

ALASKA STATE LEGISLATURE
SENATE HEALTH, EDUCATION & SOCIAL SERVICES COMMITTEE

March 15, 2001

7:59 a.m.

MEMBERS PRESENT

Senator Lyda Green, Chair
Senator Loren Leman, Vice Chair
Senator Bettye Davis
Senator Gary Wilken
Senator Jerry Ward

MEMBERS ABSENT

All members present

OTHER MEMBERS PRESENT

Senator Kim Elton
Senator Johnny Ellis
Senator Reggie Joule

COMMITTEE CALENDAR

Key Campaign

WITNESS REGISTER

Mr. Carl Evertsbusch
Center for Human Development
University of Alaska
Anchorage AK

Lori and Tim Moore
Kake AK

Ms. Sam Bush and son, Isaac
Fairbanks AK

Mr. Rick Howard
North Pole AK

Ms. Linda Thompson
Mr. Eric Behnke
Homer AK

Mr. Arthur Walters

Seward AK

Lisa and Jerry Wangberg
Wasilla AK

Ms. Lisa Klessens
Eagle River AK

Mr. Steve Lesko
Eagle River AK

ACTION NARRATIVE

TAPE 01-22, SIDE A
Number 001

CHAIRWOMAN LYDA GREEN called the Senate Health, Education & Social Services Committee meeting to order at 7:59 a.m. and announced a discussion on the Key Campaign.

MR. CARL EVERTSBUSCH, Center for Human Development, UAA, said this is the 14th year they have testified at the capitol and there has been much done to improve the lives of people with developmental disabilities. One of the most notable of those was the closure of Harborview Developmental Center in 1997. "With that closure came the total commitment to serve people with disabilities and their families in their homes and communities."

He said another milestone was the adoption of Medicaid waivers, which currently provides the means to serve over 700 Alaskans in the places they choose. This year, Mr. Evertsbusch explained, they have reached another milestone:

Nearly 1,100 families are waiting for the services that are critical to their well-being. Never before has this number been so high. More tragic still is even if funding miraculously appeared tomorrow to serve these 1,100 Alaskans, the service delivery system has the capacity to serve only 82. This is not good news. But while people wait, children become sicker; families become more fragile; aging parents become older; serious problems occur. What follows is far more expensive: hospitalization, out of home placements, incarceration; and more tragically, lives are destroyed. We are nearing the breaking point. We are asking for \$750,000 to begin fixing the system that we have already built to capacity to serve these 1,100 families. The promise of Medicaid waivers for the

valued services [provided] around people in their homes and communities and to put those people in control of their services will be lost if we don't make the repairs. And believe me, lives will be lost.

More bad news is we hear that \$700,000 for infant learning we have been asked to shift from interagency receipts to general funds and this is not new money to serve 316 infants on the wait list, is at risk for being passed over. Will Alaska deprive 316 babies of these critical services? The answer must be no.

MR. EVERTSBUSCH also informed the committee that another serious matter was preventative and restorative dental services for adults with developmental disabilities.

These services are currently not covered under the Medicaid insurance program. The Key Campaign solidly backs the Governor's Council request for \$250,000 to pilot a partnership with Alaska's dental community that will provide affordable basic dentistry to adults. The health benefits of healthy teeth are well documented.

The Key Campaign also supports SB 133, which would assure students receiving special education would have fair opportunity to earn a diploma while continuing to participate in state-wide standards testing. We urge that the final version include the three priorities of the Council's recommendations.

He said the Key Campaign has total support for universal newborn hearing screening. This would provide early detection to 30 - 40 infants annually.

MS. LORI MOORE said she lived in Kake and her special little girl is Xandi and is five years old and was born with a tumor on her face. At three months she developed seizures and she is developmentally delayed.

Mr. TIM MOORE said he wanted to speak on Xandi's behalf and that of infants who are on the waiting list for Infant Learning services. They now have seven children, but when Xandi was born they could tell she was not developing the way she should and with no hope or knowledge about what to do about their child's development, they were introduced to the Infant Learning Program when she was about 12 months old. "The Infant Learning Program was almost like our savior when they came in."

He said that the infants on the waiting list should not have to

wait another day, because one day to an infant is like a year with an adult in developmental delays. He urged them to fund additional monies to take care of the ones who are on the waiting list.

Number 161

MS. SAM BUSH said her claim to fame was that she is Isaac's mom. Isaac said he is a junior in high school and a staff sergeant in JROTC. He read a prepared letter to the committee. He said that math and English were hard for him, but he gets good grades for his work. The exit exam could keep him from getting a diploma and he supported changes so that he could.

CHAIRWOMAN GREEN said that they had spent nearly four months working on it and she thought he would like the changes.

MS. BUSH said that Isaac has many friends at school and that he is a graduate of an Infant Learning Program in Fairbanks. When he was born, there were so many things wrong with his body that she was told he wouldn't be with her long. She credits the first three years of his life with getting him off to a good start when Project Teach came to their home once a week for an hour. The time they spent with the family made a tremendous difference. She said she had other grown children:

...but, maternity had nothing to do with how you handle a child with all these special needs. If it hadn't been for that Infant Learning Program, I don't know what we would have done. It obviously got him off to a good start. The wait list now is obscene. It's terrible that babies and infants have to wait until it's almost too late. Eighteen months of age is almost too long to wait. Three years is even longer. There was money in the budget last year and somehow it didn't get down to us. It got lost because of the way it was appropriated...

Number 264

MR. RICK HOWARD, North Pole, said his son, Sydney, was 9 years old and was diagnosed as autistic at three years old. He said that they sought help and found programs, but they had no funding. "So we're on a wait list."

He said they were told there is a learning window between the ages of 3 - 5 while they were waiting. "Well, this window is being passed and I just wonder how much more of my son we could have gotten back if we could have used this early intervention

during this window time."

He concluded: "The money is needed for these kids and they can't afford to wait."

CHAIRWOMAN GREEN said last year the budget was provided and their instructions were that this money could be used for these services and after they adjourned, they heard the money couldn't be used for that.

MS. LINDA THOMPSON, Homer resident, said that she raised Eric Behnke in the bush and he is a successful story for them to hear. She is a certified teacher and always had something going on at home for him until they moved to Dillingham. In 1997, when he was 20, she got a job in Copper River and they moved to a road school, which is where things started to unfold for him. He was diagnosed with autism, Down's syndrome, and he's also an elected mute (He will only talk to certain people in certain environments). He's a very successful artist and sells works in 11 art galleries including Washington DC and Boston. She had the help of Kenny Lake vocational rehab people and Miller House Developmental Disabilities people.

In 1998 she lost her job because she was not a tenured teacher. She was able to get a job in Kenai Peninsula School District and Homer. Eric needed a safe environment while she worked and eventually he was approved for a waiver, but the money didn't come until summer. So she went through an entire year without help. She said it is a lengthy process to get a waiver and urged them to find a way to speed it up once the money is there.

CHAIRWOMAN GREEN asked if the delay was from state or federal overlay.

MS. THOMPSON replied that she didn't know, but she did know that the community "chipped in" and got her through this period.

MR. ARTHUR WALTERS said he was diagnosed with a moderate to severe hearing loss at the age of 2 and a half. He was also diagnosed with a form of juvenile diabetes. He lost his sight at age 19 due to the diabetes and relies on providers to assist him in everyday living. He wanted to talk about 2 issues. He had a difficult transition when he became blind and had only 12 hours a month of respite care at first. He now has a Medicaid waiver, which helps him in all the ways he needs to be independent and productive.

He said one day he waited for his provider to take him to the

grocery store, but he didn't show up. He had quit and went to work for a coffee shop where he was paid more. He said providers are dedicated people who leave their families to help people like him. Mr. Walters said he waited three days to be taken to the grocery store at that time because no one was available.

He also said there is not enough training. Sarah Souders who was with him today and had been with him for the last six years, didn't have any training. He said that providers need the training so that they can feel confident that they can handle a client who might be blind and communication problems too. He concluded: "If nothing is done today, tomorrow will be too late."

SENATOR WILKEN asked if care providers were also known as personal care attendants.

MR. WALTERS answered he thought they were.

SENATOR WILKEN asked what agency provided that service.

MR. WALTERS answered from CD Community Services in Seward. He said they have a hard time recruiting, retaining and keeping providers, because they are only paid \$8 per hour without benefits.

Number 473

MR. JERRY WANGBERG said they were from Wasilla.

MS. LISA WANGBERG said they appreciate the difficult talk of working on a budget and urged them to take care of people with special needs:

As the late great Martin Luther King, Jr. said, I have a dream. How awesome it would be to be a state that is at the forefront in its care of all individuals, that all individuals can dream of reaching their fullest potential, not being told they can't or we don't care enough to try.

She supported churches and families rallying around each other during times of need, but the special needs are issues beyond their expertise. Highly trained individuals with training and equipment need to be available. Parents want to learn what they can do for their children. The Infant Learning Program was invaluable to them, but it needs help, she said.

MS. WANGBERG said that you can't get insurance for these children and if you have some, there is a big battle to get unique needs

met. She urged them to fund at least the \$750,000 from last year and look at the overwhelming infrastructure needs of provider services to special individuals and families. "Communities are growing and so are special needs, but service provider agencies have not. They are suffering and we will too, if we don't find a way to help them..."

MS. LISA KLESSENS said she was speaking on behalf of her three children. She supported the Infant Learning Program (ILP) and the Medicaid Waiver System. Her son, Spencer (9) is autistic and received services from the ILP. Because of the early assistance he received, he is now in a regular third grade classroom with little assistance.

Her second son, Chandler, is two years and is probably autistic. He currently receives services from the ILP for the same things as Spencer and they hope he will do as good as he is. Their daughter, Morgan, (5 1/2 years) has a genetic storage disorder and also received ILP services as early as five months. She received a Medicaid waiver that provided equipment necessary to take care of her medical needs, in-home support, and staff support.

Number 562

MR. STEVE LESKO, Eagle River, said he had been coming before them for 14 years. He said they had accomplished a lot. One of the things Alaska has done is close down all their institutions.

Once upon a time, there was a state institution and its cost exceeded \$125,000 per day per person. Our community programs which are left, the heart of our service delivery service system costs, are far less than half that. And then a good thing happened in the terms of history. Waivers came in and waivers took in the visuals and service delivery that captured 100 percent general funding and got 50 percent Medicaid funding.

Eventually the funding was a 60/40 federal/state mix. Millions of dollars were saved and not reinvested in the program; they went other places in the budget. He said the stories they have heard today represent legitimate needs.

TAPE 01-22, SIDE B

MR. LESKO said:

Our community programs are truly in crisis. Over the past decade, our base grants and community services

have received less than one percent cost of living. How do you survive cut to the bones, trim government? We've cut to the bone in community programs and it hurts and we're bleeding and we're in crisis and we've got to have your help.

The second thing is when we started out Key Campaign 14 years ago, you worked with us and we had a wait list of 125 people and we all certainly said 125 people are too many. Today, we have about 1,100 on our waiting list. That's a shame. That's a tragedy, because if you're fiscally conservative and in my maturity, money is important. It is important how you spend it. Cost effectiveness is in community-based program. If we don't address crisis now, people will be incarcerated; people will be put back in nursing homes; people will be in our penal system and on the streets. All I'm going to ask you today is one part of the budget from my perspective is in the Governor's capital budget for \$750,000. It's a C for what we call systems reforms. It's under the title of developmental disabilities systems reform initiative...Programs will serve more people effectively, with quality and with safety, not haphazardly and not by chance.

He said there needed to be systemic reform in the Medicaid waiver system to streamline billing, to process the preauthorizations quicker and to stop the community crisis in cash flow. He begged them to maintain the \$750,000 in the Governor's capital budget.

MR. EVERTSBUSCH thanked the committee members for listening to their stories:

The small amount of money we are requesting will go a long ways towards guaranteeing the promises of Medicaid assuring that all Alaskans at risk for developmental delays receive the services they need in the early part of their lives, creating a dental care system that will assure good dental health for thousands of Alaskan adults. We support the fair opportunity for all students to receive diplomas upon graduating from public schools and the establishing of universal screening to provide parents with the information they need to help their children avoid unnecessary delays...We believe these are modest requests...

CHAIRWOMAN GREEN thanked everyone for participating and adjourned the meeting at 8:50 a.m.