptic seizures since she was two. The seizures can and do hit her at any moment. She stated these physical attacks have chipped away at her IQ. She gave examples of some of these episodes. She said as a single mother she is struggling to keep her family together and went to school to get her bachelors degree. However, she is unable to work because of her daughter's condition. She said it is essential for her daughter's well being and quality of life, as well as her families, that she come off the waiting list. She said it is not just her family but others who need these services. Funding the waiting list could save lives.

Kathy Jaspersen said her twenty four year old daughter is blind and mentally disabled. She has much anxiety which results in anger and aggressive behavior. She said she and her husband attended a number of workshops and classes to learn how work effectively with their daughter, but she responded better and more positively to others. She said respite care is vital in allowing time for her to take advantage of opportunities for her own well being. Trained

providers at day training programs have provided her daughter with opportunities for recreational activities. She said this has made an enormous difference in the family and asked that the subcommittee take the opportunity to help others in the same way.

Kathy Costanzo said until recently she was a single mother raising her daughter. She said she had a unique situation where her daughter was on the waiting list but because of a mistake by DSPD she has had to start the process all over again. She said she has checked and the state only spends \$48 million out of its own pocket of the \$167 million that funds DSPD. She said it makes her very angry that for years she pays an arm and a leg in taxes and yet when she needs help the most, help is not there for her.

Kris Fawson, Utah State Independent Living Council, said she would not take time but would let Aaron Hollingsworth and Debra Mair speak about the Physical Disabilities Waiver.

Allen Hollingsworth said he appreciated the work the subcommittee does each year. He said while he was on the waiting list he spent much of his time at home in bed. With the Physical Disabilities Waiver he has been able to learn many things with help from the care givers. He said much of the program is relief to those who give the care to those with disabilities. He said it is a wonderful program and he would hate to see any loss in the program. He asked everyone to take a moment to look into the faces of those in attendance and see the concern that is there.

Debra Mair, Director, Utah Independent Living Center in Salt Lake, stated the independent living centers in Utah are non-residential programs that teach life skills to help people with disabilities be more active participants in the community. She said she would like to speak about the Physical Disability Waiver. Through this program money is given to hire an attendant to help a person get out of bed, bath, get dressed and all the necessary things needed to start the day. She said they daily see the value this has for people. She said all people want to be in the community, participating with their families and friends, going to a job, and the waiver makes this possible for people with physical disabilities.

Jean Pfoutz said she is a single mother of an autistic son. She said to say that raising a child with Autism is difficult would be an understatement, and to say that it has been stressful would again be an understatement. She stated that one of the biggest stresses has been trying to find someone to care for her son so she could continue to work and provide a living. The church preschool he had been attending would not allow him to attend after the age of nine. She indicated she has called day care after day care and was turned down. Her son has been on the waiting list for six years. She said without funding she is in threat of losing her job.

Cheryl Smith said she came to talk about increasing funding for the line item for funding for the Autism Pre-school. She said studies from Ohio said that for every \$100,000 we spent in treating autism early, you can save up to \$2.5 million in one child's lifetime by avoiding group homes and institutional placement. You can also avoid the tragedy of broken homes. She said if a child can be made a functioning part of society it is better for all of us. There is no cure for Autism but it is one disability that can be helped with intensive early intervention. She reported there are 250 children in Utah on the waiting list for Autism funding.

Christine Jones said she was here with the Association of Community Services. She said they appreciate the consideration of the need for people with disabilities in these difficult times due to the federal situation. She said to also remember the need to keep up the existing services and prioritize the 2.5 percent COLA and \$750,000 appropriations for benefits and other costs for businesses that assist people with disabilities.

Tom Brownlee, Co-chair, State People First, said he has been on the waiting list for five years. He said People First is a state wide and national organization of people with developmental disabilities organized to help people advocate for themselves. He said there were members in attendance today from all over the state and many are needing services. He said he needed support to obtain a job and is here to ask for funding for the waiting list. He said People First members need a hand up, not a hand out.

Trudy Johnson said she is a parent of two sons with Autism. One is fifteen years old and did not receive early intervention services. Her other son is three and is receiving services and it is making a huge difference in his life.

She said her hope for the future of the three year old is bright and happy but her hope for the future for her older son is not unless something can be done to help him become independent.

Emilie Tanner, a mother of two children with Autism, said she wished to speak about the Autism pre-school funding. The children are ages three and four, both are in the pre-school program and are both thriving. She said she can totally see how the early intervention at the pre-school is so important. She said she feels it is very important to get those on the waiting list help at an early stage rather than have to deal with problems later on.

Johnny Osborn, stated he has a friend, Charlie, on the waiting list. He said he would like Charlie to have the same opportunity he has had. He said he has been on his own for two or three years.

Kelly Holt said she is also on the waiting list and has been for about five years. She moved from California to Price and is finding it difficult to find a job there with limited transportation. She said she would like to move to Salt Lake and find a job. She said she hoped money could be found to get people off the waiting list. They all would like to be independent.

Vicky Radl said she wanted to thank the subcommittee for giving everyone a chance to be heard and for listening to their concerns. She said she is a wife of a disabled veteran with a brain injury, a mother of a sixteen year old who suffered a traumatic brain injury at birth, and was a care giver of her mother who died from a stroke. She said she is also a volunteer advocate. She indicated that many families on the waiting list need just a little bit of help to be self sufficient. Let's fund the waiting list.

Tami Diaz said she would like the subcommittee to consider meeting the needs of people who want to move out into the community. She said Utah is a family oriented state. She said she had a traumatic brain injury ten years ago. She is on the waiting list and said this funding would help people to be more independent.

Jerry Costely, Disabled Rights Action Committee, said he would like everyone who has heard these testimonies, both members of the subcommittee and those in the audience, to call our congressional delegations concerning the federal budget resolution. They need to know the impact these cuts will have. There is a national call in number: 1-800-426-8073. This will be voted on February 1. He said we desperately need to fund the waiting list. He said people in need outweigh roads and other considerations.

Teri Stock said she was on the board of NAMI. She said that ten years ago she had a son who had been senior class president and was on a full scholarship when he had his first psychotic break and the family was thrown into the world of mental illness. She described the number of treatments her son has received and his out of control behavior. She indicated she was not asking for a miracle on behalf of her son, but is asking to keep in place funding to enable her son to have effective treatment.

Co-chair Killpack indicated that was the last person on the list who had signed to speak and thanked everyone who had made the effort to come to testify today. He announced that the appropriations subcommittee meetings for next Wednesday have been cancelled and that the public testimony for the Department of Health would be held on Thursday, February 2. That meeting will again be held in Room W135. He asked if there was anyone who had not signed the list who wished to speak.

Lori Cerar said she is the Executive Director of Allies for Families and this agency works with families who have children with mental illness. She said she wanted to promote and support the need for early intervention and early identification. Treatment works and the children are much better able to stay at home with their families and in their communities. She said thank you for considering children who have mental illnesses.

Melanie Lahman said that at one point she had five children in services at Wasatch Mental Health. She indicated two of her children have serious problems and this would not have been the case if there had been early intervention services available for mental health. She said preventive money goes much further than treatments later on.

Terry Hawks said his group drove from St. George this morning to be here. He said he works at the Independent

Living Center with people who are on the Physical Disability Waiver Program. He gave examples of what these services can do for these people. One example was of a forty-nine year paraplegic man who is going back to school to study drafting with equipment supplied by this program. He introduced Heidi Hawbecker, one of the clients at his center.

Ms .Hawbecker said she has been on the waiting list for seven or eight years. She said she is on the waiting list for housing because her father is abusive to her.

Rep. McGee and Rep. Mascaro both expressed appreciation for the people who have met the challenge to come here today.

#### **4. Other Committee Business**

**MOTION:** Rep. Litvack moved to have the chairs draft a letter to the Executive Appropriations Committee to outline the dramatic effects on the Department of Human Services of the pending Deficit Reduction Act and other Medicaid policy changes . The motion passed unanimously.

**MOTION:** Sen. Christensen moved to adjourn. The motion passed unanimously.

Co-Chair Killpack adjourned the meeting at 4:12 p.m.

Minutes reported by Norda Shepard, Secretary.

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Sen. Sheldon L. Killpack  
Committee Co-Chair

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Rep. Merlynn T. Newbold  
Committee Co-Chair