

ALASKA STATE LEGISLATURE
SENATE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE

February 8, 2019

1:31 p.m.

MEMBERS PRESENT

Senator David Wilson, Chair
Senator John Coghill, Vice Chair
Senator Gary Stevens
Senator Cathy Giessel
Senator Tom Begich

MEMBERS ABSENT

All members present

OTHER LEGISLATORS PRESENT

COMMITTEE CALENDAR

PRESENTATION: GOVERNOR'S COUNCIL ON DISABILITIES AND SPECIAL EDUCATION

- HEARD

PREVIOUS COMMITTEE ACTION

No previous action to record

WITNESS REGISTER

PATRICK REINHART, Executive Director
Governor's Council on Disabilities and Special Education
Anchorage, Alaska

POSITION STATEMENT: Presented on the Governor's Council on Disabilities and Special Education.

MILLI RYAN, Board Member
Key Coalition of Alaska
Juneau, Alaska

POSITION STATEMENT: Presented on the Key Coalition of Alaska.

MAGGIE WINSTON, Chair

Governor's Council on Disabilities and Special Education
Kenai, Alaska

POSITION STATEMENT: Presented on the Governor's Council on Disabilities and Special Education.

HANS WAGGONER, representing self
Nikiski, Alaska

POSITION STATEMENT: Testified about family's waitlist experience.

AMANDA WAGGONER, representing self
Nikiski, Alaska

POSITION STATEMENT: Testified about family's waitlist experience.

MICHELE GIRAULT, representing self
Anchorage, Alaska

POSITION STATEMENT: Testified about her ward's waitlist experience.

SYDNEY KREBSBACH, representing self
Juneau, Alaska

POSITION STATEMENT: Testified on the difficulty of finding a job as someone with autism.

ACTION NARRATIVE

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CHAIR DAVID WILSON called the Senate Health and Social Services Standing Committee meeting to order at 1:31 p.m. Present at the call to order were Senators Stevens, Coghill, Begich, and Chair Wilson.

Presentation: Governor's Council on Disabilities and Special Education

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CHAIR WILSON announced the presentation on the Governor's Council on Disabilities and Special Education.

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PATRICK REINHART, Executive Director, Governor's Council on Disabilities and Special Education, Anchorage, Alaska, said they were combining the Governor's Council presentation with the Key

Coalition because they are delivering the same messages. He reviewed the five roles of the council:

Developmental Disabilities Council (each state has one)

Special Education Advisory Panel (each state has one)

Interagency Coordinating Council for Infants and Toddlers with Disabilities (another federal role)

Beneficiary Advisory Board to the Alaska Mental Health Trust Authority (a state role)

Governing Body of the Special Education Service Agency (a state role)

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MILLI RYAN, Board Member, Key Coalition of Alaska, Juneau, Alaska, said that the Key Coalition been coming to Juneau for 32 years. It's a grassroots organization comprised of individuals with intellectual and developmental disabilities, their family members, service providers, and other advocates. The Key Coalition has worked with the legislature to do wonderful things to make life better for people with disabilities. One of the major things was to close Harborview Developmental Center, which was Alaska's sole institution for people with disabilities, in 1997 and to establish the groundwork for home and community-based services. They worked with the Governor's Council to pass Employment First legislation, autism insurance reform, and the reuse program of durable medical equipment.

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MAGGIE WINSTON, Chair, Governor's Council on Disabilities and Special Education, Kenai, Alaska, said last year they worked to pass legislation on the Developmental Disability Shared Vision. They have been doing amazing work to make sure Alaskans are living person-directed and person-centered lives, moving away from the medical model of disabilities to a social model. Individuals with disabilities are not broken. They are leading normal lives that have meaning. That is the whole point of the vision:

Alaskans share a Vision of a flexible system in which each person directs their own supports, based on their strengths and abilities, toward a meaningful life in their home, their job and their community. Our Vision includes supported families, professional staff and services available throughout the state now and into the future.

MS. WINSTON said they have six project teams. She co-chairs one team. This has made the work they do much easier.

MR. REINHART shared an infographic that illustrates Alaska's developmental disabilities system. They have been changing the system to a home and community-based system. He pointed out that the council was awarded an Administration on Community Living federal grant of \$1.96 million over five years to make the Shared Vision a reality. The council was one of five grantees out of many applications.

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SENATOR BEGICH asked if the grant goes directly to the council.

MR. REINHART answered that they are part of Department of Health and Social Services (DHSS) and it is a grant to the council.

SENATOR BEGICH asked whether federal money requires authorization.

MR. REINHART answered yes, and there is enough federal authority in the budget, so it does not need to be increased.

MS. RYAN said the first priority for the Key Coalition and council is to reduce the waitlist for developmental disabilities services. Alaska's home and community-based systems are funded by Medicaid with 50 percent state funding and 50 percent federal. Medicaid recognizes that the demand can exceed resources and allows states to maintain a waitlist for home and community-based waiver services. For Alaska it only affects people with intellectual and developmental disabilities. In Fiscal Year 16, the number of people drawn from the list annually dropped from 200 to 50.

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SENATOR GIESSEL joined the committee.

MS. RYAN said they know that the longer people are on the waitlist, the costlier it becomes because typically they need more services. Intellectual and developmental disabilities (IDD) affect people before age 22. Individuals with IDD require individualized, comprehensive and life-long services in order to live successfully in the community.

SENATOR BEGICH asked if there are over 800 people on the waitlist.

MS. RYAN answered that it is 982. It had been down to 500 before the number of draws decreased.

MS. RYAN displayed graphs that showed the cost of care with home and community-based services vs. institutions. It cost \$181 million to serve 2,069 individuals with home and community-based services. In institutions, the cost could be almost \$387 million.

MS. RYAN said the waitlist has gone up 447 people in the last three years. For the last four or five years, they have submitted cost savings ideas to offset the cost of increasing the number of draws. This includes technology that reduces the need for direct staff assistance. Some examples are stove sensors and remote monitors. They used to have a semi-independent living option. A change in regulation requires services to be done on a one-on-one basis, which is much more expensive. The services are primarily rehabilitation-based, which means people must learn skills and have goals associated with that. People can only have so many goals. It can be more important just to go out in the community and volunteer and do things like go to church or go to a movie. They have also made recommendations about supported employment.

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MS. RYAN said she is happy to report that Senior and Disabilities Services (SDS) has said it is working on these recommendations. Key Coalition believes that implementing these would allow an increase in the annual draw from the waitlist from 50 to 100.

MR. REINHART said they had some real-life testimony about what it was like to be waiting for services.

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HANS WAGGONER, representing self, Nikiski, Alaska, said he and wife Amanda have an 18-year-old daughter, who is nonverbal, not potty-trained, and severely autistic. A behaviorist has told them she is in the top one percent of the hardest in the state to take care of. They signed up for services before they moved and four years later, they still have no services

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AMANDA WAGGONER, representing self, Nikiski, Alaska, said her daughter is regressing because she hasn't been able to go out into the community. They have two children in their early

twenties. One stopped college and one moved from New Jersey to help with the family because they can't work. They are doing 24-hour care. The older kids are watching her while they testify in Juneau.

MS. WAGGONER said they have to take shifts to care for her. They are burned out.

MR. WAGGONER said they have polycarbonate windows so she doesn't break them.

MS. WAGGONER said it has all been family and community support in Nikiski. It is all on their shoulders. They don't know what to do. They don't think they will ever get that little bit of extra help so they can work and their kids can go back to college.

MR. WAGGONER said his parents have given everything, but they are getting older. Family and extended family have been under so much stress.

MS. WAGGONER said they would be more useful to society if they had some help.

SENATOR BEGICH asked to confirm that their daughter has been on the waiting list four years.

MR. WAGGONER responded that they had signed her up about eight different times. It gets lost in the system every time.

SENATOR BEGICH asked if she is on the waiting list now.

MR. WAGGONER said he believed so.

SENATOR BEGICH asked whether she would be included if the draw increased to 100.

MR. WAGGONER said she should be.

MS. WAGGONER said she is one of the most extreme cases.

SENATOR BEGICH asked what they would do if she doesn't come off the waiting list.

MR. WAGGONER answered, "Just keep trying to survive. Go to the food bank and just scrape by any way we can." He said they have

caretaker burnout. This is their first two-day break from their daughter in ten years.

MS. WAGGONER said that's why they were there. They have a big support system, but they are not the people who can sign the paperwork to get them help.

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MICHELE GIRAULT, representing self, Anchorage, Alaska, introduced Carrie Carson, someone she's been friends with for almost forty years. After Carrie's parents passed on, she and her husband became Carrie's legal guardians. Carrie is on the waitlist. With Medicaid reform, SB 74, there was an impetus to change the services for those who had been on grant services. In Alaska, people get qualified to have developmental disabilities services. For a number of years, she received basic supports. Carrie is a skilled artist and participated in Hope Studios in Anchorage. With the transition of grant services to ISWs (Individualized Support Waiver), the expectation was those on grant services would seamlessly transition to the ISW. That did not happen. As of December 31, a number of people were just dropped from services. Carrie is the face of the waitlist. They are there to advocate for a path for those who had services for many years. She gave an example of another person who was dropped from all services. Alaska is better than that. When they process the budget that would be coming out, she wanted to alert and educate them that there are faces behind the waitlist and people who cannot wait any longer. Carrie has a life to lead. She and her husband were told that if they kicked her out, she would score higher on the waitlist draw. That is not an option. They will be there for her, but Carrie needs to live her own life.

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SENATOR COGHILL asked whether the issues with the transition to ISWs were qualification changes, a funding switch, or bureaucratic paperwork issue.

MR. REINHART responded a little of all those things. They supported the intention of taking grant-funded services to a Medicaid waiver. A lot of them helped SDS design that waiver. It took longer than they ever thought it would, so the grant funds were extended. Getting people to switch from a grant-funded program to Medicaid was probably more complicated than families were used to. It just has been slow. The regulations took a while to get through the process. It has been a combination of a bunch of different things. A lot of people wouldn't qualify for

Medicaid, so a safety fund was set up for them, but even that utilization has been a slow transition. People have been dropped from services and are scrambling for support. It was supposed to be a smooth transition to ISWs. There were a lot of reasons why that didn't happen.

MS. RYAN said federal law mandates institutional services for individuals (if they meet the level of care) and/or families upon request. The Waggoners could ask for that. They'd rather keep their daughter at home. But if they wanted to, the state would have to provide that service. Senior and Disabilities Services (SDS) administers home and community-based services, but the funding is in the Medicaid Services budget, which includes adult dental, behavioral health, and general health. Those are generally treatment-oriented services. The expectation is that services will fix people's problems. Home and community-based services are vastly different from those Medicaid services. Disabilities will be part of people's lives. They want to make sure they have the support and flexibility to live their lives. They feel that people with developmental disabilities served by SDS require specific and augmented protections.

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MS. RYAN said they are recommending that SDS Medicaid funding be moved out of that Medicaid Services appropriation. Before SDS was formed, people with intellectual and developmental disabilities were served through the Division of Mental Health and Developmental Disabilities, which merged and became SDS. They had Medicaid funding in their budget at that time, so they think it would be good to have the funding out of the Medicaid Services appropriation.

SENATOR COGHILL asked if they had talked to the Mental Health Trust about that.

MR. REINHART responded that not everyone agrees with this concept. It is a separate conversation about a proportion of the budget that is completely different. Not all the advisory boards are in line with that yet, but they are working on it.

SENATOR COGHILL said that the legislature in many ways looks to the trust to figure out a pathway forward.

MS. RYAN and MR. REINHART said they would talk to the trust more about this.

MR. REINHART said they are passionate about jobs. A few years ago, the council and the Key Coalition worked on passing an Employment First law. It was aspirational language that if someone wanted a job, they would find ways of employing people. In 2016, 73 percent of Alaskans of working age were employed, 49 percent of those with disabilities, but only 27.6 percent of those with developmental disabilities. They have a long way to meet the Employment First ideal.

MR. REINHART said they have some ideas for working with the administration. One is a leadership group from departments involved with employment to work across silos on the issue of jobs for their beneficiaries.

MR. REINHART introduced a new member of the council, Sydney Krebsbach.

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SYDNEY KREBSBACH, representing self, Juneau, Alaska, said she is a young adult with autism on the Governor's Council on Disabilities and Special Education. She has struggled to find gainful employment. She has worked seasonal jobs in tourism, which built skills and increased her social interaction, but had not found permanent employment, even with the help of REACH and Division of Vocational Rehabilitation. In the fall of 2016, she applied for 28 jobs and no one gave her an opportunity to prove that she can do the work. Her older sister suggested she apply as a page for the legislature. This is her third year as a Senate page. This has given her confidence to create new opportunities. Last year she completed the LEND [Leadership Education in Neurodevelopmental and related Disabilities] program through the University of Alaska and she was appointed to the council. She is there to raise her voice for people with autism and other disabilities who become frustrated with the job search. Her message is never give up and persevere. She said she would speak out until Alaska made the necessary changes so that they feel they belong in their community and are given opportunities to contribute and make a positive difference.

SENATOR COGHILL said that it has been a pleasure to work with her and to see her in this role.

SENATOR BEGICH told her to keep guiding them.

SENATOR GIESSEL said that she a delight every morning when she comes into her office.

CHAIR WILSON said he wanted to echo his colleagues.

SENATOR COGHILL said the waitlist for developmental disabilities has plagued them for many years. He asked if people are placed according to need and services available.

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MR. REINHART said it is a weighted waitlist with a scoring system. People are supposed to rise higher on the list as their needs rise. Sometimes the draw is more than 50 a year because people pass away or move. Sixty-three were drawn this last year. They do ask what happens when a family has good natural supports. Those are some of the nuances they are trying to figure out. They have recently talked about the need to look at the scoring again. Every few years they talk about that. They have heard about families in crisis who should be at the top of the list. There are delays for people to become Medicaid eligible. Becoming eligible is difficult and there is a backlog. That is another reason why people are waiting for an ISW.

SENATOR COGHILL said the Waggoners up the level of frustration on their part. His guess is that they are not only ones in such desperate need. How can that can go unanswered still surprises him. Thank heaven for family support, but family burnout happens as well. They have no solution today, but the need is there. They are looking for solutions also. Resources are scarce. In Fairbanks he has noticed that the community has stepped up for transportation. He asked how that looks across Alaska.

MR. REINHART answered that the Governor's Council and many other groups are involved with the Alaska Mobility Coalition. He is president of that group. It has been a big issue for so many years. Their beneficiaries need transportation if they are going to participate in the community. Fairbanks just went through a coordinated transportation plan. Anchorage is going through the same thing. Some of the smaller communities are not getting a coordinated system. It is catch-as-catch-can many times. There is not a lot of money for this. They had some support from the legislature for matching funding in the capital budget the last few years. He thinks last year it was \$500,000 and the year before it was a \$1 million. It gets distributed from small to larger providers in the hope that they can draw federal funds for that. There is also some Mental Health Trust funding. The budget proposal put forth includes \$800,000 of general funds mental health and \$350,000 from the Alaska Mental Health Trust. Public transit often doesn't get a lot of local support. The Alaska Mobility Coalition is always trying to work with

providers to get the message out about the need. It's not just people with disabilities but also seniors, a number of folks. Some systems in the state are awesome. Juneau is a good example of a really good system.

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SENATOR COGHILL said three things are always of benefit to help people to grow and flourish: transportation, communication, and a helping hand. Respite care and transportation and communication capacity are such big deals. Communication is getting better because of technology, but transportation can isolate people.

MR. REINHART replied that technology can help with isolation. Technology is becoming less and less expensive. Things that cost \$10,000 a few years ago are apps that can sometimes be download for free. As Ms. Ryan mentioned, technology can open up so many opportunities for people to live more independently and safely in their homes. This will also be for the aging population.

SENATOR BEGICH asked about the status of respite care.

MS. RYAN said respite services are available through the home and community-based waiver. It can be written into the plan of care. It used to be funded through grants, but now is available through the ISW, so it is not as available as it once was.

SENATOR BEGICH said then those on the waiting list are not eligible.

MS. RYAN answered yes.

CHAIR WILSON said the Division of Behavioral Health will address some of these issues, as well as general behavioral health issues, in a later presentation. He said he has gotten phone calls every week about the difficulty of navigating to the ISW. It is a complex system working out the bumps. They don't want individuals to suffer during this process. They are trying to work with the administration to lessen the burden on Alaskans.

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There being no further business to come before the committee, Chair Wilson adjourned the Senate Health and Social Services Standing Committee at 2:20 p.m.