

MINUTES
SENATE FINANCE COMMITTEE
February 26, 2003
8:04 AM

TAPES

SFC-03 # 10, Side A
SFC 03 # 10, Side B

CALL TO ORDER

Co-Chair Lyda Green convened the meeting at approximately 8:04 AM.

PRESENT

Senator Lyda Green, Co-Chair
Senator Gary Wilken, Co-Chair
Senator Lyman Hoffman
Senator Robin Taylor
Senator Ben Stevens

Also Attending: SENATOR BETTYE DAVIS; SENATOR JOHNNY ELLIS; SENATOR CON BUNDE; SENATOR GEORGIANNA LINCOLN; SENATOR KIM ELTON; REPRESENTATIVE BILL STOLTZE; REPRESENTATIVE NANCY DAHLSTROM; REPRESENTATIVE CARL GATTO; Key Coalition Members: MAUREEN MCCLONE from Anchorage; WYNN LEVITT from Homer; CARY WEBB, from Anchorage; VIRON WEBB, from Anchorage; JAMIE POLTY from Anchorage; KATHY MARLEY from Fairbanks; MILLIE RYAN, Executive Director, Governor's Council on Disabilities and Special Education from Anchorage; SHIRLEY EVANS from Seward; CARLA NORMAN from Seward; CAT THOMPSON from Seward; DEBRA BABCOCK from Fairbanks; JASON SCOTT from Eagle River

Attending via Teleconference: There were no teleconference participants.

SUMMARY INFORMATION

The Senate Finance Committee, joined by other members of the Senate and the House of Representatives, heard a presentation from the Key Coalition Campaign.

Key XVI Campaign 2003 Presentation

MAUREEN MCCLONE, Coordinator, Key Coalition Campaign, thanked the Committee for the opportunity to make today's presentation. She noted that approximately 300 individuals, who include family, friends, caregivers, and medical professionals, were at the State Capitol today to present a unified voice in support of services for Alaskans with disabilities. She stated that some of these participants are attending even though "they are risking their personal privacy."

Ms McClone announced that the Key Campaign is presenting to Legislators three recommendations. The first recommendation, she identified, is that the Key Coalition be allowed to partner with the State for "a one hold harmless year" to address improved services and cost effectiveness measures for the Medicaid program. The second request, she continued, is for the Legislature to support the Mental Health Trust Authority's \$625,000 general fund request for the Medicaid Waiver Budget Review Unit (BRU). She reminded that, since 1994, these Home and Community Based Waivers have provided the matching funds necessary to attract additional federal monies and have offset, by more than 50-percent, the cost of services for more than 1,000 Alaskans with developmental disabilities (DD). She applauded the 1997 closure of the State's Harborview Institution, and, she noted, that since that time, statistics support the Coalition's claim that community-based services and home care are more cost effective than institutional care, and in addition, allow people to have a better quality of life. She specified that, on an annual basis, the waiver costs the State \$68,724, as compared to an annual cost of \$117,00 for nursing home care and \$183,000 for institutional care. She stated that, in addition to these savings, funding the waiver program would assist the State in reducing the waiver program wait list which numbers approximately 1,500.

Ms. McClone stated that the third request is that the Legislature support the Mental Health Trust Authority's request for \$625,000 for the Infant Learning Program (IFP), as she noted, it is "recognized" that early intervention improves a child's health and wellbeing and assists in reducing long-term costs of care. She attested that these funds would assist in reducing the ILP wait list that currently numbers approximately 176, and thereby, positively impact individual's eligibility for pre-school programs. She stated that this funding would also assist in the recruitment and retention of qualified program staff.

WYNN LEVITT, resident of Homer, informed the Committee that due to being granted a Medicaid waiver two years ago, her 25 year-old disabled daughter who has multiple developmental delays and a

complex seizure disorder, is able to live at home and be involved in the community. She shared that the waiver allows her daughter to benefit from 60 hours a week of attendant personal care, which, she shared, also provides the family reprieve from the stress of constant care giving. She noted that her daughter's health has improved, her seizures are less frequent, and that the family's situation has improved. She asked the Legislators to support the continued funding of these waivers and to support other DD programs, such as the Base Grant program. In addition, she urged that this funding be provided in order to allow people on the wait list to receive assistance, as she recalled how lonely and unsupported life was prior to receiving this waiver. She also attested that training and recruiting of qualified staff is an important part of the process.

CARY WEBB, Resident of Anchorage, introduced his wife VIRON WEBB and their foster child JAMIE POLTY. He communicated how Jamie has positively affected his family's life. He also noted that in years prior, he had been a student in one of Senator Bundy's classes at the University, and because of Senator Bunde's teaching, he learned that people should use their voice to speak to people in authority, such as the Legislators, as their voice could make a difference.

VIRON WEBB shared that nine-year old Jamie Polty, their foster child, joined the family four years ago, and she noted that, while caring for a child with disabilities is a challenge, the family, which consists of three of their own children, loves Jamie. She stated that Jamie has blossomed from the therapy and care that the family is able to receive through the Medicaid waiver program, and that her progress has improved to a level that "amazes" even her doctors. She stated that Jamie and other DD individuals and families all benefit from being on the waiver program, and she declared that, "the sky is the limit" as far as the advances that might be possible from the care these individuals receive. She stated that the waiver program must continue and that providing care to the 1,300 people on the waiting list should be viewed with Jamie's accomplishments in mind.

KATHY MARLEY, resident of Fairbanks, stated that she is a mother of a 23-year old special needs daughter, Lisa. She shared details of her daughter's medical condition, and how Lisa reaches out to unbuckle or "free" other people who are in wheelchairs. She stated that she loves Lisa for many reasons, one of which is for her "unique perspective of the world around her." Continuing, Ms. Marley revealed that her daughter is still on the Medicaid waiver wait-list and, as such, she, the mother, must provide constant care, and, as a result, has had to resign from her teaching position. She stated that the situation has taken its toll,

financially and health-wise. She urged the Legislators to fund the Medicaid waiver and other DD grant funding in order to allow individuals and families to receive assistance and to help avoid "a more serious fate."

Co-Chair Wilken noted that the DD wait list is comprised of approximately fourteen different categories of service, and he asked the testifier which wait list category her daughter is in.

Ms. Marley responded with uncertainty as to her daughter's specific DD category.

Co-Chair Wilken voiced that this information would be appreciated as he noted that further understanding of how people are placed on the wait list would be helpful.

MILLIE RYAN, Executive Director, Governor's Council on Disabilities and Special Education, from Anchorage, explained that the Council "tracks trends and issues that impact people with developmental disabilities and their families." She stated that "the recruitment and retention of direct service staff is a major problem not only for the DD program," but also for mental health and substance abuse programs. She stated that the caliber of staff affects the quality of the services, results in health and safety issues, and affects the continuity of the program. She stated that a survey of current and prior workers revealed that staffers leave the profession due to low wages, low social status, and the lack of value that the general population places on the jobs these workers provide. In addition, she stated that the situation is acerbated by a lack of coaches and mentors. She stated that to address some of these issues, a media campaign is being conducted and that a "whole life" and leader seminars would be conducted to boost these providers' knowledge and self-esteem. She voiced support for HB 10 and SB 28, as these pieces of legislation would assist in providing better health coverage for these health care providers.

SHIRLEY EVANS, resident of Seward, shared that her 16-year old daughter has multiple disabilities and requires "help with each and every activity." She shared that her daughter, Lela, has required numerous brain, spinal and other surgeries that the family could not have afforded without the help of Medicaid. She stated that, while her daughter would require lifelong care, the Medicaid waiver has enabled Lela to develop self-care skills such as communication skills and "hand over hand assistance" in setting the table and preparing lunch and snacks, and it has allowed her to remain living with her family. She urged the Committee to continue support of the Medicaid waiver as she stated that were her daughter institutionalized, the cost of care would be \$300,000 per year as

opposed to the cost of the \$65,000 waiver which allows her to remain in her home. She stated that the waiver has provided Lela with "opportunities to reach her potential and contribute," and she asserted that, "it is also the most humane, cost effective and sensible approach." She distributed a copy of her presentation [copy on file] to the Members.

CAT THOMPSON, Caregiver and Resident of Seward, accompanied by her 35-year old employer CARLA NORMAN, spoke on behalf of Ms. Norman, who is disabled as the result of an automobile accident she was involved in at the age of 21. Ms. Thompson communicated to the Legislators that Ms. Norman had to live for ten years in a nursing home before she was granted a waiver that has allowed her to live in her home with the assistance of a caregiver. She stated that Ms. Norman has learned sign language, participates in physical therapy, and is now able to walk a few steps and to use her left hand to eat. In addition, she stated that Ms. Norman has started a business in which she makes dog biscuits that are sold via local businesses. She explained that the profits from the business would be used to purchase a service dog. She declared that Ms. Norman is truly an amazing woman. She stated that the saddest part of the situation is that, were Ms. Norman to lose her Medicaid funding, the services she requires to live in her own home would be lost, and "she would slide backwards" and "would be forced to become invalid." She urged the Legislators to remember Ms. Norman when making their funding decisions.

DEBRA BABCOCK, Resident of Fairbanks, spoke, as a parent and a professional, regarding the Infant Learning Program (ILP). She shared that in March of 1993, she became a foster parent to three brothers whom she subsequently adopted. She stated that the boys were waitlisted for the ILP, and, when finally accepted, the oldest brother was only able to receive a few months of assistance, and therefore, missed the "window of opportunity" that the two younger brothers were able to receive. Furthermore, she stated that, as the boys, who suffer from Fetal Alcohol Syndrome (FAS), have grown, their qualifying for other programs has varied. She stated that she became an Early Interventionist for the ILP, and she stressed that early intervention is extremely important to both the child and the family, and that the collaborative care provided by the interventionists team is important. She attested that qualified IFP staff recruitment and retention is difficult, and she noted that, as a single parent, she has had to take a job with the school district because it provides better pay and benefits. She pleaded with the Legislators to support the \$625,000 request for the Infant Learning Program.

JASON SCOTT, Resident of Eagle River, Member of Focus Incorporated

Service Agency, showed the Legislators a picture of his son, Andrew, who, he shared, began to demonstrate symptoms of disability at the age of seven months. He noted that Andrew began to receive ILP assistance at that time; however, he noted that the full extent of Andrew's disabilities became apparent later on. He stated that Andrew was waitlisted for Medicaid waiver services for seven years, and has just begun receiving the waiver from the State. He shared the difficulty that the family experienced during the waitlist time, and he detailed the services that Andrew is now being provided. He stated that at the age of eleven, Andrew is now experiencing a different range of emotional issues that has "spun our family into a fair crisis situation," and he noted that the family is realizing "that Andrew's needs are certainly going to be lifelong, they won't go away, and that they would be ever-changing." He concluded that without the support of Medicaid and other services, Andrew would not be able to live at home. He urged the Committee to support the three recommendations presented by the Key Campaign, as he stated, these support systems "must stay in place," as other options are unavailable.

Ms. McClone stated that the testimony that has been presented is indicative of the situations faced by people with DD and their families. She stated that approximately 1,300 people are waitlisted for the Medicaid Waiver program and that 200 children are on the ILP waitlist. She stated that this intervention makes a tremendous difference to the individuals and families being served.

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Ms. McClone urged the Legislators to support the Key Coalitions three requests for the Medicaid waiver program; the ILP; and for one year of cooperative efforts by the Key Coalition and the State to address the issues. She thanked the Legislators for the opportunity to present these recommendations.

Co-Chair Green reiterated Co-Chair Wilken's request that any specific information the Coalition could supply to Legislators would be appreciated, as it would further assist them in understanding the needs of the program.

Co-Chair Wilken asked whether the Key Campaign could provide a copy of the programs' wait list, sorted both by city and by need.

Ms. McClone responded that the State is endeavoring to revise the wait list format so that the needs are more easily identified. She stated that currently, the lists could be sorted by age and by

region; however, she voiced uncertainty as to whether the sort could be by city.

Co-Chair Wilken asked whether a wait list sort, by city, could be managed.

Ms. McClone responded that, in addition to this being a human resource issue, it might be a database issue as people move and have changes in health status.

Co-Chair Wilken commented that a wait list, sorted by city and need, would be beneficial, as it would provide Legislators with meaningful information. He asserted that the current 26-page wait list consists "of numbers that don't tell you anything." He asked the Coalition to assist the State with "breaking" the wait list into meaningful information.

Ms. McClone agreed.

SENATOR GEORGIANNA LINCOLN stated that the Key Campaign has been presenting to the Legislature for sixteen years. She voiced appreciation for their sharing of the positive accomplishments that have occurred, however, she stated that it saddens her to realize that the Key Coalition must continue to come before the Legislature and "beg for the services for your loved ones and for Alaska's future." She voiced appreciation for their efforts, and asked that they do not to halt their efforts to raise the awareness of these issues, across the State.

Senator Bunde noted that the Coalition's desire to work with the Legislature to solve these issues is heartening. However, he noted that the State's budget deficit is substantial, and that money is scarce. Therefore, he asked that Coalition members communicate to their communities that, such things as resource development and other revenues sources would be required in order to provide for the needs of the State.

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ADJOURNMENT

Co-Chair Lyda Green adjourned the meeting at 08:58 AM