

**ALASKA STATE LEGISLATURE
JOINT MEETING
HOUSE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE
SENATE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE
February 25, 2009
8:01 a.m.**

MEMBERS PRESENT

HOUSE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE

Representative Bob Herron, Co-Chair
Representative John Coghill
Representative Bob Lynn
Representative Sharon Cissna

SENATE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE

Senator Joe Paskvan, Vice Chair
Senator Johnny Ellis
Senator Joe Thomas

MEMBERS ABSENT

HOUSE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE

Representative Wes Keller, Co-Chair
Representative Paul Seaton
Representative Lindsey Holmes

SENATE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE

Senator Bettye Davis, Chair
Senator Fred Dyson

OTHER LEGISLATORS PRESENT

Senator Lyman Hoffman
Representative Beth Kerttula

COMMITTEE CALENDAR

PRESENTATION: KEY CAMPAIGN

- HEARD

PREVIOUS COMMITTEE ACTION

No Previous Action to Record

WITNESS REGISTER

EMILY ENNIS, Executive Director
Fairbanks Resource Agency;
President

Alaska Association on Developmental Disabilities
Fairbanks, Alaska

POSITION STATEMENT: Testified in support of the Key Coalition of Alaska.

FRED VILLA

Fairbanks, Alaska

POSITION STATEMENT: Testified in support of the Key Coalition.

KAMA GREGORY

Anchorage, Alaska

POSITION STATEMENT: Testified in support of the Key Coalition.

DAYNA MCGUIRE

Anchorage, Alaska

POSITION STATEMENT: Testified in support of the Key Coalition.

RIC NELSON

Anchorage, Alaska

POSITION STATEMENT: Testified about the importance of services for the Developmentally Disabled.

JIM BECK, Executive Director

Access Alaska

Palmer, Alaska

POSITION STATEMENT: Testified in support of the Key Coalition.

SHAWN WOODARD

Fairbanks Resource Agency

Fairbanks, Alaska

POSITION STATEMENT: Testified in support of the home direct care workers.

MICHAELLA MADDUX

Fairbanks, Alaska

POSITION STATEMENT: Testified about programs for developmentally disabled.

JANET MADDUX

Fairbanks, Alaska

POSITION STATEMENT: Testified about the loss of direct service care professionals.

STEVE LESKO, President

Key Coalition

Anchorage, Alaska

POSITION STATEMENT: Testified in support for the Key Campaign.

ACTION NARRATIVE

[8:01:19 AM](#)

VICE CHAIR JOE PASKVAN called the joint meeting of the House and Senate Health and Social Services Standing Committees to order at 8:01 a.m. Representative Herron and Senators Paskvan and Ellis were present at the call to order. Representatives Coghill, Lynn, and Cissna and Senator Thomas arrived as the meeting was in progress. Senator Hoffman and Representative Kerttula were also in attendance.

Presentation: Key Campaign

[8:01:48 AM](#)

VICE CHAIR PASKVAN announced that the only order of business would be a presentation on the Key Campaign.

EMILY ENNIS, Executive Director, Fairbanks Resource Agency;, President, Alaska Association on Developmental Disabilities, said that there are 12,000 Alaskans with developmental disabilities. She explained that developmental disability occurs before the age of 22, and may be noted at birth or acquired later. She reported that there was sometimes a diagnosis, but that it was generally a lifelong limitation which required some support or service. She described the mission of the KEY coalition "to support and promote the dignity, status, and equality of all Alaskans with disabilities." She opined that bias and inequity still existed for the disabled. She allowed that extraordinary strides had been made in Alaska, but that the developmentally disabled (DD) management plan had been neglected. She explained that the DD system offered hope for a full and conclusive life, it helped families stay together, and it assured that every individual was valued.

[8:08:53 AM](#)

FRED VILLA, said that he was a recreational therapist and a provider, but that now he was also on the other side. He described the disability that his son was born with. Although it was seven months before the disability was diagnosed, he was fortunate in that having a diagnosis allowed them to receive services, and not be placed on a waiting list. He said that the phenomenal services included an educational therapist, speech therapist, occupational therapist, and physical therapist, but that the "mountain of paperwork, navigating through the forms and the issues while you're going through a grieving process, trying to understand why this happened" was overwhelming. He explained how important the social network was for his entire family. He spoke about the importance of bringing the DD community into the workforce. He emphasized the need for skilled workers to train the DD workforce. He appealed for the necessary services without any waiting lists.

[8:14:07 AM](#)

KAMA GREGORY, said that she represented her son, and other infants like him. She spoke about the tremendous difference that infant learning and early intervention had made for him. She said that he was diagnosed, but placed on a waiting list. She said that she advocated for him and, after 6 months, he was able to receive services. She said that the early intervention therapy was invaluable, and that he now walked and spoke. She emphasized that the need for infant learning and early intervention was so important. She said that the funding for infant learning had been flat for the prior five years. She referred to studies which concluded that an investment in early learning between ages 0 to 3, paid big dividends in the future. She asked for a funding increment of \$2 million to operate the infant learning programs to capacity.

[8:20:26 AM](#)

DAYNA MCGUIRE, said that she worked with her friend, Ric Nelson. She said that he spoke to the five years before about the wait list for waiver services. She stated that Ric had cerebral palsy, and that he wanted to share some of his successes.

[8:21:18 AM](#)

RIC NELSON, said that he had waited for 8.5 years for services. He shared his accomplishments, his dreams, and his successes.

8:23:26 AM

MS. MCGUIRE recounted that Ric was now finishing his Associates of Arts (AA) in small business management from the University of Alaska. She shared that he wanted to continue his education for his Bachelor of Arts, and that he wanted to own a small business. She noted that he had travelled and advocated for people with disabilities. She shared his request for continued funding to remove people from the waiting list, and to maintain the current waiver programs that had contributed to his success.

8:24:28 AM

JIM BECK, Executive Director, Access Alaska, said that a strong home and community based provider system was critical to meet the needs for long term care. He referred to the 2006 Lewin Group report that forecast for long term care costs to quadruple, while the Alaskan elder population would triple. He referred to the July, 2008, AARP report, "A Balancing Act: State Long-Term Care Reform," which stated that "Medicaid, our nation's single largest source of funding for long term services and supports does not provide the range of choices people want. Instead, it continues to allocate a disproportionate share of its resources for institutional services." He went on to summarize the report, and said that on average, Medicaid dollars can support nearly 3 adults in home and community based services for every 1 person in a nursing home. He shared that home and community based service was more cost effective, and more responsive to people with disabilities. He noted that Alaska had a balanced funding between institutional Medicaid and home and community based services, but he added that many people were still being housed in nursing homes against their desire for home care. He opined that the rate setting for home care providers was a symptom of the approach to long term care policy in Alaska that de-legitimized home and community based providers. He summarized about the lack of financial support for home care providers from both Medicaid and the state. He reported that home care were well run, cost efficient businesses. He shared his concern that the institutional health care lobby was second in size only to the oil industry lobby. He concluded with this message: "Help us keep our system strong and we will continue to help keep all Alaskans at home, in their communities, working, playing, and thriving for more decades to come."

8:31:10 AM

SHAWN WOODARD, Fairbanks Resource Agency, said that shortly after moving to Alaska in 2000, he started working with Adult Learning Programs Of Alaska (ALPA) and that the developmentally disabled (DD) community was now his extended family. He reported that work in the DD community paid half that of work outside that community. He asked for a fund increase for direct service provider wages. He explained that continuity of support personnel was paramount for the DD community.

[8:37:24 AM](#)

MICHAELLA MADDUX, said that she was on the wait list of services. She shared her dreams to work, to have her own apartment, to get married, and to live independently. She asked for funding support for services to help her reach her goals.

JANET MADDUX, said that her daughter, Michaela, attended the infant learning program for 3 years, and after that program, she attended the special educations pre-school. She explained that Michaela needed help learning the skills to match her independence. She opined that the direct service care professionals were transferring to higher paid jobs. She requested the funding to eliminate the wait list for services, to increase the living wage of direct service professionals, and to increase the state early intervention and infant learning programs.

[8:41:05 AM](#)

STEVE LESKO, President, Key Coalition, said that these stories were symptomatic, "it was the best of times, and it was the worst of times." He applauded the efforts of the legislature and its impact, and he pointed out that disabled people were institution free. He celebrated legislation that would eliminate the wait list for disability services. He decried that community programs were eroding, and he announced that somebody had to champion this cause. He opined that SB 32 was "a bright light," and he referred to it as "the community preservation act." He asked for justice, and he stressed that "justice is something you create." He referred to the slogan "Got KEY?" and concluded by stating, "if you got KEY, you got justice, and if you got justice, you will be the architects of the future of Alaska for our community programs and for our families, our brothers and sisters who experience disabilities."

[8:47:03 AM](#)

MS. ENNIS thanked the committee.

[8:47:13 AM](#)

ADJOURNMENT

There being no further business before the committee, the joint meeting of the House and Senate Health and Social Services Standing Committees was adjourned at 8:47 a.m.