

ALASKA STATE LEGISLATURE
SENATE HEALTH, EDUCATION AND SOCIAL SERVICES STANDING COMMITTEE

February 5, 2007

1:31 p.m.

MEMBERS PRESENT

Senator Bettye Davis, Chair
Senator Joe Thomas
Senator John Cowdery
Senator Kim Elton
Senator Fred Dyson

MEMBERS ABSENT

All members present

COMMITTEE CALENDAR

Overview: Promising Practices in Autism and Early Intervention Service

PREVIOUS COMMITTEE ACTION

No previous action to consider

WITNESS REGISTER

Millie Ryan, Executive Director
Governor's Council on Disabilities
and Special Education
Anchorage, AK

POSITION STATEMENT: Presented overview

Kathy Allely, Health and Social Services Planner III
Governor's Council on Disabilities
and Special Education
Anchorage, AK

POSITION STATEMENT: Presented overview

ACTION NARRATIVE

CHAIR BETTYE DAVIS called the Senate Health, Education and Social Services Standing Committee meeting to order at [1:31:42 PM](#). Present at the call to order were Senators Thomas, Cowdery, Elton, Dyson, and Chair Davis.

Governor's council on disabilities and special education

GOVERNOR'S COUNCIL ON DISABILITIES AND SPECIAL EDUCATION:
PROMISING PRACTICES IN AUTISM AND EARLY INTERVENTION SERVICE

CHAIR DAVIS announced that the committee would be having an overview from the Governor's Council on Disabilities and Special Education on its Early Intervention service, presented by Millie Ryan, the council's Executive Director, and Kathy Allely, Health and Social Services Planner III for the council.

MILLIE RYAN, Executive Director, Governor's Council on Disabilities and Special Education, explained that the council fulfills several roles: advising the state government on issues pertaining to developmental disabilities and special education, streamlining and increasing the capacity of disability services, and advocating for change in policies pertaining to such services. The board is also a beneficiary of the Alaska Mental Health Trust Authority (AMHTA). Ms. Ryan pointed out that Alaska is the only state where all of these responsibilities have been combined into one council. The council is comprised of 28 members appointed by the governor, 60 percent of which are either individuals with developmental disabilities or family members of such. The council does not receive funding from the state, but rather directly from the federal government, the AMHTA, and federal grants.

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MS. RYAN explained that the council does not provide direct services. One of the areas in which is most interested is early intervention, which has been shown to be important to improving the later quality of life for disabled children and prevent lasting harm. The window of opportunity for effective early intervention is in the first three years of life. Studies have shown that people who received early intervention at a young age were, at 40 years of age, earning more money and were less likely to be involved in the criminal justice system than those who didn't receive early intervention.

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SENATOR COWDERY asked if there was a hereditary factor in such disabilities.

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MS. RYAN replied that early intervention also works with the parents of qualified children to teach them life skills. Children with FAS certainly are the product of a drinking mother. There are certain tests that can be done to examine the parents' genetics.

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KATHY ALLELY added that there are often unknown reasons for disabilities.

MS. RYAN said that it is certain that earlier intervention with the disabled child is much less costly than dealing with later consequences.

She explained that 1-2 percent of infants have a diagnosable disabling condition at birth, like Down's syndrome or cerebral palsy. In the next few years additional problems can become evident. By pre-school, language, learning, and behavioral problems manifest. By public school age, 10-12 percent of children have some degree of disability. Some of those children could have been diagnosed and treated prior to entering public school. Available tools could be used more effectively with additional funding. By the time a disabled child reaches the age of 40, for every \$1 invested in treatment there was a \$17 return in terms of avoided costs or earned money and property of the individual.

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SENATOR COWDERY asked for an example of medical and non-medical costs associated with treating a disabled child.

MS. ALLELY replied that physician and hospital visits were different from therapies and education.

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SENATOR DYSON asked if all of the disabled children who comprised the 10-12 percent figure quoted earlier by Ms. Ryan required special accommodation in school.

MS. RYAN replied that in most cases, additional care was necessary. Children could be enrolled in special education classes or have an individualized education plan, or they could

just need the teacher or administrators to be aware of their disability.

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SENATOR DYSON asked for clarification on the number of special education students in the state.

MS. RYAN replied that there are 18,000 such students in the state, from ages 3-21. Some of these children may be declassified later on if they are properly accommodated at an early age.

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MS. RYAN continued to explain that in fiscal year 2006, the council served 1,800 children at an average cost of \$5,500 apiece. There are 17 regional grantees that provide services as well as programs run through the Statewide Consultation for Children with Hearing and Vision Disabilities, an Infant Learning Program.

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SENATOR DYSON asked for clarification on the amount of money spent on the 1,800 children served, and if \$5,500 was the total amount.

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MS. RYAN replied that 1,800 children were served at an average of \$5,500 apiece.

SENATOR DYSON asked if that amount included all services or just the services provided by the board.

MS. RYAN replied that the latter was correct.

SENATOR DYSON said that he was told that each FAS child cost \$1 million in treatment by the age of 18.

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MS. RYAN replied that the \$5,500 figure represented only the early intervention costs, which might be effective in preventing such later costs.

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MS. RYAN said that to be eligible for an early intervention program, a child must have a diagnosed condition leading to significant delays, or a 50 percent or greater delay in one area of development. Children with a 15-49 percent delay may receive services as funds allow. Alaska is more restrictive than most states in terms of services provided. Services must also be provided for children under the age of three if they have a 25 percent delay in at least two areas of development.

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SENATOR ELTON said that he didn't understand the threshold for intervention, and asked for an explanation of "delays" and who makes the determinations.

MS. RYAN replied that a diagnosis of a condition would generally be made by a doctor. Clinical opinions could qualify a child, or a developmental checklist.

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MS. ALLELY added that standardized assessment tools are used to determine disability in different areas of skill. A 50 percent delay, for example, would refer to a 12-month-old child who was at a 6-month-old's level of development.

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MS. RYAN said that many children are not identified when the intervention is most critical and least costly. In the Matanuska-Susitna School District, 109 children were eligible for preschool special education but were never enrolled. In some cases there was insufficient funding, and in others the children were not recognized as eligible until preschool.

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CHAIR DAVIS asked how the eligible children are supposed to be identified.

MS. RYAN replied that various child-find activities take place, from health fairs to doctor evaluations and child care programs.

MS. ALLELY added that child-find activities, including free basic screening, often take places in busy areas like shopping

mall. However, if the child is not severely delayed they may not be served due to lack of funds.

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CHAIR DAVIS asked if there is a variety of children whose needs are not being met, and what happens to such children once they are identified.

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MS. RYAN replied that these children may be referred to other programs in the community, but such services may not be available. The children with less severe disabilities may be those who would benefit the most from early intervention.

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MS. RYAN said that Infant Learning Program (ILP) grants were reduced 6 percent in the 2006 fiscal year. An increased number of children have been identified with autism. The Individuals with Disabilities Education Act (IDEA) was recently revised and now requires screenings and referrals for children with symptoms resulting from pre-natal drug exposure. A three-site pilot program has resulted in 100 referrals and screenings, 60 of which required a multi-disciplinary evaluation and 17 of which met eligibility, and an additional 3 cases were eligible but would only be served on an available-funds basis.

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MS. RYAN said that the council is working with the Office of Children's Services (OCS) on managing the ILP. They are doing resource mapping of state and federal funds, and are looking at possible partnerships with different agencies. A cost study will be completed by June 30th looking at service delivery costs and other sources of funds. The council will compare its findings with other states' and model alternative financing systems.

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MS. RYAN said the council is looking at ways to maximize Medicaid funds and utilize private insurance to support early intervention. The council had two recommendations for improving early intervention: a \$1 million funding increment from the AMHTA, which the trust supported but which was not included in

the governor's budget, and a legislative task force to study the feasibility of billing private health insurance.

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CHAIR DAVIS asked for clarification on the recommendation from the AMHTA.

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MS. RYAN replied that the recommendation was for the yearly budget and that the funds were not provided by the AMHTA.

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SENATOR ELTON asked if federal government funds were provided for mandated child screenings.

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MS. RYAN replied that there was a small increase in federal funds but it was insufficient. A partnership with the OCS is being explored to help fund the screenings and services.

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MS. RYAN said that one important topic was autism, which some people are calling an epidemic. The council convened a committee on autism in 2005 which created a series of recommendations.

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MS. ALLELY explained that autism is a high-profile disorder. It is classified as a spectrum disease, ranging from mild to severe and it affects social skills, communication, play, and behavior. Peer relationships, spoken language, and gestures are all affected or non-existent.

She continued to explain that autistic children are often preoccupied with certain activities or objects. Autism affects boys four times more often than girls, and while some may characterize it as an epidemic, the increased numbers have much to do with better and broader diagnosis and a wider definition of the condition. Undoubtedly there are unidentified factors that contribute to rising numbers as well.

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MS. ALLELY explained that in the 1970s the incidence of autistic births was 2 to 5 in every 10,000, and now the incidence is 1 per 166.

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SENATOR DYSON asked if the increase in autism occurrence could be due to improved diagnosis.

MS. ALLELY replied that she thought so, and that the broadening of the definition did heighten the numbers of affected people.

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SENATOR DYSON asked how long ago autism was characterized as a disorder.

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MS. ALLELY replied that she was unsure when the disorder was determined.

SENATOR DYSON replied that he thought it would have been in the last 50 or 60 years, and asked if Asperger's syndrome was a mild form of autism.

MS. ALLELY replied that Asperger's syndrome was a high-functioning form of autism.

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MS. ALLELY said that out of 10,000 births in Alaska, 60 children could be expected to be autistic. Other autistic children may be receiving special education services under a different label. She said that there have been many improvements in autism services. Fifteen years ago a pediatrician was recruited to help with diagnosis in Alaska, and a parent navigation program was launched to help families navigate the system of services.

She added that five years ago a summit was held by a group of parents of children with autism, which resulted in a resource center.

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MS. ALLELY explained how the council convened a committee to come up with suggestions for improving services. She would be presenting the top four priorities. The first priority would be expanding resource and referral services to make the Early Intervention program well-funded and independent. The program will receive \$200,000 for 2008 and 2009.

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SENATOR COWDERY asked what long-term services AMHTA provides.

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MS. RYAN replied that if a child is eligible, they may receive services from the Division of Senior Services, which could include living in a group home.

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SENATOR COWDERY asked what employment opportunities there might be for adults or teenagers with autism.

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MS. RYAN replied that an autistic person might receive job training and support.

MS. ALLELY added that AMHTA funding is not available for long-term support.

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MS. ALLELY explained that the second priority would be doing universal screening for autism in children as young as 16-18 months, helped by a checklist that can be completed by parents.

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SENATOR DYSON asked if autism can be somewhat cured or simply treated.

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MS. ALLELY replied that autism is always present, but that with proper treatment some people function without support or special education. Some children's autism can even become unnoticeable. Some medications may aid with related behavioral issues.

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MS. ALLELY said that the third recommendation would be an increased capacity for diagnosis. This would include lab work, cognitive testing, hearing and eye tests, and evaluations of motor development.

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MS. RYAN said that the final recommendation would be to change Medicaid to allow for time-limited intensive intervention services. Such intervention early in the child's life would allow for major improvement over a lifetime. School districts are unable to provide such a level of service. A possibility would be a home and community-based waiver.

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MS. RYAN said that evidence-based interventions show that half of children who receive such treatment go on to function normally after 2-3 years of treatment. There is an average gain of 22 IQ points, and one-third of subjects gained 45 IQ points.

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SENATOR ELTON asked if such services were easier to implement in an urban rather than rural environment.

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MS. ALLELY replied that that was the case, but early screening could be done effectively in a rural setting.

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CHAIR DAVIS asked which services included in the recommendations were currently being fulfilled.

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MS. ALLELY replied that the Autism Resource Center currently provides training and information to families, and the services are good if inadequate. Developmental screening is done broadly, but not specifically for autism.

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MS. RYAN added that she has been talking to Health and Social Services Commissioner Karleen Jackson about integrating an autism screening tool into current services.

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MS. ALLELY said that a clinic was in place in Anchorage for comprehensive assessment; Alaska currently has few intensive treatment models.

MS. RYAN gave an example of one such program that used to exist in Alaska but was discontinued after the professor who conducted it retired.

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CHAIR DAVIS asked for clarification on the suggestion to amend the state Medicaid plan.

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MS. RYAN replied that there were two options for doing so, either using a time-limited waiver program for intensive training, or looking at possible options and flexibility under the current state Medicaid plan.

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CHAIR DAVIS asked which organization or entity would actually present the recommendations to the legislature or appropriate destination to receive proper funding.

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MS. RYAN replied that it would be the Department of Health and Social Services.

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MS. ALLELY explained that the average lifetime cost of a person with autism is \$3.2 million, and assuming there are 60 autistic children born per year, that equals \$192 million. Three years of early intervention for those children would cost \$10 million total, but could save the state \$1.6 to \$2.8 million per person.

She said that her council is advocating a \$500,000 increase for screening and diagnosis funding. There is a need for such a subsidy for the council's clinic to continue operating.

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CHAIR DAVIS asked for the amount of the subsidy currently being provided by Providence Hospital in Anchorage.

MS. ALLELY replied that the subsidy was between \$250,000 and \$350,000 yearly.

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CHAIR DAVIS said that she didn't see how the budgetary issues connected to the Senate Health and Social Services committee in particular.

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MS. RYAN said that the AMHTA recommendation was not included in the governor's budget, but that all agreed it was needed.

CHAIR DAVIS pointed out that the budget is not controlled solely by the governor and thus the recommendation was technically still alive. She said that she appreciated the presentation and wished she could promise more concrete action.

MS. RYAN offered to supply some packets of information about studies done on autism services.

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SENATOR DYSON said that the committee would be participating in the Health caucus the following week and invited the presenters to join the audience at that meeting.

CHAIR DAVIS announced the next week's meeting regarding the longevity bonus, and, seeing no further business, adjourned the Senate Health, Education and Social Services Standing Committee meeting at [2:52:53 PM](#).