ALASKA STATE LEGISLATURE

# SENATE HEALTH, EDUCATION & SOCIAL SERVICES COMMITTEE

March 7, 2002
8:07 a.m.

## MEMBERS PRESENT

Senator Lyda Green, Chair
Senator Gary Wilken
Senator Bettye Davis

## MEMBERS ABSENT

Senator Loren Leman, Vice Chair
Senator Jerry Ward

## OTHER LEGISLATORS PRESENT

Senator Kim Elton
Senator Georgianna Lincoln
Senator Ben Stevens
Representative Ethan Berkowitz
Representative John Davies
Representative Reggie Joule

## COMMITTEE CALENDAR

Key Campaign

## WITNESS REGISTER

Ms. Maureen McGlone
Anchorage, AK

Ms. Dawn Sadler
Fairbanks, AK

Mr. Ray Nabinger
Eagle River, AK

Ms. Valerie Nabinger
Eagle River, AK

Ms. Marie Simmons
Galena, AK

Ms. Karen Timmins
Eagle River, AK

Ms. Karen Sidell
Bethel, AK

Mr. Bryan Knight
Anchorage, AK

Mr. Steve Lesko
Anchorage, AK

**ACTION NARRATIVE**

**TAPE 02-18, SIDE A**
8:07 a.m.

**CHAIRWOMAN LYDA GREEN** called the Senate Health, Education & Social Services Committee meeting to order at 8:07 a.m. Present were Chairwoman Green and Senators Elton and Wilken. Senators Davis, Lincoln and Stevens and Representatives Berkowitz, Davies and Joule arrived later.

She announced that the Key Coalition would be making their Key Campaign presentation to the committee. She asked Ms. Maureen McGlone from Anchorage to provide testimony.

MS. MAUREEN MCGLONE said she was a member of the Key Coalition. She thanked the committee for inviting the Key Coalition to meet with them. She said this was the 15th Key Campaign and explained that it began in 1988 as an effort to work with the legislature to eliminate the waitlist for community supports for people with developmental disabilities. The Key Coalition was made up of parents, service providers, adults and children with developmental disabilities who worked as a united team to advocate for critically needed supports for people with developmental disabilities.

She said the Key Campaign came to Juneau to advocate for expanded services. When they arrived they learned more about the fiscal issues plaguing the legislature and that one of the proposed solutions to the looming fiscal gap was to make budget cuts. She said budget cuts could mean service reductions in their programs. She said the Key Coalition realized that under the current conditions increases in funding were not likely.

MS. MCGLONE said the Key Coalition still needed to remind the legislature of all that they had helped create over the years. She said reductions to the waitlist and increases in communitybased services for people with developmental disabilities helped increase self-sufficiency and preserve and strengthen families. She asked the legislature to continue to ensure that community services for people with developmental disabilities would not be reduced. She said the supports and services had tremendous personal and collective value and the prospect of losing them or seeing them reduced was frightening. She said the service system was already sparse and Alaska met some fundamental needs with fewer resources than many other states. She said that effectiveness came at a price and budget cuts would mean lost services and more reductions to already minimal services.

MS. MCGLONE noted that these issues are of such concern that people who would ordinarily prefer to protect their privacy and guard their pride chose to come tell the legislature how the services helped in their lives. They came to share their private lives to remind the legislature of why community services for people with developmental disabilities needed to be protected. They represent all the families who shared similar needs and circumstances.

CHAIRWOMAN GREEN thanked her. She asked Ms. Dawn Sadler from Fairbanks to provide testimony.

MS. DAWN SADLER showed the committee a picture of her daughter Sabrina who was born with a rare genetic disorder called Cri-du-Chat. Sabrina would be five years old in May. The doctors originally said that Sabrina would need to be institutionalized, would never walk, would never speak and would never really be a part of the family. She said that was far from the truth because of the advances made in the medical field and the system in the state and the country. Sabrina was walking and signing and had some vocalization. She is called “Miss Sunshine” at school because she has a smile that lights up a room. She said that was most days and really depended on Sabrina’s mood. She told members that Sabrina was her little angel.

MS. SADLER explained that Sabrina had a lot of behavioral characteristics that were common for children with disabilities and could be very hard on a family. She thanked God that they didn’t have to put her in an institution and there were no institutions in Alaska. They were able to be at home with Sabrina and be a semi-normal family because of respite care. She received 40 hours of relief a month from qualified personnel that had been trained and had a heart for people with disabilities, which was very important because they could be very trying. Some people with disabilities had severe medical needs as well and needed trained people to take care of them. The relief allowed her to go to basketball games with her other children or have a date with her husband, which was important because a lot of divorces happened when a disabled child came into a family.

MS. SADLER said her household was very happy and Sabrina was coming up in the world but they had a lot of things they still needed to face. They have lived in Alaska all of their lives and don't plan to go anywhere. She loves Alaska and has a lot of faith in the state as it has always been a "people" state and everybody has done a great job helping her. She had a lot of faith that there would be new programs for Sabrina as she grew up.

She said children with disabilities grow up slower but they still have a lot of the same hopes and dreams that everybody else did. She said perhaps before Sabrina was born, they had hoped for Harvard, but now they hoped that she could go out into the community and be able to find a job she could do. She said Sabrina probably wouldn't be able to function at Safeway or McDonalds and would need some sort of community service special developmental job. She said some of the projects already out there would make Sabrina very happy. She said Sabrina would be able to get a paycheck and would be very proud of that. She said they want that for Sabrina as parents and want her to be in an assisted living program in a nice place.

MS. SADLER acknowledged that the legislature has some very tough issues to face. She didn't want the legislators' job any more than they wanted hers. She said there were times that she felt overwhelmed by everything that was going on and was sure the legislators felt the same way. She hoped that the legislature would do the right thing and thanked committee members for their time and for the help they had already given.

SENATOR WILKEN assured Ms. Sadler that his job was much easier than hers, knowing all that she went through and of her advocacy efforts in the Fairbanks area.

CHAIRWOMAN GREEN thanked Ms. Sadler. She asked Ray and Valerie Nabinger from Eagle River to provide testimony.

MR. RAY NABINGER thanked the committee for taking the time to meet with the Key Campaign. He showed the committee pictures of their son Jarod [ph.], a 17 year old and he was blind and deaf. He said Jarod came off the waitlist the previous May, which was very encouraging and a shot in the arm for them.

MR. NABINGER said deaf-blind people need a consistent environment and stimulating activities that allow them to expand their language, mobility and world concept. He said Jarod's world, and theirs in turn, was very confusing, frustrating and isolated. He said trying to meet all of Jarod's needs on their own was very exhausting.

He said they receive modest funding and are able to maintain an environment and allow Jarod to get out into the community. The funding expanded Jarod's opportunities and world and gave them a chance to participate in the community. He said it had taken them from despair and lack of hope to hope and from isolation to participating in the community. He said it was a joy to watch Jarod in the community because he was "a delightful little character." They are able to volunteer and help others as well.

He asked the legislators to consider this funding as an investment in the citizens and the community. He said cutting the funds could easily mean community and family disintegration, which could ultimately cost considerably more.

SENATOR LINCOLN asked what the impact of coming off the waitlist had been. She heard so much about the waitlist but the family had functioned for 17 years in some manner. She thought it was really important to hear what coming off the waitlist really meant.

MS. VALERIE NABINGER said she used to spend all of her time and energy on basic daily care needs because it was time-consuming getting through a normal day when a person depended on you for everything. She was isolated and her world was very small. She said getting off the waitlist allowed them to have the support they needed from the community through agencies like FOCUS, which sent providers to help with the daily care needs so they were free to do some fun things with Jarod. She had more time and energy to participate in the community and help other people. She said the only way she could explain it was that it had opened up their world and instead of being in a tunnel, they were out there.

CHAIRWOMAN GREEN thanked them. She asked Ms. Marie Simmons from Galena to provide testimony.

MS. MARIE SIMMONS said she was on the Governor's Council on Disabilities & Special Education. Her daughter Tisha [ph.] is a beautiful young lady who would be 25 years old on Easter Sunday. Tisha became a quadriplegic when she was in a car accident when she was 15 years old. Tisha was a typical 15-year-old at the time of the accident; she enjoyed figure skating, downhill skiing and playing basketball. Tisha’s life was yanked out from under her the day she got in the accident. She said it was a very traumatic change for the family.

She said Tisha was in a children’s hospital in Seattle for seven months and was going downhill. She said they wanted Tisha to be brought back to Fairbanks or Anchorage so that she could be around her friends and family but they were told that there were no facilities in Fairbanks or Anchorage able to treat Tisha. She wrote to her Congressmen and Senator Ted Stevens wrote letters to the agencies in Fairbanks to encourage them to make sure that Tisha came back to Fairbanks to get the services she needed. She said a team, including occupational therapists, physical therapists, respiratory therapists, doctors, nurses, personal care attendants and other people from different state and tribal agencies, went to Seattle to learn how to take care of Tisha.

MS. SIMMONS said the first 18 months were a constant battle. Her focus was primarily on taking care of Tisha so that she could survive as Tisha fought for her life every day. She said Tisha had to be turned and suctioned every two hours. She said Tisha spent about three weeks of every month in the hospital with a collapsed lung, pneumonia, abnormal calcium levels and numerous urinary tract infections.

She had to quit working to take care of Tisha, which meant she had to depend on the welfare system. She had always been very proud and thought it was the end of the world to have to go on welfare but she was able to be home and take care of Tisha because of the welfare system. She said their basic needs were met. She had to rely on food boxes during the last week of the month. She received $844 per month to pay rent and buy food to meet their very basic survival needs. She said a cut in the welfare system would be devastating to a lot of families.

She said Tisha was on the waitlist for three and a half years before they got services. She said they were able to get personal care attendants, respite and many different agencies involved in helping them take care of Tisha. She said many families had been on the waitlist a lot longer than they had. She encouraged the legislature not to cut back on services because they were desperately needed.

MS. SIMMONS said Tisha was going to finish her master’s degree in psychology in December and was working full time as a director for a children’s mental health services provider. She said Tisha is a contributing member of the Fairbanks community. She thanked the committee for listening to Tisha’s story. She was very proud of her daughter and that she had been through a long tough journey with a successful ending.

CHAIRWOMAN GREEN thanked her. She asked Ms. Karen Timmins from Eagle River to provide testimony.

MS. KAREN TIMMINS showed the committee pictures of her daughters Leigh [ph.] and Madison [ph.], her oldest children. She was married and had four children. She said Leigh and Madison looked like ordinary children but the pictures didn't show the disabilities they struggled with. She said the legislature had played a very important role in Leigh and Madison's lives. She hoped they would continue to do that for others. She thanked them for their continued sensitivity to the needs of children like Leigh and Madison.

She wanted to see her children become full contributing members of Alaska. She said they lived in Alaska and planned to stay there. She said Leigh and Madison received core services and had been on the waitlist for three and a half years.

She said, "Our generation has learned to embrace children such as Leigh and Madison, which is very encouraging to me as a mother." She and her husband participated in a training session through the Stone Soup Group's Institute for Positive Behavioral Support. She said the training session was a unique method of training using a collaborative effort to lessen or eliminate the negative behaviors that seem to be prevalent in so many children with disabilities. She said Leigh was the target child for the session because she was in a period of transition from elementary to middle school. She said that was a difficult transition for any child and even more so for a child with cognitive impairment and autism like Leigh. She said Leigh was acting out and failing to contribute to anything around her. She wanted to learn how to eliminate negative behaviors associated with that transition to help Leigh as well as those around her in school. She said the team included three teachers from Homestead Elementary, two teachers from Gruening Middle School, the principals and Leigh's psychologist. She said they met for one-day sessions once a month for three months and discussed the negative behavior and how to eliminate it. She said the training process included role-playing and actual trial and error.

MS. TIMMINS never would have imagined how successful the Stone Soup Group's program would be. She and her husband had participated in parent training seminars before but found that they didn't really apply to a child that wasn't "typical." She said they felt empowered by the training sessions. Leigh made the transition from elementary to middle school with very few disruptions and she was very grateful for that.

She noted the Stone Soup Group's program had also helped many others because the team members had used the techniques with other children. She said the domino effect must continue. She said it was necessary to continue services because they would eliminate future greater expenses by reaching children at younger ages.

She said the core services gave her time to take a break. Her husband was gone for half of the month and she had two other children. She used the core services money for respite and tutoring so that she didn't have to fight all of the battles by herself. She felt rejuvenated and ready to go after having some time for herself.

She said they plan on keeping Leigh and Madison in their home. They would be grateful for the opportunity to come off of the waitlist and get Medicaid waivers to allow them to continue to have the supports as Leigh and Madison got older and their needs changed. She said they were a very proactive family and they would continue to do everything possible to keep the girls at home and nurture and care for them. Their goal for Leigh and Madison is independence but they don't know what form that would take. She said the girls would contribute to society in a meaningful way but they could not do it alone.

She and her husband thanked the legislature. She asked them to continue to be sensitive to the needs of the disabled community. She and her family were a part of that community and loved being in Alaska. She thanked them for their time and heartfelt support.

CHAIRWOMAN GREEN thanked her. She asked Ms. Karen Sidell from Bethel to provide testimony.

MS. KAREN SIDELL said she was a mother of a four and a half year old autistic boy. She said they were number 1,038 out of 1,200 the last time she checked the waitlist in November. She said there was an effective treatment for autism called intensive early behavioral intervention for which there was a very small window of opportunity. She said if they were on the waitlist for another three years, her son would be seven and a half and she could miss the window of opportunity. She said getting the treatment in time meant the difference between a verbal child and a non-verbal child and could mean that he would be independent later on in life rather than dependent on the system. She said they were so far down the waitlist that she couldn't comprehend how long they would have to wait. Until then, they would continue to struggle to provide intensive early behavioral intervention services on their own.

MS. SIDELL asked that no cuts be made in the budget. She said one of the goals of the Key Coalition was to have no waitlist and she hoped to see that one day. She thanked the committee.

SENATOR DAVIS asked what services Ms. Sidell and her son received.

MS. SIDELL said they basically received one-time grant services from Bethel Community Services.

SENATOR DAVIS asked if Ms. Sidell's son was eligible for services through the school district.

MS. SIDELL said he is.

SENATOR DAVIS asked if Ms. Sidell was involved in that.

MS. SIDELL said they were very involved in advocating for services through the school district. They went through due process in January and would probably go back in August. Her son was getting services through the school district but it was a constant struggle and those services weren't guaranteed.

SENATOR DAVIS thought those services were guaranteed for students that needed them. She thought Ms. Sidell could get early intervention for her son at the age of four and something could be worked out if there was a problem.

MS. SIDELL said they were concerned about the type of services the school district was willing to provide. The school district was planning to provide respite care and was not willing to provide intensive early intervention services with the applied behavioral analysis technique. She said that wasn't good enough because her son had potential and they needed to access the window of opportunity.

CHAIRWOMAN GREEN thanked Ms. Sidell. She asked Mr. Bryan Knight to provide testimony.

MR. BRYAN KNIGHT gave the following testimony:

> My name is Bryan Knight. I live in Anchorage. I am 21 years old and I'm on the waitlist. I attend the ACE

> program. I work at Value Village. I live with my parents and I'm on the waitlist. As of Friday there were 1363 people on the statewide waitlist, 612 in Anchorage and Kodiak. And I am number 472. I understand [the Division of Mental Health & Developmental Disabilities (DMHDD)] recently had a draw and 24 names were pulled in Anchorage. How many more names were added in the same time period?
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> I was determined eligible for services back in 1985 but I finally just received core services last December. I should have received core years ago. I have gotten passed over. How many other people out there are like me? Thank goodness the person we work with at DMHDD straightened things out and helped me finally get core services. I'm using them for dental work because the state doesn't provide us with dental coverage.
>
> I have been working hard to become more independent. I love my parents but I don't want to live with them forever. I want my own place. I want to cook my own meals. I want to make my own decisions. But I don't know if that will ever happen. There are hundreds of people just like me across the state wondering the same thing. I know of people in their 30s and 40s that are on the waitlist and I've been told there are people in their 50s too.
>
> We are very capable people. We work. We play. We live in our communities. We contribute to our society like everybody else and we know we do. I ask myself if I were ever drawn and finally received the support I need to accomplish these things. I still don't know the answer to that question. So I guess I will just keep on waiting and waiting because I'm number 472 on the waitlist.

CHAIRWOMAN GREEN thanked Mr. Knight for sharing his story.

SENATOR LINCOLN said she heard Mr. Knight's testimony the previous night. She said it was very heartwarming to hear his testimony for all people in Alaska. She knew he would be successful because he had "the drive."

CHAIRWOMAN GREEN asked Mr. Steve Lesko to provide testimony.

MR. STEVE LESKO said he was just one person in a group of thousands across rural and urban Alaska called the Key Coalition.

The Key Coalition is in Juneau because it believes the legislators can make a difference whether they be majority or minority members.

He said the story he was going to tell was an analogy. He said the Key Coalition came to Juneau and heard that Alaska had been diagnosed with a potentially terminal disease called “fiscalitis.” He said reserve funds, surpluses and alternate methods of feeding the budget were no longer adequate to maintain Alaska’s health. Many treatment regimens have been suggested, including an income tax, state tax, sales tax, alcohol tax, cruise tax and intervention in the permanent fund or a combination of those treatments. He said they found out that some doctors had recommended surgery in the form of deep budget cuts across the board. The Key Coalition was concerned about the suggestion that surgery was going to cure Alaska. They were concerned that it would not be effective because there was no such thing as a fair across the board cut. He said legislators had the capability to be surgeons but the legislature needs to consider four things:

**TAPE 02-18, SIDE B**

1. The community programs under the budget request unit (BRU) of Community Developmental Disability Grants had received one increase in 15 years. He said that increase ranged from less than 1% to less than 2% for the 33 grantee agencies in rural and urban Alaska. Anyone with business sense could see that they could not survive very long with no cost of living or increases to the budget;

2. The infrastructure of the community services was eroding. Budget cuts would cause the beginning of the end. There were no alternatives to those community services except for nursing homes, long term care and foster care, which could also be cut;

3. 16 of the 33 grantee agencies said that 133 to 167 individuals and 300 to 358 families would lose service in their agencies alone. One agency provided services to rural communities in a 236,000 square mile area and a 5% to 6% cut in grant funds would result in at least 25 families losing respite care. When those families lost services, the providers would lose their jobs and jobs are already scarce in that area.

4. The fourth effect would be a combination of the first three. Jobs would be lost and people would lose the homes they were

renting. Respite care was the glue that held many of the families together. The costs contained in the base grants were between $2,000 and $3,000 per person per year. The State had been willing to tolerate the excesses of institutionalization for $125,000 to $150,000 per person per year not so long ago. He asked if it was unreasonable to expect the families to continue to get $2,000 to $3,000 a year. He said they were getting by on that. He cautioned that if respite was denied, there would be separations, divorce, children placed in foster care and adults institutionalized and stripped of their dignity and ability to live independently in the community.

MR. LESKO believed in people and the State of Alaska. He said that legislators were the surgeons and that was why they were there. He said the Key Coalition was there because they were the people of the State of Alaska and they cared about their families who experienced disabilities. He said the theme of the Key Campaign that year was "For Tomorrow." He said legislators had the power to change things for tomorrow. He asked what they were going to do with that power. He asked them to change the human condition and leave behind a victory for humanity instead of saying the time was squandered. He asked them not to cut the budget and learn that the surgery was successful but the patient had died. He asked them to do the right thing and keep giving the hope that their support and caring had provided for Alaska families with disabilities.

CHAIRWOMAN GREEN thanked him.

REPRESENTATIVE DAVIES asked for examples of eroding infrastructure.

MR. LESKO said the community disability programs were funded through two methods. The first was the Medicaid waiver that was in the Division of Medical Assistance BRU. The other was in the Department of Health & Social Services' Community Developmental Disability Grants BRU, which provided over $20 million to 33 grantees. He said that money provided critical interim services and the administrative and general costs of the agencies. He said they didn't have enough staff to run their programs because recruitment and retention was very difficult. He said the Governor's Council on Disabilities and Special Education had statistics on the rates of pay for people who work with the disabled. He said they could make more money at McDonald's. He said one of the main concerns of administrative and general costs was the rental market, which had gone up dramatically and health care costs had also risen dramatically.

REPRESENTATIVE BERKOWITZ said he was going to borrow Mr. Lesko’s metaphor. He said there were those that proposed cutting the budget. That would be slicing into Alaska’s heart and he didn’t think the patient could survive. He said they wouldn’t be the people they wanted to be if that happened. He asked the Key Coalition to bring to the legislature the message that the budget was an opportunity for them to be the people that they wanted to be.

MR. LESKO said the Key Coalition would make that commitment. He said he was told that they needed to share the pain. He said that was a misrepresentation. He said his own family wouldn’t be affected by the budget cuts but the weakest and the most vulnerable Alaskans would be. He said budget cuts would not share the pain; they would exacerbate the pain of an already suffering population.

CHAIRWOMAN GREEN asked Ms. McGlone to make her closing remarks.

MS. MCGLONE thanked the committee time on behalf of the Key Coalition. She asked members to remember how critically important the services are for so many Alaskans as they went forward with their difficult deliberations. She said many of the proposed cuts would cut into services that weren’t covered by Medicaid. She said those services represented the basic supports that helped keep families together and strengthened the infrastructure that made Medicaid effective. She said they also supported people who could face serious jeopardy without those services.

CHAIRWOMAN GREEN thanked the Key Campaign for coming before the committee and sharing with them.

ADJOURNMENT

There being no further business before the committee, the Senate Health, Education & Social Services Committee meeting was adjourned.