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

February 23, 2012
8:01 a.m.

MEMBERS PRESENT

Representative Beth Kerttula
Representative Bob Miller

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

MEMBERS ABSENT

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

Senator Kevin Meyer

OTHER MEMBERS PRESENT

Representative Mia Costello

COMMITTEE CALENDAR

PRESENTATION: KEY CAMPAIGN

- HEARD

PREVIOUS COMMITTEE ACTION

No previous action to record

WITNESS REGISTER

EMILY ENNIS
Fairbanks, Alaska

POSITION STATEMENT: Testified during the Key Campaign presentation.

MAUREEN PINTNER
Anchorage, Alaska
POSITION STATEMENT: Testified during the Key Campaign presentation.

LAURIE MATTHEWS
Eagle River, Alaska
POSITION STATEMENT: Testified during the Key Campaign presentation.

KIM CHAMPNEY
Juneau, Alaska
POSITION STATEMENT: Testified during the Key Campaign presentation.

JOE HAYES
Fairbanks, Alaska
POSITION STATEMENT: Testified during the Key Campaign presentation.

SANDRA HORN
Metlakatla, Alaska
POSITION STATEMENT: Testified during the Key Campaign presentation.

LAEL FORD
Anchorage, Alaska
POSITION STATEMENT: Testified during the Key Campaign presentation.

DENNIS HAAS
Soldotna, Alaska
POSITION STATEMENT: Testified during the Key Campaign presentation.

STEVE LESKO, past President
Key Coalition of Alaska
Anchorage, Alaska
POSITION STATEMENT: Testified during the Key Campaign presentation.

ACTION NARRATIVE

8:01:42 AM

CHAIR BETTYE DAVIS called the joint meeting of the House Health and Social Services Standing Committee and the Senate Health and Social Services Standing Committee to order at 8:01 a.m. Representative Miller and Senators Davis, Egan, and Dyson were present at the call to order. Representative Kerttula and Senator Ellis arrived as the meeting was in progress. Representative Costello was also in attendance.

Presentation: Key Campaign

CHAIR DAVIS announced that the only order of business would be a presentation by the Key Campaign.

8:02:54 AM

EMILY ENNIS thanked the committee members for their support, and stated that that this was a momentous day for the Key Campaign. She reported that it had been 25 years since the first visit to Juneau by the Key Campaign, on behalf of individuals who experienced disabilities and their families, who were waiting for needed services. She emphasized that, in Alaska, more than 13,000 children and adults experienced intellectual or developmental disability. She noted that one-third of these people received services in their home communities, either funded by Medicaid waivers or state grant funds through the Department of Health and Social Services. She confirmed that 75 percent of the nearly 880 individuals remaining on the wait list met the level of care required for placement in a nursing home or institution, and qualified for Medicaid waivers. She stressed that people with intellectual and developmental disabilities had many abilities. She declared that the ambition, the hard working ethic, the valuing of a job, and the identity of being an adult contributing to society made these individuals exceptional employees, good citizens, and good neighbors. She confirmed that the investment in a home and community based service system, rather than institutional care, had made it possible for "the opportunity for inclusive lives in Alaska's villages, towns, and cities."

8:06:25 AM

MS. ENNIS detailed the difficulties these individuals and their families coped with in waiting for home and community services, which would allow them the chance to work, and the chance to prove their independence. She declared that "life is precious. If we can help it, not one moment should be wasted, waiting."

8:09:08 AM

MAUREEN PINTNER shared a picture of her 13 year old son, Max. She declared that her purpose was to tell her family story, and to encourage endorsement for the funding of $650,000 to the Complex Behavior Collaborative Consultation and Training Program (CBC). She declared herself to be "a relentless, volunteer parent advocate for two of my children with disabilities." She shared that Max had multiple diagnoses, which included high functioning autism, severe executive dysfunction, mood disorder, depression, seizure disorder, and learning disabilities. She confirmed that this had been exhausting on her family. She shared the odyssey of admitting Max into the North Star Behavioral Health hospital and the subsequent realization that the psychiatric model at North Star was not equipped for children with autism or learning disabilities. She relayed that North Star began an investigation for an out-of-state option, and had discharged Max after three weeks to a no-demands home bound program, to wait for an opening in a specialized, neuro-psychiatry, out of state residential psychiatric treatment facility. She disclosed that Max sat at home for two months, heavily medicated, with no school services. She shared that her other two other children found this approach "confusing and unfair." She reported that Alaska now has an alternative program for complex behaviors, the aforementioned CBC. She lauded the program and repeated her request for funding to the program.

8:14:05 AM

LAURIE MATTHEWS shared that her husband was in the Alaska Air National Guard, and that she had two children with disabilities. She spoke in support of the CBC. She shared that her five year old son, Cole, loved Star Wars, Legos, and snuggling into soft piles. She explained that he had high functioning autism, with horrific melt downs several times each day. She described the crisis mode this had brought on to her family, and that during a two year span, her family had sought help from a psychologist, two psychiatrists, and their pediatrician, with none able to offer the necessary help. She detailed that a recent alternative to keeping children with extreme behavior problems at home was now available. She declared her excitement with the CBC program, as this was an option for children, instead of being placed in residential treatment. She said her family was eligible for applied behavior analysis. She said her son, Cole, was progressing, and learning the necessary skills to interact appropriately without "defaulting into explosive rages." She urged support for the services of CBC, and proposed HB 79, which would require insurance coverage for autism spectrum disorders. She declared these to be two critical resources.

8:18:04 AM

KIM CHAMPNEY established that she had been a service provider for people with disabilities for the past 14 years, and that she was currently the program director at REACH, Inc. She shared the story of a magnet, which she kept as a reminder to continue to advocate. She testified in support of the CBC program. She declared that providers worked hard to make communities better, and to make a difference. She shared the difficulty of not being able to provide services, or for a support plan that was not working. She stated that this was most difficult for the person with the complex behaviors, who was not able to make themselves understood. She confirmed the hesitation and loss of confidence by an agency when support services did not work. She stated that the CBC provided many solutions that other agencies were not able to offer. She requested additional funding for CBC.

8:21:45 AM

JOE HAYES stated that the Key Coalition was not a want, it was a need. He declared his support for proposed HB 79, expressing his desire for its passage and confirming his understanding of legislative decisions for distributing funds. He emphasized that people's needs and services "should rise to the top, the quality of someone's life, the dignity that someone must have to live involved in their community, to assist their families..." He stressed that any safety net could provide the difference for holding a family together. He requested support for the Key Coalition.

8:24:13 AM

SANDRA HORN declared her support for early infant learning. She shared that she had nine children, with three having received services from early infant learning. She explained that her son had failed hearing tests, and had received a referral to an audiologist. She stressed the necessity to recognize children's needs early, to "build a better foundation for our kids, for them to have success and to be really involved and successful people in our communities ..." She declared that early infant learning had made a difference in her family and her community.

8:26:47 AM

LAEL FORD, testifying that she lived in an assisted living home, addressed the problem of the long wait list for assisted living services. She shared that she had waited for more than two years for services. She offered her belief that "people with autism have been put aside, and not given enough medical aid." She explained that her disability had been recognized, which allowed her to receive the necessary medical coverage. She appealed for funding for CBC and for counseling services. She announced that her adoptive father was wonderful and supportive for her independence. She stated that "hopefully we can get all this stuff passed so other people don't have to suffer."

8:29:33 AM

DENNIS HAAS described that his daughter, Katie, had contracted spinal meningitis at five weeks of age, and that she had 80 percent brain damage. He shared that, although he had been told that her life expectancy would be about 12 years, she was now 30 years of age. He declared that, as a result of the disability support programs, she was able to live at home, with 24 hour a day care. Although she was blind, and did not speak, he shared that Katie enjoyed her life, shopping, listening to music, and spending time with friends and family. He described the pleasures for Katie when her family visited its cabin in Kodiak. He expressed his worries for what would happen to Katie if something happened to him. He stated that the current programs allowed people to stay in their home and community, and receive care at home. He encouraged continued support for disability programs.

8:32:40 AM

STEVE LESKO, past President, Key Coalition of Alaska, declared that he had been with the Key Campaign for all of its 25 years. He stated:

> the people here with me today have been my colleagues, my associates, my friends, and in so many ways, my heroes. You see, I don't need Batman and Green Lantern, and I don't need Superman, because I've got the real thing in back of me. These parents, these individuals who experience challenges, have come here

> for a quarter of a century, and they have told you their stories. I think some of you, but not everyone, realizes that for every story you've heard for 25 years, there's a price that these people pay. I can't even tell you how many times when something like this is over, the parent is in the hallway crying, when the memories come flooding back of broken families, spouses that have left, siblings that have gone apart, the family unit disintegrates. The price our family's pay is pain, and that is an awful thing to exact from anybody.

MR. LESKO referenced a story about the Good Samaritan told by Martin Luther King the day before his death, which explored the necessity to ask the right questions. He compared the ethnic devaluation of people in this story with the same devaluation toward people with disabilities today, citing that people are still shipped out of Alaska because there are no resources here. He further recounted:

> people pass this man by because they ask the wrong question. They said, 'what will happen to me if I stop and help him.' Wrong question. We should be asking, 'what will happen to him if I don't stop and help him.' It changes everything. If you take the egocentricity out of it, and you look at our families, you look at our people experiencing disabilities, and say to yourselves, as Alaska State Legislature and administration, 'what will happen to our families if you don't respond.'

MR. LESKO declared that the [proposed] autism bill [HB 79] had been called a mandate, and he offered his belief that:

> until the day I die, the greatest mandate you have and I have and we have is to preserve our family unit. Nothing is greater than that. So, if you want to prioritize, put our families first as so many of you have done. We want to just say to you, because of you, who've been heroes to us too, you have made such a difference in the lives of Alaskans. Is there anything else we can do in our lives than to say we've touched each other? ... When my time comes, I want to say, as Horace Mann did, I would be ashamed to die unless I had won some small victory for humanity. On behalf of my heroes for 25 years, we applaud you; we applaud you our legislature, for all of the

> differences you have made in the lives of our Alaskan families. ... Our job, if anything else with our families with disabilities, is to say ... that we care enough that you don't have to lose sleep and wonder and ask that question time and time again, what will happen to my son, my daughter when I am gone. You will never have to worry about that again. To you, our legislature, thank you for 25 years of incredible support.

MR. LESKO, in conclusion, asked that the priorities, including autism insurance reform and CBC, be addressed and he declared to the committee: "We love you and we thank you."

8:39:44 AM

CHAIR DAVIS thanked Mr. Lesko for all his service.

8:40:37 AM

ADJOURNMENT

There being no further business before the committee, the joint meeting of the House Health and Social Services Standing Committee and the Senate Health and Social Services Standing Committee meeting was adjourned at 8:40 a.m.