

MINUTES
SENATE FINANCE COMMITTEE
March 03, 2004
8:02 AM

TAPES

SFC-04 # 27, Side A
SFC 04 # 27, Side B

CALL TO ORDER

Co-Chair Lyda Green convened the meeting at approximately 8:02 AM.

PRESENT

Senator Lyda Green, Co-Chair
Senator Gary Wilken, Co-Chair
Senator Ben Stevens
Senator Fred Dyson

Also Attending: SENATOR GEORGIANNA LINCOLN; SENATOR JOHN COWDERY;
REPRESENTATIVE NANCY DAHLSTROM; REPRESENTATIVE BILL STOLTZ;
REPRESENTATIVE REGGIE JOULE; REPRESENTATIVE DAVID GUTTENBERG;

Attending via Teleconference: There were no teleconference participants

SUMMARY INFORMATION

Key Campaign Presentation

EMILY ENNIS, Executive Director, Fairbanks Resource Agency, told of the over 250 Key Members present in the State Capitol for the 17th annual Key Campaign. She listed parents, families, agency providers, friends, supporters, and children and adults with developmental disabilities, as those among those participating. She noted that "hundreds more" were unable to join this event, as they are unable to speak for themselves. Over the past 16 years the Key Campaign has been making presentations to the Senate Finance Committee, she remarked that the legislators have listened and that their decisions have made a difference. She gave examples of a toddler with disabilities who would have a better chance at life, and the parents of a newborn with severe brain damage, or a child severely injured in a car accident, who would have access to services such as respite care, in-home support and chore services.

Ms. Ennis defined disability as a physical or mental impairment that limits or restricts major life functioning, which could be mobility, self-care, language, or the ability to hold a job. She continued that developmental disability happens before the age of 22, is usually life long and causes substantial impairments. In Alaska, she reported that approximately two percent, or 12,000 to 15,000 residents could experience a developmental disability of substantial nature, and require services over the course of their lives. She expressed hope these individuals could receive services to allow them to remain in their homes and in their communities.

Ms. Ennis compared the "handful" of services available in 1974 when she began working with disabled people. She recalled that parents provided care for their disabled children, despite questioning from their doctors, family and friends. She stated these parents had no training, respite care, or medical assistance; yet she expressed, "there was hope."

Ms. Ennis told of the development of programs to assist people with developmental disabilities that have received national acclaim. She feared that efforts made to date would be compromised with inadequate funding to sustain these programs.

Co-Chair Wilken asked about changes of the Department of Health and Social Services to reduce the length of time those needing services spend on the wait list. He requested the status of these efforts and whether they are successful and provide a measurement of success.

JOHN HARRIS, Wasilla, testified that he was born in Alaska and has four children, the youngest of which has autism. He referenced a handout [copy on file] detailing his son, Aaron's condition and treatment needs. He spoke to the financial constraints and the significant impact of any assistance. He stated that with the early intervention and diagnosis of the Infant Learning Program his child would likely be mainstreamed into school and society. He spoke of the inability for others to understand what his situation is like, comparing this to the cancer suffered by his wife.

CINDY TURNBOUGH, Fairbanks, testified about her daughter, Clair, and the virus that calcified Clair's brain during her pregnancy. She told of the joy that Clair has brought to the family, as well as the fear of not knowing the extent of Clair's disabilities. She also described the medical care necessary for Clair's care, including oxygen, a feeding tube and "suctioning". She told of the Complex Medical Care Waiver and the services provided by the Fairbanks Resource Agency and the Special Education Service Agency

(SESA) to ensure Clair could live up to her potential, such as in-home respite care, four surgeries, a wheelchair and travel for medical treatment. She stated this assistance helped her family adjust to Clair's situation. She indicated she would support taxes and offered to relinquish her permanent fund dividend, as she did not think the payments are entitlements. She remarked that her friends agree. She pointed out that there is no "Dr. Spock" book on how to raise Clair and that her family has had to learn this themselves. Ms. Turnbough exclaimed that Clair "fights to live through every illness" and that she has the right to live her life to its fullest potential. She understood budget decisions are not easy.

Co-Chair Green noted the Committee recently reauthorized the extension of the SESA program and she was grateful to hear of a situation where the program is being implemented.

PAT BUONGIONNE, Delta Junction, introduced his wife Griselda and his son, Robin, who was diagnosed at birth with Downs Syndrome. He told how the Tanana Chiefs Conference and its family services have been a positive presence in his son's life. He detailed the therapeutic and medical equipment provided to them at no cost. He furthered that Robin receives a set amount of funds through the Core Services Program to help with educational, medical, nutritional and respite care. He noted that Medicaid does not cover nutritional support because it is classified as alternative treatment. He hoped these services, many of which are provided in Alaska but not in other states, would not incur funding reductions. He expressed desire that there were no disabled children, but "there are and they are with us." He was hopeful for continuation of these programs in the future.

Senator Lincoln asked if the family traveled to Fairbanks to receive services from the Tanana Chiefs Conference, or whether services were brought to their home.

Mr. Bounjionne replied that a speech therapist travels to their home, although they have traveled to Fairbanks to receive some services. He also told of grants received to upgrade a room in their home for therapy use. In addition, he stated that because of concerns about a nearby creek, funds were provided to build a fence to prevent Robin from fall in.

Senator Lincoln hoped that in her lifetime, people would not have to travel to Juneau to request services, because the services would be provided.

KIM SIMPSON, residential habilitation provider for FOCUS, Inc. in

Chugiak, formally known as a foster care provider, read a letter from Aubrey as follows.

Thank you for being a key to my success. My name is Aubrey and I'm two years old. I've been receiving services under the Children with Complex Medical Conditions (CCMC) waiver through FOCUS, Inc. for the past year. And oh, what a year it's been! I've gained 7 1/2 pounds and grew 4 inches. I've learned how to sit up, crawl and pull myself up on the furniture. I only had to stay overnight at the hospital five nights, we went to the emergency room a couple of times, but they let me go home with my Mom and Dad. I didn't have to have any surgeries this year! I was even healthy enough to visit my other Mom, Dad, sisters and brothers in the village. I have so many people who love me, care for me, support me, teach me and keep me safe. Some people come to our house, but Mom has to drive me to other places. They watch my weight, how much I eat, take pictures of my heart, give me shots and take my blood - not fun. They're also teaching me to eat, walk and talk, I'm learning sign language and how to play with other kids. Now that's fun. I love Elmo and Nemo, looking at books, taking baths, listening to Mozart and playing with all my toys. When Mom and Dad need a break, I go to Saige's house. She's my respite provider and she's really nice. The nurse from FOCUS told Mom that I have the CCMC waiver for another year, as long as there is money. I know I'm getting all the help I need, but there are other kids who need help and have to wait. Please don't make them wait: they need help, too.
Thanks again, and we'll see you next year, Aubrey

Ms. Simpson told of Aubrey coming to her home and concerns about the impact on her other children if he died while in their care. However, he has improved and the hole in heart is closing on its own. She reported Aubrey is receiving speech therapy and other services, but still experiences some seizures. She told of the patience, and appreciation of little things she has learned from Aubrey.

DENNIS HAAS, Soldotna, introduced his friend, Roger Randell and told Roger's story, beginning ten years ago, of his father buying 22-year old Roger a mobile home, moving Roger in and then leaving town. Mr. Haas stated that soon afterwards, "rowdy" teenagers moved into the trailer, ate Roger's food and took his money. Luckily, Mr. Haas reported that concerned citizens stepped in and signed Roger up for services. Told of the closure of the Harborview residential treatment facility and placement of residents back into their communities when possible. He informed that for those remaining, most who had many needs, property was purchased and a home was

built and that Roger was able to reside there. Mr. Haas commented that neighbors expressed concern at first, but now embrace these residents.

Mr. Haas continued that Roger's goals included home ownership and marriage. With the receipt of a sizable dividend from the CIRI Native Corporation, of which Roger is a shareholder, Mr. Haas reported that Roger, was able to make a down payment on a home and plans to marry Molly this spring. Mr. Haas emphasized that the amount of funding necessary to assist Roger and Molly has decreased each year and would continue to do so.

Mr. Haas noted that people with disabilities are like everyone, they shop, pay taxes and enjoy society. He shared the Key Coalition believe that the community is a place for everyone and that individuals who experience a disability have the right to live in the community. He furthered that individuals and their families must have the power to assume a meaningful role in their community. He stressed that government has a primary responsibility to provide a realistic, non-intrusive, non-segregating community for all of its citizens.

CYD BARTEE, Anchorage, testified about her six year old son, Jerry, diagnosed at age three of PICA, ODD, and autism, after she suffered multiple injuries at his doing. She spoke of her difficulty in deciding to take him to a doctor, and the feeling of failure as a parent. She stated that her son requires 24-hour care due to his violence toward himself, his younger brother, family pets, other children and caregivers. She brought a pumice stone to demonstrate teeth marks Jerry made in it when left in the bath unattended for three minutes. She understood that had she intervened with treatment earlier, Jerry's prognosis would be better, but stressed that he has made progress. She told of developmental disabilities experienced by her four year old son and the success he has realized through treatment.

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Ms. Bartee stated that Jerry qualified for (CCMC) waiver because he is violent. She told of the treatment he is now receiving, and the significant medication he takes. She expressed, "I am drugging my child so he can remain in society." She stressed that Jerry has high potential despite his horrible behaviors. She warned that if she were not provided the services necessary to assist her son, he would become a burden and would be unable to contribute to society. She furthered that if this occurred, she would become a burden as

well. She did not want her family diminished and told of efforts they have made, including moving into her in-laws home. She also detailed Jerry's communication improvements, and described them as an incredible experience. She admitted that the State spends a lot of money on Jerry and commented that she does not deserve to receive a permanent fund dividend because of this. She requested that funding for these programs not be reduced any further.

STEVE LESKO, Anchorage, testified that it is bittersweet that the Key Campaign has had to lobby the legislature for so many years. He expressed no doubt that the delivery of services in Alaska is second to none in the nation. He attributed this to the efforts of the legislature, the various gubernatorial administrations, families and service providers.

Mr. Lesko told about his reasons for moving to Alaska and remaining here. He stated the Alaskan spirit has allowed the creation of service systems, along with the ability to learn from mistakes made in other states, such as the institutionalization of those suffering from developmental disabilities.

Mr. Lesko pointed out that the increased spending for the (CCMC) waiver program is not all due to "people". He indicated that funding transfers to the Medicaid program were made to garner additional federal funds.

Mr. Lesko expressed that there is no recidivism in developmental disabilities. He added that with effective delivery of services costs can and do decrease. He remarked that "all of us" have a challenge to provide a soft landing for a "rainy day" when oil revenues decline. He surmised that communities and neighbors are willing to make sacrifices to allow continuation of programs. He encouraged broad based taxes, and a reduction in permanent fund dividend payments. He suggested, "Together we can solve this."

Ms. Ennis concluded by thanking the Committee and shared photos demonstrating that community builds life.

ADJOURNMENT

Co-Chair Lyda Green adjourned the meeting at 09:05 AM