

ALASKA STATE LEGISLATURE
HOUSE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE

February 6, 2020

3:14 p.m.

MEMBERS PRESENT

Representative Tiffany Zulkosky, Chair
Representative Ivy Spohnholz, Vice Chair
Representative Matt Claman
Representative Harriet Drummond
Representative Geran Tarr
Representative Lance Pruitt

MEMBERS ABSENT

Representative Sharon Jackson

COMMITTEE CALENDAR

PRESENTATION: ADVOCACY FOR PEOPLE WITH DISABILITIES

- HEARD

PREVIOUS COMMITTEE ACTION

No previous action to record

WITNESS REGISTER

DENNIS HAAS, President
Key Coalition
Anchorage, Alaska

POSITION STATEMENT: Testified and offered information during the presentation on Advocacy for People with Disabilities.

KRISITN VANDAGRIFF, Executive Director
Governor's Council on Disabilities & Special Education
Division of Senior and Disability Services
Department of Health & Social Services
Anchorage, Alaska

POSITION STATEMENT: Introduced witnesses and provided information during the presentation on Advocacy for People with Disabilities.

COREY GILMORE, Chair
Governor's Council on Disabilities & Special Education

Division of Senior and Disability Services
Department of Health & Social Services
Anchorage, Alaska

POSITION STATEMENT: Testified during the presentation on Advocacy for People with Disabilities.

ART DELAUNE, Legislative Committee Chair
Governor's Council on Disabilities & Special Education
Division of Senior and Disability Services
Department of Health & Social Services
Anchorage, Alaska

POSITION STATEMENT: Testified and offered information via PowerPoint during the presentation on Advocacy for People with Disabilities.

ACTION NARRATIVE

[3:14:33 PM](#)

CHAIR TIFFANY ZULKOSKY called the House Health and Social Services Standing Committee meeting to order at 3:14 p.m. Representatives Zulkosky, Spohnholz, Claman, and Drummond (via teleconference) were present at the call to order. Representatives Tarr and Pruitt arrived as the meeting was in progress.

Presentation: Advocacy for People with Disabilities

[3:15:24 PM](#)

CHAIR ZULKOSKY announced that the first order of business would be a presentation on Advocacy for People with Disabilities.

[3:15:45 PM](#)

DENNIS HAAS, President, Key Coalition testified that he is, "first and foremost, Katie's (ph) dad." The Key Coalition celebrates its [twenty-second] year of advocacy for Individuals with Developmental Disabilities (IDD) in Alaska. At the time of its formation, there was to be a large cut to program services, and as a result, 30-40 people traveled from Anchorage and other locations across the state to Juneau to contest the cuts. The group's activity resulted in less substantive cuts to programs, and therein the citizens decided that it would be necessary to organize to continue advocacy work each year to maintain funding.

MR. HAAS related his personal story of caring for a child with severe developmental disabilities. He explained that his family is required to write and submit a new plan for his daughter's care each year. His daughter, Katie, is blind, severely disabled, doesn't talk, and is living without a pancreas. He testified that this year, his daughter's care plan was rejected, resulting in cuts to the in-home support services they have been receiving, from 56 hours per week to only 23.5 hours of care per week. He postulated that this reduced amount of service is not enough hours to keep his daughter alive. He noted that his fear of danger to his daughter is compounded by his and his wife's advancing age. Mr. Haas declared deep gratitude to the State of Alaska for the services that they have received to date and emphasized that those services are lifesaving.

MR. HAAS explained that there is a waitlist for services that consists of 730 people who, due to lack of funding, may continue to wait for several years to receive necessary services. The Key Coalition's priority is to advocate until all the individuals on the waitlist receive care.

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MR. HAAS noted that the service providers for programs for IDD service providers haven't received any additional funding for approximately four to five years. As a result, the servicing agencies cannot effectively recruit and retain direct service providers to provide necessary levels of care.

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REPRESENTATIVE SPOHNHOLZ asked whether there was a reason given for the cuts to Mr. Hass' weekly services from 56 to 23.5 hours.

MR. HAAS replied that "they keep changing the rules." He explained that he received a 64-page document outlining the changes to his daughter's care plan, in which he found it difficult to interpret any reason that the plan was rejected. He gave an example of how one of the specificities outlined in the revised care plan is not adequate for his daughter's fragile health conditions.

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REPRESENTATIVE SPOHNHOLZ asked for confirmation that the waitlist consists of individuals waiting for home- and community-based services.

MR. HAAS confirmed yes.

[3:24:09 PM](#)

KRISTIN VANDAGRIFF, Executive Director, Governor's Council on Disabilities & Special Education, Division of Senior and Disability Services, Department of Health & Social Services, noted that she had provided the committee with a hard copy of a PowerPoint regarding "2020 Update GCDSE," [included in the committee packet]. In the interest of time, she explained she would not present the PowerPoint, and instead she introduced the next speaker.

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COREY GILMORE, Chair, Governor's Council on Disabilities & Special Education, Division of Senior and Disability Services, Department of Health & Social Services expressed that he is honored to testify before the legislature once again. He thanked the State of Alaska and the Alaska State Legislature, noting that the legislature passed "DD [Developmental Disability] Shared Vision" changing how care is delivered, which places the individuals receiving the services in control of the planning for their own care that works the best for their own lives.

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ART DELAUNE, Legislative Committee Chair, Governor's Council on Disabilities & Special Education, Division of Senior and Disability Services, Department of Health & Social Services testified for the purposes of providing the legislature with program progress updates and to request continued support for the programs. He drew attention to a PowerPoint presentation regarding "2020 Update GCDSE," to slide 8, entitled "Supported Decision Making Agreements Act." He said he supports the Act. The SDMA (Supported Decision Making Agreements Act) was passed during the 30th Legislature in November 2018. The SDMA changed how care is received and allows the option for guardianship. The SDMA allows the disabled person to direct his/her own care with the help of supporters, formalizing the agreement between the individual and his/her supporters. The SDMA clarifies responsibilities and allows the individual to direct goals and priorities toward a more meaningful life. Mr. Delaune provided a personal example of his family's positive experience with this change; his disabled son has been able to remain employed. He said the council has provided materials to the House Health and

Social Services Standing Committee in the hopes of increasing program visibility to possible qualified recipients.

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MR. GILMORE acknowledged his disability and the limitations in routine activities and personal care that he cannot perform for himself. The service levels provided through the program are not at completely adequate levels; however, the services that are in place are highly effective and support not only the individual's personal hygiene and care, but also allow the recipient to participate in his/her own community and perform activities such as outreach and mentoring to children with disabilities and special needs. Referring to the PowerPoint previously cited, Mr. Gilmore drew attention to slide 13, entitled "Home and Community Based Services are Cost Savings". These types of support services are more cost effective than would be institutionalization, by an estimate of 2.5 times less cost. Mr. Gilmore left the committee with the sentiment that all people need help at some point in their lives, and these services need to remain available now and in the future.

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MR. DELAUNE indicated that the Key Coalition is working with the state to recommend removal of barriers to efficiency such as: unnecessary regulations, application processes, re-evaluations, and reporting requirements that individuals who have received Medicaid waivers must fulfill to maintain services. These individuals have lifelong static medical conditions which are not going to be resolved through medical care, and current methods of reporting and monitoring of these conditions is wasteful of limited resources. Another recommendation is [to include transportation costs as part of the program that employs people with disabilities]. This would open more employment opportunities and thereby reduce costs by reducing their reliance on other welfare programs' funds. Another recommendation is to eliminate burdensome processes and bureaucracy to increase flexibility for purchases for the home, especially consumables such as diapers. The program requires recipients to procure through limited, authorized suppliers, which is inflexible, inefficient, and costs more.

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MR. DELAUNE, referring to the PowerPoint previously cited by Mr. Gilmore, drew attention to slide 17, entitled "Increase savings

and self-determination by offering an option for people with I/DD to more closely direct their services." He indicated a potential increase in savings by streamlining or consolidating care programs for IDD's. Currently there are multiple sources of funding with separate administrative requirements, and the Council recommends that these funds be combined to streamline resources available for an individual's self-directed care. Mr. Delaune explained his personal experience of losing some of these services for his son. He testified that the Adult Companion Service available hours were capped in 2018, and that the Adult Companion Service is a low-cost way for individuals with disabilities to participate meaningfully in their own communities. Prior to cuts, his son was socially active three times per week and benefitted from these community activities and social opportunities that the services provided. He is now socially isolated except for the time he spends out of the home while at work. Mr. Delaune left the committee with the sentiment that the manner in which we treat individuals with disabilities and the elderly reflects the values that are and should remain important.

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REPRESENTATIVE TARR indicated that she had several questions regarding the Council's recommendations per the materials provided, and in the interest of time would follow up separately, save for one clarification. She asked that in a circumstance in which a need for increased services was [determined], would the individual be able to initiate the increased services, or otherwise, for continuing services, re-apply on an annual renewal basis?

MR DELAUNE answered that an IDD has "plans of care", and they can make changes to those plans.

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KRISITN VANDAGRIFF specified that it would be through a plan of care amendment.

[3:36:43 PM](#)

CHAIR ZULKOSKY offered thanks to the presenters.

[3:37:29 PM](#)

ADJOURNMENT

There being no further business before the committee, the House Health and Social Services Standing Committee meeting was adjourned at 3:37 p.m.