ALASKA STATE LEGISLATURE
HOUSE HEALTH, EDUCATION AND SOCIAL SERVICES STANDING COMMITTEE
February 8, 2007
3:07 p.m.

MEMBERS PRESENT

Representative Peggy Wilson, Chair
Representative Bob Roses, Vice Chair
Representative Anna Fairclough
Representative Mark Neuman
Representative Paul Seaton
Representative Berta Gardner

MEMBERS ABSENT

Representative Sharon Cissna

COMMITTEE CALENDAR

PRESENTATION: EARLY INTERVENTION AND AUTISM SERVICES

- HEARD

HOUSE BILL NO. 29
"An Act relating to infants who are safely surrendered by a parent shortly after birth."

- BILL HEARING CANCELED

PREVIOUS COMMITTEE ACTION

No previous committee action to record

WITNESS REGISTER

MILLIE RYAN, Executive Director
Governor’s Council on Disabilities and Special Education
Office of the Commissioner
Department of Health and Social Services
Anchorage, Alaska
POSITION STATEMENT: Presented an overview on early intervention and autism services, and responded to questions.

KATHY FITZGERALD, Chair
Governor’s Council on Disabilities and Special Education
Anchorage, Alaska

POSITION STATEMENT: Presented an overview on early intervention and autism services, and responded to questions.

KATHY ALLELY
Health and Social Services Planner
Governor’s Council on Disabilities and Special Education
Anchorage, Alaska
Department of Health and Social Services
POSITION STATEMENT: Presented an overview on early intervention and autism services, and responded to questions.

ACTION NARRATIVE

CHAIR PEGGY WILSON called the House Health, Education and Social Services Standing Committee meeting to order at 3:07:08 PM. Representatives Wilson, Fairclough, Neuman Seaton, Gardner, and Roses were present at the call to order. Representative Cissna was excused.

PRESENTATION: EARLY INTERVENTION AND AUTISM SERVICES

3:07:24 PM

CHAIR WILSON announced that the only order of business would be a presentation on Early Intervention and Autism Services.

3:09:33 PM

MILLIE RYAN, Executive Director, Governor’s Council on Disabilities and Special Education, Office of the Commissioner, Department of Health and Social Services (DHSS), explained that the Governor's Council on Disabilities and Special Education (Council) consists of 28 members who are appointed by the governor. Sixty percent of the Council's members are persons with disabilities or family members of persons with disabilities; the remaining members are representatives of state agencies, service providers, or university representatives. The Council is not a direct service provider; rather it helps to plan, advise, and assist the state in providing services for those with developmental disabilities and other severe disabilities. She explained that the Council works with various stakeholders and service providers to examine issues, such as autism, and develop recommendations for future state services and allocation of funds.

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MS. RYAN explained that the Council also reports to the Alaska Mental Health Trust Authority (AMHTA) about the status and needs of people with developmental disabilities and makes budget recommendations. The three types of budget recommendations the Council makes to the AMHTA are recommendations for systems change, short-term capacity building projects, and general fund allocations. If accepted by AMHTA, these funding recommendations are forwarded to the governor, who may then choose whether to include the requested items in the budget presented by the governor to the legislature, she said.

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MS. RYAN turned to the PowerPoint titled, "Early Intervention in Alaska", which was provided to the committee. She informed the committee that early intervention provides a "once in a lifetime window" to help those with disabilities develop in a healthy way. Early intervention is a less costly, more successful approach than later intervention, she opined. She then informed the committee that at birth 1-2 percent of infants have discernable disabling conditions, such as spina bifida, Down's syndrome, or cerebral palsy. During the next few years of life, other additional cognitive, emotional, and motor problems become evident. By the time children enter pre-school or kindergarten, 10-12 percent have some degree of disability. The research indicates that some of those children could have been diagnosed and provided early intervention prior to school. Furthermore, for those with less severe delays, receiving early intervention may not have resulted in needing special education or not as much of it.

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MS. RYAN informed the committee that several studies have illustrated the benefit-cost ratio of early intervention. The longest conducted study is the [Lifetime Effects: The High/Scope Perry Preschool Study through Age 40]. She said that when compared to the control group, those who received early intervention required less special education, had less involvement with the law, tended to earn more money [than the control group], and participated more in the community. She noted that there have been several other studies that concluded at "age 21 or so." The "benefit-cost ratio ranges" from $17-$4, she related. The Colorado Intervention Program was a study in which children with disabilities participated in an early intervention program in which the return was $4.00 to $1.00.

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REPRESENTATIVE NEUMAN asked whether the term "benefit-cost ratio" means benefit to society or benefit in economic value to the communities as compared to what the state has invested.

MS. RYAN replied that the term encompasses both societal and economic benefits to the individual. In further response to Representative Neuman, Ms. Ryan indicated that the committee packet should include information regarding how the benefit amount was established. She mentioned that the [Lifetime Effects: The High/Scope Perry Preschool Study through Age 40] utilized economists to develop how to collect and analyze the information.

REPRESENTATIVE NEUMAN expressed the need to have on record the accountability of the figures used.

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CHAIR WILSON stated that last year the committee heard a presentation from an economist who addressed this issue and explained how the numbers are calculated. Last year's speaker explained that early intervention really made a difference in the long run because the study subjects weren't going through the court system, she recalled.

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REPRESENTATIVE SEATON expressed concern with regard to the lack of discussion/information regarding any steps being taken to prevent autism. He related his understanding that lead and one other thing accounts for at least one third of the autism. There has also been recent information, he recalled, regarding the use of sonograms during pregnancy perhaps contributing to autism.

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KATHY FITZGERALD, Chair, Governor’s Council on Disabilities and Special Education, Department of Health and Social Services, responded that autism is a diagnosis that has been late to be recognized or defined. Furthermore, there is a great deal of speculation and controversy within the medical community about what causes autism. Autism tends to run in families and thus there is a genetic component to autism. However, the parameters of the genetic components are not defined. There is still a controversy about what causes autism, therefore the steps to prevent it are not yet clear. This is an issue that is being studied, she told the committee, particularly in view of the [fact] that 1 in 166 people are being diagnosed with autism. However, there is not even consensus within the autism community itself as to how to treat autism. Therefore, if the Council has not brought forward anything on prevention, it is because it really does not have anything to offer in that realm other than that early intervention tends to lessen the [degree] of the condition. "I don't think there's anything out there that's telling us now that we can prevent it, other than perhaps avoiding immunizations that have mercury in them," she said.

MS. RYAN informed the committee that with enactment of "The Combating Autism Act of 2006" at the federal level, there should be a lot more money for research and development of data systems for autism.

CHAIR WILSON commented that many doctors are limiting the use of ultrasound technology during pregnancy and there are efforts to remove mercury from vaccines.

REPRESENTATIVE SEATON related that not all doctors or ultrasound technicians are necessarily aware of the research linking ultrasound use with the increased incidence of autism.

MS. RYAN characterized Representative Seaton's suggestion that the Council provide some literature on the possible linkage between excessive ultrasound use during pregnancy and autism as an excellent suggestion. She mentioned that the Council works closely with the Division of Public Health in terms of prevention activities.

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MS. FITZGERALD emphasized that there is still a great deal to learn about autism and much of the information is passed along in an informal way, such as recommending that parents assure that any vaccines offered their children are indeed free of mercury. However, documented knowledge as to what causes or contributes to autism is minimal at this time and until there is more known, much about autism is speculation, she cautioned.

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MS. RYAN turned to the State Early Intervention/Infant Learning Program (EI/ILP), which in fiscal year 2006 (FY 06) served 1,800 children from birth to age 3, at an average cost of $5,500. Of those served, approximately 14 had a diagnosis of autism. The state provides a mix of services that focus on both the child and the parent. She told the committee that children with a diagnosed condition that will lead to a significant delay, such as Down's Syndrome, severe cerebral palsy, spina bifida, or a developmental delay of 50 percent or greater in one area of development must be served by the EI/ILP under the state and federal guidelines. In contrast, children with a 15-49 percent delay may receive EI/ILP services as funds allow. Alaska has a very restrictive eligibility criteria in comparison to other states, some of which set their eligibility criteria at around 25 percent, while Alaska's is set at around 50 percent. Therefore, many of Alaska's children [in need] aren't being served. Moreover, research indicates that some of those children [not being served] are the ones who would benefit the most from early intervention and be less likely to need special education. She highlighted that preschool special education services must be provided to children with a 25 percent delay in two areas of development. Ms. Ryan, in response to Chair Wilson, related her belief that this restrictive criteria is contained in regulation, not statute.

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MS. FITZGERALD noted that in special education a 25 percent developmental delay is considered very significant and children are screened for it. However, that same population is excluded from infant learning services, which would make a difference.

MS. RYAN clarified that if there is sufficient funding, children with a 25 percent developmental delay can be served.

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MS. RYAN related that in 2005-2006 in the Matanuska-Susitna School District 109 children were determined to be eligible for preschool special education, but were never enrolled in EI/ILPs. Although some of them may not have been identified, some of these children were identified as having delays in the range of 15-49 percent. However, those children didn't receive any services due to lack of funding. These aforementioned children were identified in preschool. Therefore, if children aren't enrolled for preschool, they may not even be identified or receive services until they enter kindergarten at age five.

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MS. RYAN, in response to Representative Neuman, explained that the school district is prepared and has to serve these children under the eligibility [criteria]. The difficulty is that the EI/ILP doesn't have enough funds to serve all potentially eligible children.

MS. FITZGERALD mentioned that Alaska was one of the first states to provide infant learning programs prior to it being a federal [requirement]. The state, she recalled, was cautious when it did so and the thinking was that as the state progressed the [criteria] would be brought down to the 25 percent. However, the state hasn't reached that point.

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MS. RYAN interjected that a number of things are occurring this year. For instance, the EI/ILP grants were reduced by 6 percent as some of the refinancing ideas didn't come to fruition. Furthermore, more children with autism and Fetal Alcohol Spectrum Disorder (FASD) are being served, which places pressure on the existing system. Moreover, the federal directive to increase child find and enrollment places [states] in a bind when they can't really serve those children. Federal law now requires that a child must be referred for early intervention screening when there is a substantiated case of child abuse or neglect or the child is affected by illegal substance abuse or withdrawal symptoms from prenatal drug exposure. The aforementioned merely determines whether the child needs a multi-disciplinary evaluation. The sites of Anchorage, Fairbanks, and Juneau have produced findings from 100 referrals and screenings, as follows: 60 multi-disciplinary evaluations were done, 17 required service, and 3 were eligible but would only be served if funds are available.

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REPRESENTATIVE NEUMAN inquired as to whether the 6 percent reduction in grants were from the federal or state government or a combination thereof.

MS. RYAN specified that there is a mix of federal and state funds that is managed by the Infant Learning Program and the Office of Children Services (OCS). She answered that the reduction was to the state grants. She related her understanding that some financing [possibilities] didn't come to fruition. In further response to Representative Neuman, Ms.

Ryan said she would provide the committee with information regarding how much money the state puts into this program and how much it has been reduced/increased over the last two years.

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MS. RYAN continued her presentation by relating that the Council is working with OCS on ways in which to increase funding for early intervention. In fact, Targeted Case Management through Medicaid was implemented in August 2006 and programs are beginning to bill. Although Medicaid can be billed, the concern, she opined, is that still no more children are being served if the grants continue to decrease. She then informed the committee that intensive resource mapping is occurring at the state and federal level with the assistance of a national technical assistance expert who knows what other states have done. The Council is also reviewing how it can partner, particularly with the child protective side of OCS. She then related that a presentation is scheduled for the EI/ILP providers in regard to developing a broad stroke financing plan both at the state and local level. There will also be a cost study in order to identify the following: costs to deliver services in urban, rural, and remote locations; other sources of funds being used to deliver early intervention; compare findings against other states; and model alternative financing systems and structures.

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CHAIR WILSON asked if the aforementioned cost study will review the cost of not having early intervention.

MS. RYAN said that the Council has the opportunity to influence that.

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REPRESENTATIVE NEUMAN inquired as to how programs such as EI/ILP will be impacted by the [proposed] revamping of the health care system.

CHAIR WILSON reminded the committee that there have been some large changes in health care over the last five years that are just beginning to settle. Therefore, she said that the committee would invite the department to explain how all these changes [and the proposed changes] will fit together.

REPRESENTATIVE NEUMAN related his interest in hearing from the department how individual divisions are impacted.

CHAIR WILSON highlighted that the committee can recommend what it feels is important and pen a letter with those to the department. Chair Wilson opined that there is so much more that can be done for intervention and prevention and it would save money in various areas, including the correctional system, the court system, and the schools.

3:46:26 PM

MS. RYAN continued reviewing promising solutions. She highlighted that the [Council] is reviewing how to maximize Medicaid funds; how other states have maximized the use of private insurance to support early intervention; and how to deliver services through distance technology. Ms. Ryan then moved on to the recommendations, which include the state funding a $1 million increment for EI/ILP. The aforementioned isn't included in the governor's budget, she noted. However, the aforementioned funding would enable the state to serve those children with the less severe delays as well as to better screen, evaluate, and provide services of children who are victims of abuse and neglect. Furthermore, [the funding] would build the capacity of the providers to better serve children with autism and socially emotional problems.

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CHAIR WILSON inquired as to who performs the early intervention screening.

MS. RYAN answered that screenings can come from the hospitals, the visiting nurses, parents, or a health fair.

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REPRESENTATIVE GARDNER inquired as to how the distance learning would work when it seems that many of the interventions, particularly for autism spectrum disorders, are labor intensive one-on-one situations.

MS. RYAN confirmed that parents could be taught to perform the interventions or aides may do so. Ms. Ryan opined that more distance education could be provided.

3:49:19 PM

REPRESENTATIVE FAIRCLOUGH inquired as to the average case load of an individual training those for actual interventions if the $1 million investment actually occurs.

MS. RYAN responded that it would vary because a child may be receiving occupational therapy from an occupational therapist and speech therapy from another individual.

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REPRESENTATIVE FAIRCLOUGH asked, "How can you quantify for me why I should invest $1 million and what does it accomplish?"

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KATHY ALLELY, Health and Social Services Planner, Governor's Council on Disabilities and Special Education, Department of Health and Social Services (DHSS), informed the committee that the average case load is 12-15 families.

MS. RYAN, in further response to Representative Fairclough, related that the average cost is about $5,500. Therefore, dividing the $1 million by the $5,500 would provide an idea as to how many children would be served.

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REPRESENTATIVE FAIRCLOUGH pointed out that there will be fairly significant administrative overhead costs, which is why she was interested in the number of cases that can be addressed over a one-year period with the investment of $1 million. She then asked if the $1 million for FY 08 would be spent in one fiscal year or would there be a ramp-up time such that the $1 million would carry forward longer.

MS. RYAN reminded the committee that there was a $700,000 increment a few years back in which there was no difficulty spending. She said that there are definitely kids in need of services. However, she acknowledged that sometimes there is a shortage of staff, which may slow things.

MS. FITZGERALD related that intensive infant care is one of the areas in which [the Council] has heard from infant learning providers and families that there is a need for in-depth technical assistance to work with infant learning providers and families with regard to the mental health issues of children ages up to age three. Currently, the infrastructure or expertise to provide some of the [in-depth technical assistance] doesn't exist. Therefore, part of the $1 million would provide technical assistance statewide to the existing ILP staff as well as providing services to more children.

MS. RYAN estimated that approximately 100 children would probably be served with the $1 million.

REPRESENTATIVE FAIRCLOUGH related that when someone makes a financial request, she is accustomed to a budget accompanying it.

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MS. RYAN continued her presentation and highlighted the other recommendation, which is for the establishment of a legislative task force to study the feasibility of billing private health insurance in a manner similar to that of New Mexico. Bringing health plans to the table will create a variety options, she opined.

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MS. ALLELY turned to the presentation regarding autism. She related that in Alaska 1 in 166 children develop autism. She then highlighted the slide entitled, "What has been done," which relates what has been done to improve the situation for families and children with autism. The result has been to convene an Ad Hoc Committee on Autism, which met to develop recommendations to present to the legislature and the administration. The Ad Hoc Committee on Autism prioritized what it wanted to work on as follows: screening, identification and diagnosis, and services. The committee formed because although much had been done, there is an urgent need [to bring recommendations to fruition]. Ms. Allely then focused on the top four recommendations. The first recommendation is to expand autism resources and referral services so that the program is well funded, independent, and highly visible. The Alaska Mental Health Trust Authority and the Department of Education and Early Development, she related, have and will continue supporting this goal. This goal is important because parents, stakeholders, and providers need help understanding autism and knowing what to do about it.

MS. ALLELY then turned to the second recommendation, which is the universal screening for autism spectrum disorders. The aforementioned could be accomplished during well-child checkups and would use a Modified - Checklist for Autism in Toddlers (M-CHAT). The checklist, which can be done in a short time and easily scored, consists of 23 questions to be completed by the parent. In response to Chair Wilson, Ms. Allely said that the checklist is quite easy and can be downloaded from the Internet. However, she emphasized that the screening doesn't take the place of a diagnosis, rather it's simply a check to determine if there needs to be an evaluation. In further response to Chair Wilson, Ms. Allely specified that this particular check can be utilized at ages as early as 16-18 months. The prevalence of autism is believed to be rising substantially, and therefore it's important to screen so as not to miss any children.

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MS. ALLELY moved on to the third recommendation, which would increase the capacity for comprehensive, timely assessments and diagnosis using a multidisciplinary team and systematic referral to appropriate services. She explained that the comprehensive assessment is what children would be referred to if a screening exhibited cause for concern. The comprehensive assessment needs to be a multidisciplinary evaluation with a medical provider who specializes in neurodevelopmental aspects of early childhood. Such a medical provider is necessary in order to rule out any medical condition that could be responsible for what's happening to the child.

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CHAIR WILSON inquired as to how many physicians in Alaska can [perform the assessments].

MS. ALLELY replied one.

MS. FITZGERALD interjected that it took a long time to recruit for that one physician.

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MS. ALLELY informed the committee that the other aspects of this type of evaluation and assessment would be cognitive testing that's performed by a psychologist; a speech and language assessment; a fine and gross motor evaluation; and a hearing and vision evaluation.

MS. FITZGERALD related that with her daughter, the lack of response to her name led to hearing tests. She explained that the combination of symptoms makes it difficult to identify autism as other potential causes have to be ruled out. Therefore, a multidisciplinary team is necessary.

MS. ALLELY opined that one of the benefits of an evaluation is determining the appropriate intervention for the diagnosis. Furthermore, the evaluation identifies the child's strengths and weaknesses in order to build on the strengths.

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MS. ALLELY moved on to the fourth recommendation, which is to change Medicaid to ensure that children with autism spectrum disorders are able to receive time-limited, intensive intervention services. The aforementioned could be accomplished by applying for an autism home and community-based waiver; amending the state Medicaid Plan such that "it's a service that's offered under straight Medicaid." She mentioned that earlier this week she learned that the "11(15)(a)" waiver might provide a way in which the state could [provide] services for children. However, the services are time-limited because there is an early window of opportunity during which the child's development can be influenced. Offering such to families with autistic children for a three-year period would make an enormous difference.

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MS. ALLELY then directed the committee's attention to a study based in Wisconsin, which is included in the committee packet. This study replicated one of the earliest studies performed on autism and reviewed the specific intervention of applied-behavioral analysis. That Wisconsin study was able to replicate the findings of the original study and found that about half of the children gained normal functioning after two to three years of treatment. Furthermore, an average of 22 IQ points were gained, but one-third of the subjects made gains of 45 IQ points.

MS. ALLELY summarized that basically the Council wants to surround families as well as providers with resources, referral, and parent support. Ms. Allely characterized this as a package of recommendations because offering screening without an assessment leaves families in a difficult situation. Likewise, when a parent learns that his/her child has autism and that treatment is available, but it's not made available to families it's similar to telling an individual with diabetes that he/she can't have insulin. This package of recommendations provides savings to the state and heartache for the families and children.

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MS. FITZGERALD added that another piece is that [autistic] children are ostracized in the public due to the lack of information and education available, which serves to isolate families. Therefore, early intervention and support impacts the entire family. She provided a personal anecdote as a parent of an autistic child.

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MS. ALLELY related that some recent studies indicate that on average it costs approximately $3.2 million over the life of an autistic child. Therefore, with 60 births of autistic children in the state, there's a cumulative annual cost of $192 million. However, intervention provides a savings of $1.6-$2.8 million per person, which is a substantial savings to the state. Therefore, [the Council] is requesting a $500,000 increment for increasing the ability to perform screening and diagnosis. She reminded the committee that there's only one medical provider in the state. The clinic [with that medical provider] has found it difficult to have a psychologist because it's not a service billable under Medicaid unless that psychologist is working under a supervising psychiatrist or is practicing as part of a mental health center. However, those individuals don't necessarily have the training in diagnosing autism in a two-year old child. Therefore, this increment would help fund those essential psychology evaluations to confirm a diagnosis of autism. This increment would also support family care coordination and an infrastructure for scheduling, clerical, and medical records.

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MS. ALLELY highlighted that across the country there are no neurodevelopmental centers or clinics that operate without a subsidy of some sort. The reason, she related, is because it's a very time-intensive evaluation that includes review of all of the child's medical, developmental, and testing records. Providence Hospital has been supporting and subsidizing the neurodevelopmental clinic. However, this year Providence announced that it would either severely cut back the services provided by the clinic or close it. A number of concerned individuals pulled together a number of stakeholders and asked them to reconsider and make changes in the clinic and its funding mechanisms and billing of Medicaid. The aforementioned seems to be working, she opined. She related that part of the plan is to build in a lower level pediatric nurse practitioner who can perform some of the evaluations and not cost as much as having a neurodevelopmental pediatrician. An additional medical provider offers the ability to increase screening and diagnosis.

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MS. RYAN corrected her earlier response by saying that the $1 million funding level could provide service to about 150-160 children, depending upon the degree of the disability or delay of the child.

4:14:21 PM

CHAIR WILSON, in regard to obtaining funding, asked if autistic children are categorized as mentally ill.

MS. FITZGERALD said that initially autistic children were viewed as having a mental/psychiatric disorder. However, in the last 20 years that has been reversed and autism is identified as a neurological, physical, and sensory disease. Still, autistic individuals can be diagnosed with mental disorders as well. In further response to Chair Wilson, Ms. Fitzgerald noted that autistic children have qualified for services under a mental health diagnosis in order to receive [AMHTA] funds. However, the concern is in regard to whether the proper treatment is administered and that the child would then have a diagnosis/label that would follow him/her to school.

4:17:07 PM

REPRESENTATIVE GARDNER returned to the earlier information that 60 births per year are autistic children and the average cost of care for such an individual over a lifetime is about $3.2 million. Therefore, the cost to care for an individual who lives to be 60 years of age would be roughly $58,000 per year. Since individuals aren't receiving that level of service, she inquired as to what the $3.2 million consists of.

MS. ALLELY called attention to the spreadsheet in the committee packet, labeled "Table 20.1 Per Capita Lifetime and Total Annual Costs of Caring for Individuals with Autism in the U.S. (in 2003 dollars)." The spreadsheet reviews the cost of a low level disability and high level disability and the services that such an individual would have over his/her lifetime as well as the individual and his/her parents' lost productivity. She then mentioned that committee members could view a short video on the Internet entitled, "Autism Everyday" in which she was struck with regard to the financial impact to the families with autistic members.

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CHAIR WILSON requested that copies of the Council's report that will be completed in June be made available to the committee.

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MS. FITZGERALD related her personal experience with her daughter who had a three-second attention span and for whom she couldn't find daycare. Therefore, she had to quit her job to care for her daughter, which meant that the family had to make sacrifices. Only once the family was fortunate enough to be selected for a waiver was she able to go to work, she said. One result of the situation, she related, is that she doesn't have retirement. The reality is that the financial and emotional costs to raise a child with significant disabilities are astronomical. Furthermore, it's difficult for parents to ensure that a child with significant disabilities is as independent as possible in the future. Parents are under much pressure to obtain the services that will make a difference for their child.

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CHAIR WILSON inquired as to the divorce rate related to the stresses caused in families with a child with significant disabilities.

MS. FITZGERALD offered to find that statistic and provide it to the committee. She related that with her daughter the family endured at least three years of sleepless nights in which she and her husband spelled each other every three hours in order to ensure that their daughter didn't wake and hurt herself. Many families experience these issues and the family either becomes really strong or dissolves quickly.

4:24:24 PM

REPRESENTATIVE FAIRCLOUGH asked if the average life expectancy of an individual with autism is different than of the typical individual.

MS. FITZGERALD answered that she didn't believe that at this point one could predict that children with autism will have a shorter life expectancy. However, it is known that children with autism experience more stress, which may or may not cause other health problems. At this point, Ms. Fitzgerald said she expected her daughter to have a fairly typical life span.

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REPRESENTATIVE FAIRCLOUGH asked if a child with autism who has a language barrier would have additional health issues that wouldn't surface until later because of the language problems. She suggested that the lack of diagnosis [of other health issues] may place them at a disproportionate disadvantage for health care.

MS. FITZGERALD related that it isn't uncommon for individuals with autism to die from an appendicitis because they couldn't express any symptoms. Furthermore, individuals with autism typically have a higher tolerance for pain. She noted that across the spectrum of autism there are children with very little functional language. She further related the difficulty in these children accurately relating what they are experiencing. In response to Chair Wilson, Ms. Fitzgerald explained that her daughter, as do many others with autism, has a repertoire of things that mean something to him/her or the family. As one is around and/or works with an individual with autism, he/she needs to become familiar with and interpret the repertoire of things the autistic individual does.

REPRESENTATIVE ROSES referred to the M-CHAT survey that was mentioned earlier, and asked how it's typically distributed.

MS. ALLELY explained that it really isn't being distributed, although it's possible that some of the ILPs are using it. Ms. Allely opined that the M-CHAT isn't incorporated widely into well-child checkups at this point. Therefore, a strong public awareness effort would be required to pass the word to physicians and other medical providers to utilize the M-CHAT. Furthermore, it would be great if other developmental screening was performed at the same time.

AN UNIDENTIFIED SPEAKER related that the Southeast Alaska Regional Health Consortium (SEARHC) is using the M-CHAT.

REPRESENTATIVE ROSES opined that the M-CHAT is a fairly simple form that would be required to be utilized by those [providing medical care] to a child under a certain age. He emphasized that it seems appropriate to require the use of the M-CHAT for anyone receiving care from Medicare or through any state agencies, any things over which the state has control over the requirements for being paid.

4:31:28 PM

MS. ALLELY said that such could be done and hopefully it will. These recommendations have just come out and the work begins to get them through. The screening, M-CHAT, shouldn't require a lot of money to implement, but rather is more of a public awareness piece, she said. She related that [the Council] has spoken with the commissioner of DHSS regarding the M-CHAT. There are also other avenues, such as the "All-Alaska Pediatric Partnerships of the Alaska Chapter of the American Academy of Pediatrics" through which this recommendation can be promoted. Moreover, the recommendation can be promoted through the Division of Public Health.

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CHAIR WILSON commented that public service announcements (PSAs) could be utilized to get the word out. She expressed hope that the Council is garnering ideas during its visit to the capital to continue the process.

4:33:14 PM

REPRESENTATIVE ROSES clarified that his approach would be that part of the mandatory requirements for [services tied to state funding] would be the inclusion of the M-CHAT.

4:33:49 PM

REPRESENTATIVE GARDNER remarked that performing a checklist during well-child visits may not be novel as that seems to already occur. The question is, she opined, what happens when the responses aren't standard or what is expected. Representative Gardner further opined that there's no point in requiring these screenings if nothing is offered [to serve those with nonstandard responses].

4:34:33 PM

MS. ALLELY, in response to Chair Wilson, explained that the child fails [the M-CHAT] when two or more of the six critical items are failed or any three items are failed.

4:35:24 PM

REPRESENTATIVE FAIRCLOUGH emphasized the importance of taking a more holistic approach with regard to what physicians ask. She highlighted that there isn't a medical professional on the Council to help standardize the [M-CHAT] in order to help physician's self-identify. The medical community, she said, must be brought into the fold with regard to developing solutions for early intervention. Perhaps, the funding should go toward paying for the involvement of a medical professional. She provided some ideas of how to acquire a higher preponderance of evidence when qualifying individuals for the exam. Representative Fairclough opined that there needs to be review of an overall means to providing early intervention for various issues versus taking up each individual issue.

4:41:14 PM

CHAIR WILSON called for the committee members to be more proactive in regard to recommendations. Early intervention, she emphasized, is definitely important and needs to be addressed.

4:42:34 PM

REPRESENTATIVE FAIRCLOUGH mentioned the need to provide the criteria utilized to arrive at the $17.00 [to $1 benefit-cost ratio] and the need for early intervention.

MS. RYAN indicated that articles in the committee packet provide that information.

4:45:19 PM

ADJOURNMENT

There being no further business before the committee, the House Health, Education and Social Services Standing Committee meeting was adjourned at 4:45:29 PM.