ALASKA STATE LEGISLATURE
JOINT MEETING
SENATE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE
HOUSE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE

February 24, 2011
8:01 a.m.

MEMBERS PRESENT

SENATE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE

Senator Bettye Davis, Chair
Senator Dennis Egan
Senator Johnny Ellis
Senator Fred Dyson

HOUSE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE

Representative Charisse Millett
Representative Sharon Cissna

MEMBERS ABSENT

SENATE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE

Senator Kevin Meyer

HOUSE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE

Representative Wes Keller, Chair
Representative Alan Dick, Vice Chair
Representative Bob Herron
Representative Paul Seaton
Representative Bob Miller

OTHER LEGISLATORS PRESENT

Representative Mia Costello

COMMITTEE CALENDAR

PRESENTATION: KEY COALITION OF ALASKA - KEY CAMPAIGN

- HEARD

PREVIOUS COMMITTEE ACTION

No previous action to record

WITNESS REGISTER

EMILY ENNIS, Key Coalition of Alaska
Fairbanks, AK
POSITION STATEMENT: Presented report on behalf of Key Coalition.

STEVE WILLIAMS, Program Officer
Alaska Mental Health Trust
Department of Revenue
Anchorage, AK
POSITION STATEMENT: Presented information about the HUB component of the Alaska Complex Behaviors Collaborative.

JOANNE MASON, Parent
Juneau, AK
POSITION STATEMENT: Related personal stories regarding Key Coalition issues.

MICHAEL BAILEY, Fiscal Controller
Hope Community Resources
Anchorage, AK
POSITION STATEMENT: Testified for Hope Community Resources.

WENDY CLOYD, parent
Fairbanks, AK
POSITION STATEMENT: Related personal stories regarding Key Coalition issues.

LORIE KING, parent
Juneau, AK
POSITION STATEMENT: Related personal stories regarding Key Coalition issues.

DANA GRAHAM, parent
Anchorage, AK
POSITION STATEMENT: Related personal stories regarding Key Coalition issues.

BARBARA GORMAN, retired school librarian and parent
Fairbanks, AK
POSITION STATEMENT: Related personal stories regarding Key Coalition Issues.

STEVE LESKO, Key Coalition Member

Anchorage, AK
POSITION STATEMENT: Related personal stories regarding Key Coalition issues.

ACTION NARRATIVE

8:01:32 AM

CHAIR BETTYE DAVIS called the joint meeting of the Senate and House Health and Social Services Standing Committees to order at 8:01 a.m. Present at the call to order were Senators Egan, Ellis and Chair Davis and Representative Millet.

Presentation: Key Coalition of Alaska - Key Campaign

EMILY ENNIS, Key Coalition of Alaska, said for over two decades the Key Campaign has come to Juneau to speak for themselves, as well as for others who cannot speak for themselves. In Alaska over 13,000 children and adults have a developmental disability (DD). The Key Campaign believes that a disability should not prevent a child or an adult from having a full life. A developmental disability is one that occurs before the age of 22, and perhaps is noted at birth or early childhood, or acquired from an illness or accident. Such a disability generally causes substantial limitations and impairments and is expected to be life-long. Some form of support or service will be needed, usually life-long. In Alaska over 13,000 children and adults have a developmental disability. Over one-third of them are receiving DD services in their home communities, funded through the Medicaid waiver or Alaska state grant funds. At last count, around 840 remain on the DD registry, the lowest number on the DD waitlist in many, many years. The Key Campaign's dream is that eventually they will end the DD waitlist, and their dream is coming closer to a reality thanks to the legislature's commitment.

MS. ENNIS said she would speak about four priorities of the Alaska 24th Annual Key Campaign. The first is the Alaska complex behavior collaborative [Hub] component. This establishes a critically needed expertise to make sure that children and adults with behavior challenges do not have the leave the state and their homes and their families to receive the necessary treatment and services.

The second priority is the autism insurance reform, to make sure that over 1,500 children in Alaska today with autism are not excluded from medical coverage because of their autism diagnosis.

The third priority is a periodic rate review, to assure that DD community services can continue to meet the needs of Alaskans with disabilities.

The fourth priority is to maintain Alaska's commitment to eradicate the DD wait-list in the state.

8:07:39 AM
MS. ENNIS gave an example of the benefits of support from the state of Alaska, as follows:

> Twenty-four years ago an infant boy was born in Alaska. At birth it was noted that he had many significant disabilities. His parents were devastated by the loss of the child that they dreamed of and looked forward to, yet they loved him deeply and then began to build the hope that he could have a good life. Right away they received in home supports and respite care from a community service provider. That helped ease their stress and their fatigue, and also helped them navigate the complex medical service system. In a short time their infant son was receiving early intervention services, speech therapy, and physical therapy. And although he still had delays, it was amazing to see how well he did when he began elementary school. His parents still continued to receive respite care a few hours a week, which they called their lifeline. It assured that their marriage stayed strong and that they had time with their other children. Over the years they had a care coordinator who continued to help them identify and locate the needed resources and other services for their child. By the time their son was 21 years old he was part of a supported employment program and he had a job coach. Before long he had his first real job. He was feeling his independence, and his parents recognized that they were growing older. Before his 23rd birthday their son moved into a supported living residence with other young adults who were learning to live on their own. Today he volunteers in the community, he works, and he has a great social life with friends. An agency that he and his parents selected is now there to support him, and will continue to do so as his needs change. His parents feel comfort knowing that he will be fine after they are gone.

MS. ENNIS thanked the legislature for the services that made this story possible. Yet, for many other families who wait, she said this story is only a shared dream.

8:10:04 AM
STEVE WILLIAMS, Program Officer, Alaska Mental Health Trust, Department of Revenue, Anchorage, said he would discuss one of their HUB components, the Alaska complex behavior collaborative. This collaborative took root two years ago. Adults with disabilities were being sent out of state to institutions because their behaviors were becoming too challenging for their caregivers to deal with. Two years ago the Department of Health and Social Services (DHSS) contracted with the Western Interstate Commission for Higher Education (WICHE) to take a look at the depth of the issue and the complexities around it, and to come up with a set of recommendations to address this issue.

The Hub component pulls together experts to work on multiple diagnoses and associated behaviors, so that early intervention can be provided either in the group home or the community placement setting or with the family. The target population is not just adults with developmental disabilities, but also seniors with challenging behaviors. There are multiple divisions within the Department of Health and Social Services that aid in this. The trustees are recommending $500,000 of GFMH to the governor for the Hub. The trustees have also committed $150,000 of the trust fund for this effort.

8:16:04 AM
JOANNE MASON said she was the parent of a twenty-year old severely developmentally delayed son who has lived outside of Alaska for the last four years. Because of the lack of services in their community, the family was forced to send their child across the country to help with his severe autism. They took this drastic step because they were no longer able to cope with the difficult behaviors of their son's disability. During the last year, he has learned to cope with his behaviors and to be successful in a group environment. It was their long term wish to bring their son home. Today he still has episodes of challenging behavior, but has grown into a wonderful young man. Their son recently returned home on Alaska Medivac. She thanked the governor for helping bring their son home and said they are now caring for their son. They need help to care for their son, but they currently have no support. She said it is a blessing, though, to have him home.

8:19:15 AM
SENATOR DYSON joined the meeting.

8:19:25 AM
MICHAEL BAILEY, Fiscal Controller, Hope Community Resources, Anchorage, said two questions come to mind: fiscal sustainability and parity. Having the cost rates of reimbursement adjusted every few years is very important. However, regulations change frequently and sustainability is still in question. He asked that the legislature put in place a statute that has a cost based methodology. The current DSHS regulations are a good attempt towards that end, but regulations change often, and if they change again the sustainability is still in question. This is why a regular review of rates, using cost based analysis, needs to be put in statute. Most providers of these services are nonprofit organizations and they have no way to absorb losses. The service providers are also looking for parity in the methodology used by the hospitals and long-term care institutions to establish rates.

8:22:47 AM
WENDY CLOYD, parent, said she was told 14 years ago to avoid using the word "autism" in any insurance related paperwork for her child. When early intervention therapies were recommended, she was unable to afford them. She said that she did not realize what she was missing until her child attended a one-week behavioral therapy session sponsored by the school district. This makes her wonder what more they could have done if he had access to services at an earlier age. She asked that insurance companies treat autism as any other medical need and include it in coverage.

8:24:55 AM
LORIE KING, parent, said she has a daughter, 20 years old, who experiences autism. She said that their family's journey along the autism spectrum began at birth. By fifteen months their daughter was still not walking, and seemed to prefer being alone. By age three she was throwing earth-shaking tantrums and attacking her older sister for no apparent reason. The results of her daughter's evaluation took a long time, while her daughter's behavior became worse and worse. She could not be left alone with her older sister out of fear for their physical safety. The family started with a diagnosis of ADD, then added OCD and ODD. Their insurance appeared to be more of a barrier than a help. No matter how she worked to help her daughter, she would run into another wall. On top of all of this, her older daughter was not receiving the attention that she needed.

8:31:24 AM
MS. KING said her daughter was not effectively diagnosed with autism until she was eight years old. She said that they have struggled to keep their daughter in their home over the years. She shared an article with the committee from the University of Wisconsin in Madison: research found that mothers of children with autism have the same stress level of individuals in combat. She urged the committee to support any bill about autism insurance reform.

8:34:17 AM
DANA GRAHAM, parent, said that she had a daughter who was born with multiple disabilities that were not diagnosed before she was born. She said her daughter passed away only 20 months after she was born. She said imagine being told that you were going to have a baby, and that child could not see or hear you, and could not feed without your help. She said this was her daughter, who was the 16th child diagnosed with Bohring-Opitz Syndrome in the world. The family was directed to HOPE in Anchorage after many months of extreme stress in trying to care for their daughter. At first, she explained, she was apprehensive about the home visits. Once she allowed HOPE into their home, they became a huge emotional and physical help for her. She said she does not know what it takes to fund a service like HOPE, but this community service helped them exponentially. She explained how important it was to keep their daughter in their home. She said that her family no longer needs their assistance, but every day there is a child that is born or injured and those services are needed now and in the future.

8:42:48 AM
BARBARA GORMAN, retired school librarian and parent, said she was there to represent the other end of the spectrum, and the end of one's life. She has three children, and her family is geographically dispersed, but they love each other. She explained that when their son was born they did not know that they would have expense issues, because they had insurance. However, the insurance didn't kick in until he was 30 days old and by that time the family was $50,000 in debt. Because of her age (85) she is thinking about what will happen to her son when she is no longer around. When their son was in elementary school, the local school was not able to deal with him so the family sent him to a school in Edmonton, Alberta, Canada, where he spent ten years. She asked the committee to erase the DD waitlist so that people with developmental disabilities can stay at home in Alaska.

8:48:37 AM
CHAIR DAVIS said the committee had run out of time, but she would like to have the final testimony in writing.

8:48:54 AM
STEVE LESKO, Key Coalition Member, presented the committee members with butterfly pins, and emphasized that everyone can make a difference.

8:49:43 AM
There being no further business to come before the committee, Chair Davis adjourned the meeting at 8:49 a.m.