

ALASKA STATE LEGISLATURE
HOUSE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE

February 1, 2018

3:05 p.m.

MEMBERS PRESENT

Representative Ivy Spohnholz, Chair
Representative Bryce Edgmon, Vice Chair
Representative Sam Kito
Representative Geran Tarr
Representative Jennifer Johnston
Representative Colleen Sullivan-Leonard
Representative Dan Saddler (alternate)

MEMBERS ABSENT

Representative David Eastman
Representative Matt Claman (alternate)

COMMITTEE CALENDAR

PRESENTATION: 2018 UPDATE GOVERNOR'S COUNCIL ON DISABILITIES &
SPECIAL EDUCATION

- HEARD

PREVIOUS COMMITTEE ACTION

No previous action to record

WITNESS REGISTER

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

POSITION STATEMENT: Presented a PowerPoint titled "2018 Update."

MAGGIE WINSTON, Chair
Governor's Council on Disabilities & Special Education
Kenai, Alaska

POSITION STATEMENT: Presented a PowerPoint titled "2018 Update."

JEANNE GERHARDT-CYRUS, Chair

FASD Workgroup
Kiana, Alaska

POSITION STATEMENT: Presented a PowerPoint titled "2018 Update."

ACTION NARRATIVE

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CHAIR IVY SPOHNHOLZ called the House Health and Social Services Standing Committee meeting to order at 3:05 p.m. Representatives Spohnholz, Tarr, Sullivan-Leonard, Johnston, Kito, and Saddler (alternate) were present at the call to order. Representative Edgmon arrived as the meeting was in progress.

**Presentation: 2018 Update Governor's Council
on Disabilities & Special Education**

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CHAIR SPOHNHOLZ announced that the only order of business would be a PowerPoint presentation by the Governor's Council on Disabilities & Special Education.

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PATRICK REINHART, Executive Director, Governor's Council on Disabilities & Special Education, presented a PowerPoint titled "2018 Update" and he discussed slide 1, "Council Roles:" He reported that the council had multiple roles in state government, listing their work as the Developmental Disabilities Council, the State Interagency Coordinating Council (ICC) for infants and toddlers with disabilities, the Beneficiary Advisory Board to the Alaska Mental Health Trust Authority, the Governing Body of the Special Education Service Agency (SESA), and the Special Education Advisory Panel (SEAP) for the state on behalf of the Department of Education and Early Development. He pointed out that the role and responsibility of the council covered multiple state departments. He moved on to slide 2, "State 5 - Year Plan:" and reported that they had just finished a five-year plan with input from all over the state. He noted that most research was done by survey. He declared that they had arrived at five different goal areas: empowered to live and thrive in communities; competitively employed in integrated settings; skills for education success and independence; receive appropriate services and supports; and improved quality of life.

He stated that all the objectives and activities for the council would fall into these five areas.

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MR. REINHART reported that he would offer an overview of two bills that the council was developing. He introduced the first of these two bills, slide 3, "Developmental Disability (DD) Shared Vision:"

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MAGGIE WINSTON, Chair, Governor's Council on Disabilities & Special Education, spoke about slide 3, and reported that the council was working on this shared vision for developmental disabilities and the State of Alaska. She explained that the project teams were meeting with state agencies, service providers, families, care coordinators, and individuals to provide better services for individuals with developmental disabilities. She stated that the goal was to make services more person centered, so that people were in control of the services they received in an integrated home and community setting of their choosing.

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MS. WINSTON declared that person centered care allowed an individual to add more meaning to their life. She shared a personal anecdote about her life and the services which she received. She acknowledged that, given the current budget climate, there would be a difference in opinion for how these services should be provided. She directed attention to slide 4, "Moving Forward Together:" and stated that the goal was to set a sustainable future in statute that would enable people to look forward to the future and be safe in knowing that the services would be provided.

CHAIR SPOHNHOLZ asked about the cut in her personal services from 24 hours each day, seven days a week, to 35 hours each week.

MS. WINSTON, in response, explained that this cut was currently in the appeals process, and that if this happened, she would need to move from her home with her two teenage children into a nursing facility, which was more expensive than her current home support.

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MR. REINHART spoke about the graphic on slide 4, and the savings for this move toward home and community-based services from institutional care, which amounted to about one-third the cost. He reported that this had been the chosen direction since the mid-1990s.

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REPRESENTATIVE JOHNSTON reflected that 6 - 8 percent of the population were the big cost drivers for health care, and she asked about the percentage of home-based costs over a ten-year period.

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MR. REINHART replied that, although he did not have a ten-year projection, the department had compared each of the four types of waiver costs and that the average cost for a developmental disability waiver was about \$89,000 per person, with some people costing more and some people costing less.

REPRESENTATIVE JOHNSTON asked for further information.

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REPRESENTATIVE KITO asked what situation prompted the proposed change from 24-hour care to 35 hours of care each week.

MS. WINSTON explained that there had been changes in certain convoluted regulations for group home services, and that she had opted to choose different supported living services for more freedom and independence.

REPRESENTATIVE KITO asked if this was a situation that was happening to other people with developmental disabilities.

MS. WINSTON expressed her agreement, stating that it was happening to many individuals.

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REPRESENTATIVE SULLIVAN-LEONARD asked if this was a state change or a Medicaid change.

MS. WINSTON replied that it was a state change.

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MR. REINHART moved on to slide 5, "DD Shared Vision Bill," and explained that it would put this in statute, so that all future administrations would look at this when reviewing the home and community-based services waiver programs. He reported that they were working on some draft aspirational language which could be added to the statute, "a lens that we just want to put over the top of all these services" which would lead to "meaningful lives for citizens with disabilities."

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JEANNE GERHARDT-CYRUS, Chair, FASD Workgroup, addressed slide 6, "Supported Decision Making:" and explained that it referred to a third opportunity for people who, in the past, had been automatically granted either a full or limited guardian. She said that supported decision making went along with the vision for developmentally disabled to have more control over their lives and be able to choose where and how they wanted to live. She declared that this was a civil rights issue. She acknowledged that, although some people may need full guardianship, not everyone did. She pointed out that although people may need help with some things, this would allow them the right to maintain decision making power over their own lives. She moved on to slide 7, "Supported Decision Making Bill," and stated that this bill was very close to being presented to the legislature. She reported that the recommended ratio of guardian to ward was 1 to 20, and in Alaska, as this ratio was 1 to 109, the opportunity to do any planning or discussion with the individual was "pretty limited if non-existent." She declared that supported decision making would provide equal access for the individual and allow them to establish a team of people they wanted to have discussion and input for life decisions. She opined that there had been positive support for similar legislation in other states.

MR. REINHART added that they supported the increase for the Office of Public Advocacy which had been included in the governor's budget.

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MS. GERHARDT-CYRUS pointed out that she was the Chair of the FASD [Fetal Alcohol Spectrum Disorders] work group. She presented slide 8, "FASD 5 - Year Plan:" and reported that the

workplan and the vision had now been finalized. She stated that the goal was for Alaska to become an FASD informed state.

MS. GERHARDT-CYRUS moved on to slide 9, "FASD 5 - Year Plan:" and explained that FASD was a range of disabilities and did not affect everyone together, as it depended on the time and amount of exposure, as well as genetic differences. She stated that a goal was to reduce the incidence of alcohol exposed pregnancies, pointing out that this was 100 percent preventable, providing there were the supports and services necessary for women and families to assist with healthy pregnancies "because it's not just a woman's issue." She declared that it was important to address the stigma associated with FASD for birth moms and individuals. She listed the need to reduce the co-occurrence of childhood trauma and FASD by increasing support for families. She pointed out that many people with FASD did not qualify for services in the developmental disabilities program and would not qualify for a waiver unless they had a diagnosis outlined in the federal regulations. She reported that these people could have chronic failure as they may not respond to typical strategies at home and in school. She reiterated that reducing the co-occurrence of childhood trauma and FASD, addressing FASD informed care, and advocating for fully funded appropriate services were all goals. She relayed that five work groups had been formed, with funding from the Alaska Mental Health Trust Authority and partnerships with 18 entities. She reported that there would be quarterly meetings, with a focus on developing action plans, reviewing finances, and identifying resources for the top three objectives listed on slide 9. She noted that behavioral health issues were often a result of chronic failure co-occurring disorders.

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REPRESENTATIVE JOHNSTON stated that, as diagnosis was often a stigma, families would not allow diagnosis, and asked if that had been addressed to allow follow through with the remainder of the goals.

MS. GERHARDT-CYRUS said that it continued to be an issue. She reported that the All Alaska Pediatric Partnership would conduct its own developmental screenings for all neuro developmental issues as early as possible. She opined that this would help with diagnosis.

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REPRESENTATIVE TARR recalled that the state had previously funded a project for pregnancy tests in bathrooms. She asked if there was any discussion in the community about the success of this project, and whether there had been any follow up. She asked whether this would be a part of any prevention strategy.

MS. GERHARDT-CYRUS replied that, although she was not on the prevention workgroup, anything that was effective for preventing alcohol exposed pregnancy was helpful. She shared an anecdote about five women who had written in with thanks after taking the test.

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REPRESENTATIVE TARR suggested that this could be a lower cost alternative.

MS. GERHARDT-CYRUS relayed that currently there were not a lot of asks to the Legislature, although the priority area groups could bring many ideas forward.

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CHAIR SPOHNHOLZ acknowledged the in-depth, comprehensive work plan addressing FASD by Ms. Gerhardt-Cyrus, and she expressed her "hope for the future" after reading it. She shared a personal anecdote about her daughter and the struggles with testing for FASD.

MS. GERHARDT-CYRUS stated that now was a time for action.

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MR. REINHART reported that there was an autism ad hoc group and shared that the state would now have two pediatric neurodevelopment specialists, slide 10, "Autism Update:" He noted that there were 11 rural outreach clinics and that the Center for Human Development at the University of Alaska had started Alaska ECHO Autism, which included the expertise from providers around the country in a video conference format to deal directly with practitioners and discuss the issues and problems encountered in diagnosis and service.

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MR. REINHART moved on to slide 11, "Autism Update: ABA - EBSDT Regs," and shared the suggestion that the state adopt

regulations that allowed for applied behavioral analysis, an evidence-based treatment. He reported that the council reviewed and commented on the draft regulations and shared that Medicaid payment for this treatment was getting closer.

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MR. REINHART directed attention to slide 12, "Universal Developmental Screening." He stated that the sooner there was a diagnosis for young children experiencing developmental disabilities, the sooner they could get into services.

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MS. WINSTON spoke about slide 13, "ABLE Update:" and reported that the ABLE Act had been passed in August 2016 and the first accounts had been opened that December. She reported that there were currently 94 ABLE accounts with quite a bit of funding and it enabled individuals with disabilities to save for things related to their disabilities. She shared that the number of accounts being opened was increasing, and that the outreach continued through presentations and social media to benefit more individuals.

MR. REINHART thanked Representative Saddler for his work in passage of the ABLE Act in Alaska.

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MR. REINHART moved on to slide 14, "Employment First Update:" and shared that the legislation had been aspirational language in the expectation for employment of individuals with disabilities. He stated that continued emphasis for expectation would create a long-term shift in policy and attitude, and that young people now in school had the expectation for employment. He pointed to the repeal of sub minimum wage for people with disabilities. He shared that there was work across many departments.

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REPRESENTATIVE TARR asked about a U.S. Supreme Court case related to services for children with disabilities in school, which challenged the Department of Education for definition of service.

MR. REINHART said that he would research the case.

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CHAIR SPOHNHOLZ expressed her excitement with the employment first update and the progress being made. She declared that we gained meaning in our lives from our work and, in our culture, how we work was how we defined ourselves. She emphasized that it was important to be able to work in a way that provided meaning in our lives, and she detailed how this developed happiness, confidence, and respect from adults and peers. She offered her belief that work gave individuals meaning and focus in their lives.

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ADJOURNMENT

There being no further business before the committee, the House Health and Social Services Standing Committee meeting was adjourned at 3:50 p.m.