ALASKA STATE LEGISLATURE
HOUSE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE
February 2, 2017
3:02 p.m.

MEMBERS PRESENT

Representative Ivy Spohnholz, Chair
Representative Sam Kito
Representative David Eastman
Representative Jennifer Johnston
Representative Colleen Sullivan-Leonard

MEMBERS ABSENT

Representative Bryce Edgmon, Vice Chair
Representative Geran Tarr
Representative Jonathan Kreiss-Tomkins (alternate)

COMMITTEE CALENDAR

PRESENTATION: AUTISM & FASD

- HEARD

PREVIOUS COMMITTEE ACTION

No previous action to record

WITNESS REGISTER

CHRISTIE REINHARDT, Program Coordinator
Governor's Council on Disabilities & Special Education (GCDSE)
Division of Senior and Disabilities Services
Department of Health and Social Services
Anchorage, Alaska
POSITION STATEMENT: Presented a PowerPoint titled "Autism & FASD."

JEANNE GERHARDT-CYRUS, Chair
FASD Work Group
Kiana, Alaska
POSITION STATEMENT: Testified and answered questions during FASD presentation.

JILL BURKERT, Chair
Governor's Council on Disabilities & Special Education (GCDSE)

Program Coordinator for Special Education
University of Alaska Southeast
Juneau, Alaska
POSITION STATEMENT: Testified during the PowerPoint presentation.

ACTION NARRATIVE

3:02:41 PM

CHAIR IVY SPOHNHOLZ called the House Health and Social Services Standing Committee meeting to order at 3:02 p.m. Representatives Spohnholz, Sullivan-Leonard, Johnston, and Eastman were present at the call to order. Representative Kito arrived as the meeting was in progress.

Presentation: Autism & FASD

3:03:25 PM

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

3:03:51 PM

CHRISTIE REINHARDT, Program Coordinator, Governor's Council on Disabilities & Special Education (GCDSE), Division of Senior and Disabilities Services, Department of Health and Social Services, directed attention to a PowerPoint titled "Autism & FASD" and introduced slide 2, "Title V Maternal Child Health Program." She explained that a federal grant had included a survey of more than 1,000 families raising children with special health care needs, which had identified three predominant needs of those families: mental and behavioral challenges, social isolation, and bullying.

3:06:08 PM

REPRESENTATIVE SULLIVAN-LEONARD asked whether this included the tracking of cyber bullying.

MS. REINHARDT replied that she would provide more information on bullying. She continued with slide 3, "What the Council Did," and shared that the council collected the information and developed a five year plan. She relayed that the council

conducted focus groups in 15 communities across Alaska, in which they asked basic questions about issues, including early intervention and education, developmental disability services, employment, childcare, and transportation. She declared that other issues were consistently raised, including discussion regarding the huge gaps in service for screening and diagnosis, particularly around neuro-behavioral disorders or hidden disabilities. These hidden disabilities included autism, fetal alcohol spectrum disorder (FASD), and traumatic brain injury, as it was often not possible to visually detect these disabilities. She stated that there were gaps in early intervention and education. She reported that families raising children with behavioral challenges found it next to impossible to find child care, which impacted their work. She relayed that another consistently raised issue was for children at 22 years aging out of school age services, declaring that there was "a cliff that those kids just drop off." She allowed that screening and diagnosis of these neural behavior disorders had improved over the past 20 years and that, although programs for early intervention and for schools were developed, there had not been any catch-up with adult services. She opined that there was not a social system developed which had anticipated a doubling of autism diagnoses in this short period of time. She declared that FASD was prevalent in Alaska.

MS. REINHARDT, in response to Representative Johnston, pointed out that FASD included the full spectrum of disorders, similar to any reference for autism to include the full spectrum of disorders. She stated that, as it was unclear whether FASD was a behavioral health or a developmental disorder, it was a question for services, and, in this sense, Alaska was a pioneer for FASD services. She asked how the services could be coordinated, offering her belief that this was still emerging.

MS REINHARDT moved on to slide 4, "Disparities," and said that the council had heard that there were large disparities in referrals, with inconsistent screenings, screening tools, and clinic days. She shared that there were not many pediatric neural developmental specialists, and she listed the many difficulties for hiring to bridge the gap in services. She pointed to the disparity for the locations of generalists and sub-specialists in the state.

3:12:44 PM

MS. REINHARDT moved on to slide 5, "Limited Access," and said that there was a necessity for evidence based practices,

appropriate education for individuals with brain based disabilities, and professional training for early educators, service providers, and first responders. She emphasized that these support systems needed to be sustainable through insurance and Medicaid. She declared a need for employment, housing, and ways to have meaningful lives which included community engagement instead of isolation.

MS. REINHARDT addressed slide 6, "Prevalence," and pointed out that FASD was not a low incidence disability, as there were 24 - 48 incidences per thousand. In response to Chair Spohnholz, she said this national data had just been released, and that she would supply the actual release data.

REPRESENTATIVE EASTMAN asked why there was such a wide range in the prevalence.

MS. REINHARDT replied that this was national data and offered her belief that it was very difficult to obtain firm FASD data, as different states had different diagnosis screenings. She noted that it was necessary to have documentation for pre-natal exposure to drugs or alcohol. She shared that the FAS data from two years ago had projected 2 - 5 incidences per thousand.

REPRESENTATIVE KITO asked if there was multi-year historic data to help detect any trends.

MS. REINHARDT replied that she would provide the data. She shared that there was research being conducted for prevalence data in Alaska, noting the difficulty to obtain this as there was not any requirement to screen for FASD.

CHAIR SPOHNHOLZ shared that screening for FASD was very difficult, as there was a need for the biological mother to acknowledge alcohol consumption during pregnancy. She shared that the physiological marker was only a small part of the diagnosis, and she offered a personal example.

REPRESENTATIVE JOHNSTON added that some rural communities had school systems which had not even attempted diagnosis.

3:19:37 PM

JEANNE GERHARDT-CYRUS, Chair, FASD Work Group, referred attention to slide 7, "FASD," and stated that FASD was a medical diagnosis. She declared that the features were easier to recognize with a syndrome; whereas with FASD, there may not be

any of these features, hence a much greater challenge. She declared that the state did not have a good screening tool for FASD, as FASD was so varied. She shared that she and her husband were the parents of a number of children with FASD. The majority of referrals for diagnosis of FASD came through the Office of Children's Services (OCS), as there was more access. She opined that the stigma with FASD was very real and should be addressed. She pointed out that although alcoholism was recognized as a disease, there was still a stigma for FASD. She reported that many of the children were first diagnosed with FASD while in the foster care system when their behaviors were first recognized. She shared that although there were several diagnostic teams across Alaska, some were consistent while others varied in diagnoses. She stated that FASD children were often seen in emergency rooms, corrections, and residential treatment. She declared the need for a sustainable infrastructure to provide the necessary range of services for all ages. She explained that often for kids with FASD the issue was that they appear competent, and therefore would not qualify for developmental services, although there was a developmental disability. Their behaviors were often assumed to be malicious, resulting in mis-diagnosis, and subsequently, FASD can be completely missed. She declared that the State of Alaska was the only state with FASD listed in the educational regulations, and the only state which recognized the role of nurse practitioners for assisting with diagnosis, making the state a pioneer in the field. She offered her personal experiences with FASD.

3:28:04 PM

JILL BURKERT, Chair, Governor's Council on Disabilities & Special Education (GCDSE), Program Coordinator for Special Education, University of Alaska Southeast, directed attention to slide 8, "Autism," and speaking about the prevalence data, she noted a similarity to FASD of issues with inconsistent screening and identification. She stated that autism was first identified and included in the Individuals with Disabilities Education Act (IDEA) in 1990, and the Centers for Disease Control and Prevention (CDC) prevalence data was 1 in 1,000. She reported that three years prior, the prevalence data was 1 in 200, whereas today the prevalence data was 1 in 68, consistent with the State of Alaska prevalence data. She referenced the data for FY2016 on the Department of Education and Early Development website which listed 18,390 special education students in the state, of whom 1,335 were identified as having autism. She suggested that some of this data should be more closely

evaluated as there were many small school districts with fewer than five students, which may not have identified or reported students with autism. She reiterated the difficulty for determining the number of students although, she acknowledged there had been more effort to identify younger children with autism, ages zero to three. She pointed out that this self-report questionnaire was more of a screening device. She reported that due to a lack of qualified personnel it was often necessary to fly out of Alaska to achieve a diagnosis, as without a diagnosis, it was difficult to develop a treatment plan.

3:32:19 PM

MS. REINHARDT concluded by sharing that the Governor's Council on Disabilities & Special Education had two committees working to ensure that efforts around autism and FASD were not siloed, but were coordinated efforts with Public Health, Behavioral Health, Education, Early Intervention, Human Development, service providers, and parental support organizations. She reported that a five-year plan for autism and FASD had been developed. She offered to provide information for the types of systemic improvements necessary.

REPRESENTATIVE SULLIVAN-LEONARD reflected on the shortage of physicians and asked if there was any homegrown concept in conjunction with the Washington, Wyoming, Alaska, Montana, and Idaho (WWAMI) Medical Education Program.

MS. REINHARDT replied that there were several models being reviewed, which included the opportunity for pediatricians and advanced nurse practitioners in Alaska to receive the specialized training necessary for diagnosis. She added that there was the possibility for training family navigators for the bridge between diagnosis and services. She reported that current diagnosis in Alaska consisted of two pediatric neuro developmental specialists from the University of Washington.

3:35:07 PM

ADJOURNMENT

There being no further business before the committee, the House Health and Social Services Standing Committee meeting was adjourned at 3:35 p.m.