

ALASKA STATE LEGISLATURE
SENATE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE

March 2, 2018

1:32 p.m.

MEMBERS PRESENT

Senator David Wilson, Chair
Senator Cathy Giessel
Senator Peter Micciche

MEMBERS ABSENT

Senator Natasha von Imhof, Vice Chair
Senator Tom Begich

COMMITTEE CALENDAR

PRESENTATION: KEY CAMPAIGN

- HEARD

PREVIOUS COMMITTEE ACTION

No previous action to record

WITNESS REGISTER

MILLIE RYAN, Executive Director
REACH, Inc.;
Member
Board of Directors
Key Coalition of Alaska
Juneau, Alaska

POSITION STATEMENT: Presented Key Campaign

COREY GILMORE, Advocate
Key Coalition of Alaska
Juneau, Alaska

POSITION STATEMENT: Advocated for Key Coalition priorities.

SABRINA RICHMOND, Advocate

Key Coalition of Alaska
Juneau, Alaska

POSITION STATEMENT: Advocated for Key Coalition priorities.

LINDA THOMPSON, Advocate
Key Coalition of Alaska
Homer, Alaska

POSITION STATEMENT: Advocated for Key Coalition priorities.

SHELLY VENDETTI-VUCKOVICH
Key Coalition of Alaska
Anchorage, Alaska

POSITION STATEMENT: Advocated for Key Coalition priorities.

ROBERT FRICK, Advocate
Key Coalition of Alaska
Juneau, Alaska

POSITION STATEMENT: Advocated for Key Coalition priorities.

ACTION NARRATIVE

[1:32:48 PM](#)

CHAIR DAVID WILSON called the Senate Health and Social Services Standing Committee meeting to order at 1:32 p.m. Present at the call to order were Senators Giessel and Chair Wilson. Senator Micciche joined shortly thereafter.

PRESENTATION: KEY CAMPAIGN

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CHAIR WILSON announced the business before the committee was a Key Campaign presentation.

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MILLIE RYAN, Executive Director, REACH, Inc.; Member, Board of Directors, Key Campaign, stated that the campaign has distributed a one-page list of priorities and a page on home and community-based Medicaid waivers for people with developmental disabilities. Because the system is incredibly complicated and difficult to explain, they have put together information for them. It lays out what developmental disabilities are, where and how services are funded in the budget, what the intellectual and developmental disabilities waiver program is, whether they save the state money, whether they work, what the wait list for services is, what the return on investment is for reducing the waitlist, and some recommendations for reducing the waitlist.

MS. RYAN thanked Senator Micciche and the Senate for taking the lead on increasing the day rehabilitation soft cap from an average of eight hours a week to 12 hours a week. It made a big difference in people's lives. Day habilitation helps people get out and be part of the community's activities. People need extra support to do that when they have intellectual and developmental disabilities.

SENATOR MICCICHE said many Alaskans don't know how day habilitation helps families keep individuals [with disabilities] at home. If the stress becomes too much for families, the cost of institutionalization is much more than remaining at home. Home-based care includes lots of volunteer labor helping to keep loved ones at home. The further day habilitation is cut the more likely it will be that the labor will be replaced by paid care. Institutionalized care is exceedingly more expensive. He said he wants to educate people that the cost shift could be in the tens of thousands of dollars a year.

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MS. RYAN said institutions cost \$200-220,000 a year. Services can be provided in the community for much less and it keeps families together. Research and experience shows the stress is incredible. The divorce rate is higher. It is hard for people to stay together without the supports and services they need. Families already contribute to the cost of caring for loved ones, which is far more than caring for children, particularly adult children, without disabilities.

SENATOR MICCICHE said he believes in helping the public to understand that. People don't understand that costs for community and home-based care is so much less than institutionalization, and day habilitation helps keep those costs lower.

MS. RYAN said the Medicaid system works backwards. Now, if people meet the level of care for an institution, the state has to provide that service, which means people end up out of state at vast expense and away from their families and that support. Services like day habilitation keeps people in state. Otherwise the state has a mandate to provide services in an institution, even though it can be provided at much less cost using services like day habilitation.

MS. RYAN thanked Senator Micciche for his leadership in the Senate passing SB 174. She said a priority for the Key Campaign is a stable and sustainable fiscal plan for Alaska. One reason

is to reactivate the commitment to reduce the waitlist. Currently 652 people are the waitlist. When demand for waiver services outstrips the resources for providing them, Medicaid allows states to maintain a waiting list of individuals waiting to receive services. The waiver for intellectual and developmental disabilities is the only waiver that requires the state to do that. The other reason is they are not seeing much flexibility for the day habilitation cap. Twelve hours is enough for some people. Duane Mayes, Director of the Division of Senior and Disabilities Services at the Department of Health and Social Services (DHSS) said of the 117 requests for day habilitation over the cap, only five were funded. Some people with medically complex needs require 24-hour assistance. Having the day habilitation cut makes it more difficult for them to continue living in the community. With a fiscal plan, they could look at increasing the day habilitation cap and moving more people from the waitlist.

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SENATOR MICCICHE asked if the waitlist prioritizes.

MS. RYAN said people receive points based on a variety of things. People with higher scores are placed at the top of the list. For example, person whose caregiver's health is failing might be placed higher on the list. The state once drew 200 people from the waitlist every year. The state has drawn 50 the last several years. If people don't get served at the right time they go into crisis and then they need more services. It helps keep families together when they get the services they need.

MS. RYAN said the Key Campaign has recommendations to reduce the cost of home and community-based waivers. The Employment First bill helps more people get to work so they can pay for some of their services. The ABLE Act enables people to save for some of their own expenses. The durable medical equipment re-use bill was passed several years ago. Key continues to provide recommendations around the use of technology, companionship services and semi-independent living services. She said Key continues to believe that individuals with intellectual disabilities and their families have already contributed to efforts to reduce the state budget, such as the day habilitation "soft cap" of 624 hours annually. Day habilitation is the only service that helps individuals be a part of their local communities. Out-of-pocket expenses to care for a child with developmental disabilities is estimated at \$8,000 annually beyond what it takes to raise a child without a disability. A

child with disabilities is always going to need extra support and services.

COREY GILMORE, Advocate, Key Coalition of Alaska, advocated for the Key Coalition priorities. He said just a moment ago Ms. Ryan talked about the need for families to stay together. He and Sabrina Richmond, his significant other, have been together eight years. His goal in his plan of care is that he will make a difference in his community and the lives of others. That is his job. On Monday nights they present a Bible story to a youth group. Neither he nor Sabrina see very well, so they practice it the entire week to memorize the story to present it to the youth group. Wednesdays and Fridays they go to work at the Auke Bay integrated preschool. They teach kids the alphabet and that it is okay to be different.

SABRINA RICHMOND, Advocate, Key Coalition of Alaska, advocated for the Key Coalition priorities.

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MR. GILMORE said they are struggling with the cap. They have just been told that when Sabrina's plan gets renewed, she may lose supported living hours. He asked Ms. Richmond where she will end up if she loses supported living hours.

MS. RICHMOND said she will go home to Petersburg.

MR. GILMORE said her family in Petersburg will be totally responsible for her care. He will have to go to a group home in Anchorage. He cannot imagine not having Ms. Richmond by his side. He asked how the committee would feel if someone came to their houses and said, sorry there is a possibility your services will be cut and you may have to be split up. He said stuff like this happens to them all the time. They don't want to just be in the community. They want to be of the community. He always says to the Governor's Council on Special Education and Disabilities that life requires audience participation. If they are going to make them participate, they need the services. Even if he works more, he needs help to get up and to get out of the house.

MS. RICHMOND asked the committee not to cut day habilitation. It helps them to be in the community.

MR. GILMORE said if they are not at the preschool, someone will have to explain to the kids where Mr. Corey and Miss Sabrina

are. The kids look forward to that every week and wont understand why they aren't there anymore.

MR. GILMORE said he won't understand.

MS. RICHMOND said she also won't understand.

MR. GILMORE said Ms. Richmond keeps him together in the morning just like committee members' significant others do for them. Without her he will fall apart. He cannot imagine living with five other people. This is the person who said she will spend her life with him. This is the one person who will put up with him that much.

MS. RICHMOND responded, "He's right. He's my other half."

MR. GILMORE said they don't know what her services will be, and they may have to take her away from him. They don't know if they'll see each other again. He knows he loves her and he doesn't know what kind of life they can have.

SENATOR MICCICHE said they are a beautiful couple and amazing advocates. He said he didn't know if they choreographed that.

MS. RICHMOND said they role play constantly.

MR. GILDMORE said this is how they tell stories at preschool. They have to memorize stories, but they didn't even have a chance to practice today. They just knew what they had to tell the committee.

MS. RICHMOND expressed appreciation.

1:56:26 PM

LINDA THOMPSON, Advocate, Key Coalition of Alaska, advocated for the Key Coalition priorities. She said her son, Erik, was born when she trapped at Lake Clark and she was told to put him in an institution. She took her child home. She has always been an advocate for Erik. She had three children with disabilities. One died due to her profound disabilities. One is working on his master's in Fairbanks, which is difficult with a hearing impairment. She is here to talk about what has happened to her and her son, who is 40. He has Down's syndrome, autism, and is an elective mute.

She said her son has been a successful artist for 20 years. He has had art shows across the United States, but now he is

changing. He is becoming elderly, 40 is elderly for him. He no longer sleeps. For over five years she has been a sleep-deprived caregiver. After collapsing in November at the age of 70, she applied for a change in his waiver services to move him to a group home, one with three shifts of people. Due to state policy, as soon as she applied, his services were cut from 42 hours to 15 hours a week. She said she begged for the 42 hours back but was told she must rescind the request for the group home. December 21, after seven weeks of sleeplessness, he was admitted into a group home. He now has a fresh shift of people doing an excellent job of care, but Christmas Eve she went into the hospital with extreme exhaustion. She does not understand why DHSS did this to her, cut his hours from 42 to 15. There is no logic to that other than saving money.

MS. THOMPSON said decisions are being made without considerations of the disabled person or the family. Services should not be cut when someone is transitioning into a new home. The state saved money at her expense. The state did pay for her health care because she is a retired teacher. As a single parent she has no backup except the state. Now residential care is at her side working together, but people have decided day habilitation is not important. She said her son depends on her. Three days a week she fills in the hours the state has cut. But in May, when her store on the Homer Spit opens, she cannot volunteer her services. She sells Erik's art and spreads the word that people with a disability can have a career and be successful. A cut in services means increases down the line. If Erik only sits and rocks he will stay in his imaginary world. He needs day habilitation every day to get him out of there. She does not want another parent like herself to be put in same situation. Other parents here in the Key Campaign are getting old and need state support, she said.

[2:04:45 PM](#)

SHELLY VENDETTI-VUCKOVICH, Advocate, Key Coalition of Alaska, advocated for the Key Coalition priorities. She said her claim to fame is that she is Claire's grandmother. They advocate all over the state for disabled children. Claire receives waiver services. At three months she was injured and abused by her biological parents who nearly killed her. People think these are your children. It is your responsibility to provide for your children. Yes, for things within people's normal lives. Everyone here is one catastrophe away from living in their world. They spend at least \$20,000 a year for uncovered expenses, but she is grateful for the services they do receive. Claire was never supposed to walk or talk. She dances, she runs. She is blind,

but she is the light of her life. Day habilitation helps Claire be more independent for the day when Ms. Vendetti-Vuckovich is not there. But she hears stories like the one they just heard, and that day is coming faster. Claire is 10. At dinner last night Claire fell asleep in her lap. She can no longer carry Claire. She asked what does she do when she can't care for her. She can't imagine someone coming in her home and controlling her life.

She said it is all about who they are as Alaskans, who they are in their souls, and what is important to them. It isn't just her family. They are going to protect everyone in the community who is vulnerable, whether they are a child, elderly, or disabled. She wants to be the person that her grandparents were, who provided for their neighbors. For generations before, integrity meant something. She wants that in Alaska. The whole reason for a stable and sustainable fiscal plan is so that all of them continue to be Alaskans. She asked them to do whatever it takes to help all of their families. It will benefit all of them.

ROBERT FRICK, Advocate, Key Coalition of Alaska, advocated for Key Coalition priorities. He said he has been with REACH 20 odd years. He has worked at Costco for 18 years. Back in December he suffered a heart attack. He was abusing his health and REACH helped him realize what he was doing wrong. They stood behind him all the way. He emphasized the need to continue funding for REACH. Everyone here deserves that. He said, "We're a pack here."

[2:13:51 PM](#)

MS. RYAN said the Senate passed SB 80 last year, which is a telecommunication bill that would require telephone utilizes to provide services to subscribers who are deaf, hard of hearing or speech impaired, so they can communicate by telephone with hearing persons. The Juneau members of the Key Coalition that afternoon will be asking Representative Kito to schedule SB 80 in Labor and Commerce. She said yesterday the House Health and Social Services Committee heard HB 336, the Supportive Decision Making Act. This would empower Alaskans with guardians to form Individualized Supported Decision Making Agreements, which foster greater independence for adults with disabilities to make life decisions with a trusted team. Thirty years ago, Alaska had one of the most progressive guardian laws, but things have changed. They are hoping HB 336 will move out of the House soon and over to the Senate.

CHAIR WILSON thanked the presenters.

2:16:19 PM

There being no further business to come before the committee, Chair Wilson adjourned the Senate Health and Social Services Standing Committee at 2:16 p.m.