ALASKA STATE LEGISLATURE
HOUSE HEALTH, EDUCATION AND SOCIAL SERVICES STANDING COMMITTEE
January 31, 2006
3:06 p.m.

MEMBERS PRESENT

Representative Peggy Wilson, Chair
Representative Paul Seaton, Vice Chair
Representative Vic Kohring
Representative Sharon Cissna
Representative Berta Gardner

MEMBERS ABSENT

Representative Tom Anderson
Representative Carl Gatto

COMMITTEE CALENDAR

HOUSE BILL NO. 357
"An Act updating the terminology in statutes for persons with disabilities; and providing for an effective date."

- MOVED CSHB 357(HES) OUT OF COMMITTEE

HOUSE BILL NO. 312
"An Act relating to pregnant women; requiring hospitals, schools, and alcohol licensees and permittees to distribute information about fetal alcohol effects and fetal alcohol syndrome; relating to the consumption of alcoholic beverages by and the sale or service of alcoholic beverages to a pregnant woman; requiring involuntary commitment of a pregnant woman who has consumed alcohol; creating a fund for the prevention and treatment of fetal alcohol syndrome and fetal alcohol effects; relating to fines and to the taking of permanent fund dividends for selling or serving alcoholic beverages to pregnant women; and increasing taxes on sales of alcoholic beverages to fund treatment and education related to fetal alcohol syndrome and fetal alcohol effects."

- HEARD AND HELD

PREVIOUS COMMITTEE ACTION

BILL: HB 357
SHORT TITLE: STATUTORY REFERENCES TO DISABILITIES

SPONSOR(s): REPRESENTATIVE(s) WILSON

01/11/06	(H)	READ THE FIRST TIME - REFERRALS
01/11/06	(H)	HES, FIN
01/24/06	(H)	HES AT 3:00 PM CAPITOL 106
01/24/06	(H)	Heard & Held
01/24/06	(H)	MINUTE(HES)
01/31/06	(H)	HES AT 3:00 PM CAPITOL 106

BILL: HB 312
SHORT TITLE: FETAL ALCOHOL SYNDROME/EFFECTS PREVENTION
SPONSOR(s): REPRESENTATIVE(s) WEYHRAUCH

01/09/06	(H)	PREFILE RELEASED 12/30/05
01/09/06	(H)	READ THE FIRST TIME - REFERRALS
01/09/06	(H)	HES, JUD, FIN
01/31/06	(H)	HES AT 3:00 PM CAPITOL 106

WITNESS REGISTER

AARON DANIELSON, Intern
for Representative Wilson
Alaska State Legislature
Juneau, Alaska
POSITION STATEMENT: Presented HB 357 and CSHB 357, Version G, on behalf of Representative Wilson, sponsor.

BILL HOGAN, Deputy Commissioner
Office of the Commissioner
Department of Health and Social Services (DHSS)
Juneau, Alaska
POSITION STATEMENT: During hearing on HB 357, answered questions and offered information on HB 312.

JACQUELINE TUPOU, Staff
to Representative Bruce Weyhrauch
Alaska State Legislature
Juneau, Alaska
POSITION STATEMENT: Presented HB 312 on behalf of Representative Weyhrauch, sponsor.

REPRESENTATIVE BRUCE WEYHRAUCH
Alaska State Legislature
Juneau, Alaska
POSITION STATEMENT: Testified as prime sponsor of HB 312.

MARGARET VOLZ, Pediatric Nurse Practitioner

The Children's Place;
Volunteer Medical Provider
Fetal Alcohol Spectrum Disorders (FASD)
Matsu Diagnostic Team
Wasilla, Alaska
POSITION STATEMENT: Testified on HB 312.

STEPHANIE BIRCH, Section Chief
Women & Children, Family Health
Division of Public Health (DPH)
Department of Health & Social Services (DHSS)
POSITION STATEMENT: Testified on HB 312.

LAURA ROREM, Parent Navigator
Fetal Alcohol Spectrum Disorders (FASD)
Juneau Diagnostic Team
Juneau, Alaska
POSITION STATEMENT: Testified in support of HB 312.

LARRY ROREM, Pastor
Shepard of the Valley Lutheran Church
Juneau, Alaska
POSITION STATEMENT: Testified in support of HB 312.

DR. TOM NIGHSWONDER, Medical Director
Fetal Alcohol Spectrum Disorders (AFASD) - Alaska Program
Juneau, Alaska
POSITION STATEMENT: Testified on HB 312.

DALE FOX, Executive Director
Cabaret Hotel Restaurant & Retailer's Association (CHARR)
Anchorage, Alaska
POSITION STATEMENT: Stated concerns for HB 312 and testified in support of the Committee Substitute (CS), Version Y.

CONNIE MORGAN, Program Coordinator
Covenant House Alaska Crisis Center
Anchorage, Alaska
POSITION STATEMENT: Her testimony on HB 312 was read by Patricia Senner.

PATRICIA SENNER, Nurse Practitioner
Covenant House Alaska Crisis Center
Anchorage, Alaska
POSITION STATEMENT: Answered questions on behalf of Connie Morgan's testimony on HB 312.

HEATHER AMY SCOTT
Anchorage, Alaska
POSITION STATEMENT: Her testimony on HB 312 was read by Cheryl Scott.

CHERYL SCOTT, Parent Navigator
Training Coordinator
Stone Soup Group
Anchorage, Alaska
POSITION STATEMENT: Testified on HB 312.

MICHAEL BALDWIN, Mental Health Clinician;
Fetal Alcohol Spectrum Disorders (FASD)
MatSu Diagnostic
Anchorage, Alaska
POSITION STATEMENT: Testified on HB 312.

DIANE CASTO, Section Manager
Prevention and Early Intervention Section
Division of Behavioral Health (DBH)
Department of Health and Social Services (DHSS)
Juneau, Alaska
POSITION STATEMENT: Testified on HB 312.

ACTION NARRATIVE

CHAIR PEGGY WILSON called the House Health, Education and Social Services Standing Committee meeting to order at 3:06:26 PM. Representatives Wilson, Seaton, Kohring, Gardner, and Cissna were present at the call to order.

HB 357-STATUTORY REFERENCES TO DISABILITIES

3:06:38 PM

CHAIR WILSON announced that the first order of business would be HOUSE BILL NO. 357, "An Act updating the terminology in statutes for persons with disabilities; and providing for an effective date."

AARON DANIELSON, Intern for Representative Wilson, Alaska State Legislature, reminded the committee that Representative Wilson introduced HB 357 on behalf of the disabled community and the Department of Labor & Workforce Development (DLWD). The legislation modifies several existing statutes by replacing the term "handicapped" with "person with a disability." In lieu of the amendment discussed at the last hearing on HB 357, the

sponsor has provided a committee substitute (CS), he pointed out.

3:09:16 PM

REPRESENTATIVE GARDNER moved to adopt CSHB 357, Version 24-LS1407\G, Bannister, 1/30/06, as the working document. There being no objection, Version G was before the committee.

CHAIR WILSON explained that Version G encompasses the changes discussed last week. On page 2, line 3, the language "**students who are deaf**" was inserted. On page 13, lines 6-7, the language "**persons with developmental disabilities**, **persons who are**" replaces the language "the developmentally disabled, the". On page 3, lines 9-10, the language "**persons with mental illness, persons with physical disabilities**" replaces the language "the mentally ill, the physically handicapped". On page 2, line 11, the language "**persons with substance abuse disorders**" replaces the language "alcoholic and drug addicts". On page 17, line 27, of HB 357 the language "**disabled**" was replaced with "**impaired**".

REPRESENTATIVE SEATON turned attention to page 2, lines 5-6, and asked if the language "health-impaired **in other ways**" is a catchall. He expressed the need to be sure that there is no designation that could mean that someone who is merely ill could be categorized as health-impaired. He asked if the aforementioned language on page 2, lines 5-6, would qualify ill individuals for special education services meant for persons with disabilities.

CHAIR WILSON opined that although the wordage was changed, the meaning was not.

3:15:40 PM

BILL HOGAN, Deputy Commissioner, Office of the Commissioner, Department of Health and Social Services (DHSS), explained that usually a medical condition doesn't qualify an individual for special education services. Typically, the medical condition as well as a functional impairment qualifies an individual for special education services. In response to Representative Seaton, Mr. Hogan said that's how he would read this language.

REPRESENTATIVE SEATON moved to report CSHB 357, Version 24-LS1407\G, Bannister, 1/30/06, out of committee with individual recommendations and the accompanying fiscal notes. There being

no objection, CSHB 357(HES) was reported from the House Health, Education and Social Services Standing Committee.

HB 312-FETAL ALCOHOL SYNDROME/EFFECTS PREVENTION

CHAIR WILSON announced that the final order of business would be HOUSE BILL NO. 312, "An Act relating to pregnant women; requiring hospitals, schools, and alcohol licensees and permittees to distribute information about fetal alcohol effects and fetal alcohol syndrome; relating to the consumption of alcoholic beverages by and the sale or service of alcoholic beverages to a pregnant woman; requiring involuntary commitment of a pregnant woman who has consumed alcohol; creating a fund for the prevention and treatment of fetal alcohol syndrome and fetal alcohol effects; relating to fines and to the taking of permanent fund dividends for selling or serving alcoholic beverages to pregnant women; and increasing taxes on sales of alcoholic beverages to fund treatment and education related to fetal alcohol syndrome and fetal alcohol effects."

3:17:13 PM

JACQUELINE TUPOU, Staff to Representative Bruce Weyhrauch, Alaska State Legislature, presented HB 312 on behalf of Representative Weyhrauch, sponsor, paraphrasing from the following written statement [original punctuation provided]:

> Fetal Alcohol Spectrum Disorders [FASD] are a scourge to our society and 100% preventable. FASDs are the most common cause of mental retardation in Alaska's children, causing permanent birth defects, retarding brain function, arrested emotional and physical development, causing poor behavior, deformed facial features, and harming learning and sleeping patterns. It is deplorable that Alaska ranks first in the United States for the highest number of children born with FASD.
>
> Each child born in Alaska with FASD costs millions of dollars over the life of that child. A 2005 study conducted by the McDowell Group estimates the total lifetime costs for providing services to an individual with FAS are estimated at $3.1 million. This drain on limited funds covers special education services or assistance for health services, and juvenile and adult justice costs. Eliminating FASD in children born in Alaska is in the best interests of the public.

House Bill 312 requires a newborn to be screened for alcohol exposure. This is an important piece of information that can lead to an early diagnosis. Early diagnosis reduces the risk of problems in life associated with FASD, including troubles at school, with substance abuse and with the law.

Additionally, this legislation also mandates an aggressive public education campaign. It requires hospitals and schools to distribute information on preventing FASD, and tasks the State Department of Education with developing the materials and sponsoring a public education campaign on FASD.

Fetal Alcohol Spectrum Disorders are a problem of massive proportion to our state. FASD affects those who suffer from it, their families and love ones, communities and our state as a whole physically, emotionally, and financially. I offer House Bill 312 as a step towards the goal of eradicating this plague that causes such sorrow and aguish for our Alaskan children.

3:19:54 PM

REPRESENTATIVE BRUCE WEYHRAUCH, Alaska State Legislature, testifying as sponsor of HB 312, provided a history of the bill and the provisions previously considered in its purview. Although it was not entirely supported by the legislature, as originally presented, the bill has been redrafted to a more workable scope focusing on public education, early screening for FASD, and the appropriate disclosure of a child's prenatal records, he said.

3:22:10 PM

REPRESENTATIVE WEYHRAUCH stated that evidence indicates the importance of providing adoptive parents with applicable information of the child's exposure to alcohol in the womb. Also, early screening and diagnostic measures are being focused on across the nation, and similar programs should be implemented in Alaska. He maintained that providing parents an opportunity for early detection, treatment, and support of FASD children is paramount.

REPRESENTATIVE CISSNA inquired as to the possibility of incorporating additional funding with the educational fiscal note to encompass treatment programs for at risk women. Also, she suggested that FASD diagnosis at birth is difficult and not necessarily conclusive and thus perhaps not the best time to conduct this test.

REPRESENTATIVE WEYHRAUCH responded that if the state would like to incorporate additional funding to include alcohol treatment programs for mothers, the scope of the bill could be broadened. Currently, the bill is drafted to focus on FASD.

3:26:09 PM

REPRESENTATIVE CISSNA underscored the need to provide programs for expectant alcoholic mothers. She related her understanding that some expectant women who try to enter state alcohol treatment programs are denied access due to space availability. Therefore, she suggested that pregnant women be offered a priority status.

3:26:56 PM

REPRESENTATIVE GARDNER reiterated Representative Cissna's concerns regarding the viability of obtaining conclusive test results on newborns who do not present physical symptoms of FASD.

MS. TUPOU directed the committee's attention to the form in the committee packet titled "Alcohol Exposure Screening Test: Newborns," introducing it as an example of what could be used to diagnose an infant or to provide benchmark data for future diagnosis. Meconium testing will also give the doctors an indication of FASD, although it's not an absolute diagnosis. This benchmark information would be helpful throughout the life of the child, who may otherwise be misdiagnosed and not receive appropriate support for his/her condition.

3:30:04 PM

CHAIR WILSON pointed out that meconium testing does not indicate the level of drinking that has occurred, nor are the mothers always forthcoming in interviews about their alcohol usage during pregnancy. She commented that, without a means to accurately diagnose, some of the FASD symptoms are not evident until the child attends school where behavioral, social, and learning issues manifest. The bill analysis indicates that the

percentage of children diagnosed at birth is minimal compared to diagnosis at a later age, and in reviewing the three-page sample screening form provided, she opined that it would be difficult to answer the questions accurately for a newborn.

3:32:34 PM

REPRESENTATIVE SEATON asked for clarification as to how the language on page 1 line 8, and page 2, line 14, regarding testing of the newborn, relates to the screening form test questions.

MS. TUPOU explained that the screening form provides data that may assist in later analysis. She pointed out that diagnosis of FASD is not an accurate science, but an evolving technology. The bill contains permissive language to allow for the best and most appropriate medical mechanisms to be implemented for FASD detection.

3:34:48 PM

REPRESENTATIVE SEATON expressed concern that page 2, line 13, requires that whomever attends "a newborn child shall cause the child to be tested," which is followed by the consequence on page 2, line 25, that the attendant "who violates this section is guilty of a misdemeanor ... punishable by a fine of ... $500." With the possibility of becoming a felon, he stressed the need to clarify exactly what the attendant to a birth will be instituting.

3:35:41 PM

MS. TUPOU called the committee's attention to the language on page 2, line 17, which read: "The department shall adopt regulations regarding the method used and the time or times of testing as accepted medical practice indicates". The aforementioned language allows the department to determine and adopt into regulation appropriate screening or testing measures.

CHAIR WILSON underscored that there is not a diagnostic test, at this time, which can entirely determine the various aspects of FASD.

3:37:30 PM

MARGARET VOLZ, Pediatric Nurse Practitioner, The Children's Place; Volunteer Medical Provider, Fetal Alcohol Spectrum

Disorders (FASD), MatSu Diagnostic Team, emphasized that there is not a newborn screening test for FASD, thus it is important to have prenatal exposure information available for determining risk assessments on children beginning at three years of age. With that in mind, she recommended that the bill include language to ensure that medical providers document this vital, prenatal information, stressing that for children to receive services they must have a diagnosis, and this critical prenatal information is often not contained in their files.

CHAIR WILSON reminded Ms. Volz that standard questions are asked routinely during prenatal visits, and suggested that the pertinent information is perhaps available but isn't being disseminated.

3:40:04 PM

MS. VOLZ pointed out that in the newborn record, prenatal information may be available, and if it indicates a history of alcohol use, availability of that documentation is important for the future diagnosis of FASD. In answer to a question, she agreed that FASD cannot accurately be tested for at birth, but that the discovery of prenatal exposure via screening methods would be accurate.

3:41:47 PM

STEPHANIE BIRCH, Section Chief, Women & Children, Family Health, Division of Public Health (DPH), Department of Health & Social Services (DHSS), echoed Ms. Volz's testimony regarding the inability to reliably test a newborn for determining when alcohol consumption occurred, or the quantities ingested, which is of vital importance to determine the possibility of FASD. She explained that the reason for the two fiscal notes attached from DPH is to support the collection of this critical data and for its analysis to determine the effectiveness of programs initiated for the prevention of FASD. In response to a question, she agreed that regular prenatal visits do provide for standard questioning. However, drawing from her experience, she related that women who are heavy users of alcohol typically do not avail themselves of early prenatal care and tend to come for medical care when they are in labor. Analyzing why these women drink would be the core issue, and she echoed Representative Cissna's thrust for addressing the situation from a proactive preventative program approach.

3:46:25 PM

CHAIR WILSON pointed out that often women who are heavy drinkers do not eat well and thus deplete their systems. Furthermore, they may not even realize that they are pregnant.

3:46:52 PM

REPRESENTATIVE SEATON asked Ms. Birch to provide her opinion on the language of the bill that requires FASD screening to be performed by the attendant of the birth.

MS. BIRCH opined that if the FASD screening required is a biochemical method utilizing urine/blood/meconium measures, she would not consider it to be particularly helpful. A history taking at the time of delivery is helpful, but would not need to be mandated, as it is already the standard of care. She offered that in order to test a child accurately for FASD, four or five providers often require multiple appointments, and explained that newborns do not have a mature enough neural system to display detectable indicators for an accurate diagnosis.

3:49:52 PM

CHAIR WILSON paraphrased from the Bill Analysis, 1/31/06, page 2, paragraph 2 and page 3, paragraph 1, which read respectively:

> Unless a newborn has been severely impacted by maternal alcohol consumption, few signs of disability will be visible at birth. Age three is about the earliest a full diagnosis can occur ... ."; "The average age of diagnosis at this time is ten years of age and we would like to see children being diagnosed earlier (by age six is recommended) ....

CHAIR WILSON asked for an opinion on the bill language that refers to the testing of infants.

MS. BIRCH opined that the bill would be improved by removing the requirement for infant testing.

3:51:00 PM

LAURA ROREM, Parent Navigator, Fetal Alcohol Spectrum Disorders (FASD), Juneau Diagnostic Team, stated support of HB 312 as a safety net for adoptive parents. Explaining that she is the mother of two FASD adult children who were presented to her and her husband as healthy newborns, she described the difficulty of

rearing them without the benefit of an accurate diagnosis until they were young adults. She maintained that early detection would have been extremely helpful as parents and for the school district; however, the difficulties of parenting adult FASD children continue. She related her efforts to protect her unborn grandson when her FASD, alcoholic daughter became pregnant. She related that her daughter repeatedly denied her alcohol use, when the prenatal doctor made the standard inquiries. In conclusion, Ms. Rorem advocated for early intervention, diagnosis, and disclosure.

3:58:16 PM

LARRY ROREM, Pastor, Shepard of the Valley Lutheran Church, stressed that inappropriate services create costs to society, as families work to cope with, and suffer through, the reality and intensities of raising FASD children, and supporting them as adults.

3:59:23 PM

REPRESENTATIVE CISSNA asked Mr. & Ms. Rorem whether they thought that their daughter would have entered an available treatment program.

MS. ROREM opined that she would not have utilized a program.

MR. ROREM interjected that their daughter considers herself to be self-sufficient and does not willingly seek help from anyone.

4:01:38 PM

REPRESENTATIVE GARDNER pointed out that part of the thrust of this bill is to identify individuals who will utilize available services. She inquired as to what services Mr. & Ms. Rorem would deem helpful and useful.

4:02:35 PM

MS. ROREM said that, provided an early diagnosis, her children might have qualified for special education, and benefited from a level of understanding from the school district to help them finish their schooling. She explained that today it is an on-going effort to keep them out of jail.

MR. ROREM echoed the need for public education to help society understand and learn to accommodate the FASD afflicted individuals while supporting the parents.

4:04:45 PM

REPRESENTATIVE GARDNER highlighted that in the end they are individuals who have permanent brain damage.

MS. ROREM opined that they still don't belong in jail or deserve the treatment they receive in society today. She expressed concern for the future of her children as adults.

DR. TOM NIGHSWONDER, Medical Director, Fetal Alcohol Spectrum Disorders (FASD) - Alaska Program, explained that the FASD diagnosis was not established until 1972 and at that time the disorder was first described based primarily on facial features, which only about 10 percent of FASD sufferers actually display. Since that time the full scope of the condition has been studied and better understood as a syndrome which encompasses a range of symptoms that are "underneath the water ... called alcohol-related birth defects." He said that one of the most difficult FASD characteristics to deal with is the inability of the afflicted to learn from experience, as evidenced through the manifestation of a myriad of disruptive behaviors and inappropriate actions. He stressed that early diagnosis is very important to minimize the presentation of what are termed "secondary disabilities." However, he pointed out, that the earliest possible age for an accurate test is about age three. He counseled that the birth screening and tests described in the bill would prove costly and be of little value, but maintained that an accurate, prenatal history is critical albeit hard to obtain. Further, he stated that Alaska's typical FASD child will be in foster care until age 18 and then graduate directly into the juvenile justice system, and he opined that state jails are possibly housing an excessive number of undiagnosed FASD adults.

4:12:41 PM

DR. NIGHSWONDER, emphasizing the tragedy and costly life-long endeavor that an FASD birth represents, said "Anything we can do to beef up the prevention and keep pushing it is very useful." The Alaska Native Tribal Health Consortium (ANTHC) and Southcentral Foundation operate Dena A Coy, a successful residential program for alcoholic mothers. He emphasized that this is small facility is the only one of its kind, has 20 beds,

and only serves Alaskan Natives. He mentioned that Senator Fred Dyson has suggested a registry of all pregnant women who are drinking. In response to a question, he confirmed that Dena A Coy houses pregnant mothers with their other children, and reiterated that it is the only residential program in the state. He said that although there are other alcohol treatment programs in the state that serve a broader spectrum of needs, additional resources targeted for expectant, alcoholic mothers are necessary. He acknowledged that public education about FASD has been expanded, but questioned whether it's reaching the right audience.

4:17:23 PM

DALE FOX, Executive Director, Cabaret Hotel Restaurant & Retailer's Association (CHARR), stated that the concerns originally held by the hospitality industry for HB 312 have been addressed in the committee substitute (CS). He reported that his organization supports: funding extensive education, continuation of the programs for public service announcements (PSA's), and a program analysis to establish whether the target market is being reached. He said that the lack of treatment programs for pregnant women, or treatment that comes too late, are the critical areas. He then emphasized the need for funds to assist people in getting clean and sober. He stated:

> Alcohol in this state is taxed at five to six times the national average. We don't have programs that are five to six times the national average that we ought to have. ... There's plenty of tax money going into the till to ... do the education, to do the treatment, that's the will of the legislature to spend it ... appropriately to prevent this terrible problem that we think needs your attention.

4:20:53 PM

CONNIE MORGAN, Program Coordinator, Covenant House Alaska Crisis Center, testimony was read by Patricia Senner [original punctuation, spelling, and grammar provided]:

> My name is Connie Morgan and I am the Program Coordinator for Covenant House Alaska's Crisis Center. Covenant House Alaska serves over 2,500 homeless and at risk teenagers a year, and the Crisis Center houses over 600 youth a year.

In recent years we have become aware that as many as 60% of the youth we serve at the Crisis Center are affected by FASD. The majority of these youth have never received a formal diagnosis in spite of the fact that many of them have had difficulties in school, have been in foster care, or have been served by the juvenile justice system. There is no one in Anchorage who will diagnosis a teenager affected by FASD.

The youth we serve who are affected by FASD are our most challenging youth to work with. We have found that these individuals have the following service needs:

Education - Most of these youth do not do well in school and frequently drop out at a young age. Most of these youth can read and do basic arithmetic and can advance with individual instruction. It never ceases to amaze us that many of these youth have not had IQ [intelligence quotient] tests in spite of years of struggling in the school system.

Employment - Many of these youth are able to find a job, but are unable to maintain it due to difficulties following instruction, difficulties multi-tasking, and most of all, difficulties knowing how to get along with employers and employees. Inability to problem solve is one of the main weaknesses of youth affected by FASD, and this translates into them having a short fuse and inability to read social situations.

Housing - Since these youth have difficulties maintaining employment they have difficulty paying for housing. Many of them couch surf, living with a friend who has an apartment or hotel room.

Keeping Appointments - One of the hallmarks of an individual affected by FASD is there inability to keep track of time. Keeping appointments that are scheduled weeks or months in the future are next to impossible. Because these youth can not keep appointments they are frequently discharge or fired by agencies and medical providers. It is ironic that the youth most in need of these services are being denied services because of their disability.

> One adoptive mother stated that people with FASD need life-long external brains. We couldn't agree more! We serve youth up to age 21, but sadly after that there are few services available other than the prison system. These individuals should be viewed as having a developmental disability, and needing the same types of services as individuals who are mildly retarded. Most of these youth do not qualify for DD [developmental disabilities as defined under AS 47.80.900] services because their IQ falls in the borderline range.
>
> In closing, I want to emphasize that if we are to properly serve youth and adults with FASD there needs to be a set of services adapted to meet their needs. There is a critical need for employment, housing and case management services. Without these services these individuals will continue to fail and many will end up in jail. We are optimistic that with help, there can be a productive future for individuals with FASD.

4:27:03 PM

CHAIR WILSON asked what approach Covenant House could recommend to identify and fund appropriate, meaningful programs for these type of at-risk young adults.

PATRICIA SENNER, Nurse Practitioner, Covenant House Alaska Crisis Center, reported that funding was received recently from DHSS, enabling Covenant House to establish a supportive job program for its FASD clients, although the benefit and analysis of this program will not be available until 2007. However, she said, "I don't think it's quite as hopeless as people may think." Some of these youth have IQs ranging from 20 to 130, and the higher functioning individuals can be quite successful when provided a job coach.

REPRESENTATIVE GARDNER cited a study from the Pine Ridge Indian Reservation, which reported how the fetal alcohol affected populace had entered a cycle of multi-generational proportions. The study indicated that fetal alcohol effected women tended to have more children, at an early age, and bore children with FASD.

4:30:33 PM

MS. SENNER reported that a large number of the FASD afflicted young women do become pregnant, and said that Covenant House is currently sheltering a young mother and her four children. It is a problem that needs addressing, she said, pointing out that fetal exposure to methamphetamines (meth) and cocaine is as detrimental as alcohol. It has been reported that one in six children have had prenatal exposure to cocaine, statistics which could be extrapolated to include other drugs. In response to a question, she said that residency at Covenant House is passive, requiring the applicant to voluntarily commit to the program. Additionally, she attributes the program's success to a community that supports nonresidential clients as well.

4:33:37 PM

CHAIR WILSON asked how they identify an alcoholic mother and determine who becomes a resident at Covenant House.

MS. SENNER replied that some mothers party more than drink on a regular basis, and some have a stable and supportive home life that can be incorporated into the program.

4:34:57 PM

HEATHER AMY SCOTT, had her testimony read by her mother, Cheryl Scott, as follows:

> I'm here as a sibling of a young adult who has FASD. I want to see that this bill will help provide life-long support for my brother such as medical, housing, and job support. I would like to also request support in education for young people with FASD so they don't have babies that are affected like both parents of my foster baby.

CHERYL SCOTT, Parent Navigator, Training Coordinator, Stone Soup Group, stated that Ms. Heather Scott's son is a second generation FASD, and he has an adopted uncle who is a third generation FASD. She said that although FASD is not a genetic disorder, simply stated it remains easy for young women to drink during pregnancy. In response to a question, she opined that the examples presented today represent unplanned pregnancies.

4:37:55 PM

MS. CHERYL SCOTT reported that she regularly receives requests from parents for counsel regarding placement of an FASD child in

out-of-state residential programs. This is the outcome for many families who are not able to receive in-state assistance. She opined that if children were diagnosed at an earlier age and could receive appropriate support, this demand could be lessened. Also, despite the state-approved FASD training courses that are offered for medical service providers, she stressed that local obstetrics/gynecologists (OBGYNs) currently tell expectant mothers that a glass of wine once a week is allowable; a direct contradiction to the facts. She suggested that perhaps the bill could mandate that prenatal information is to be chronicled as part of the newborn's birth record. As a voice for over 300 families in Alaska who are parenting FASD children, she requested that legislation be created for life-long support of these afflicted constituents.

4:44:09 PM

CHAIR WILSON highlighted that including the prenatal information as part of the birth record is a measure that could be included without fiscal impact.

4:45:41 PM

MICHAEL BALDWIN, Mental Health Clinician; Fetal Alcohol Spectrum Disorders (FASD), MatSu Diagnostic Team, highlighted the need for funding and infrastructure of treatment programs as a means for prevention, and opined that applying funds for programs that educate future mothers before "the damage is done," is an investment in the future as it reduces the need to fund life-long support facilities. In response to a question, he concurred that the technology is not available to accurately diagnose FASD prior to age three. In terms of multigenerational FASD occurrences, he reported that two thirds of his caseload would meet that profile.

4:51:05 PM

BILL HOGAN, Deputy Commissioner, Department of Health and Social Services (DHSS), echoed that early diagnosis of FASD is essential and said that the disorder has wide ranging impacts that involve many sections and divisions of DHSS, as well as other state departments. The department has developed screening and diagnostic procedures currently being used by 14 diagnostic teams across the state. He reported that many of the FASD children who are being referred to Lower 48 centers have multiple diagnoses. Additionally, he stated that DHSS supports: increased public awareness of FASD, increased ability to screen

and diagnose the problem, and treatment options. He underscored the need for ongoing surveillance to determine the effectiveness of the various programs. He noted that substance abuse treatment centers throughout the state do prioritize pregnant women, although there is limited space available in the programs.

4:54:09 PM

DIANE CASTO, Section Manager, Prevention and Early Intervention Section, Division of Behavioral Health (DBH), Department of Health and Social Services (DHSS), stated support for HB 312 and reported that Alaska has some of the best surveillance data available because of the birth defects registry, which mandates reporting and follow-up work with a diagnostic team. Responding to Chair Wilson, she said that statistics alone indicate that Alaska has a high rate of alcoholism, and the state licensed medical providers do a good job of tracking and reporting birth defects. She repeated the previous concern for access to prenatal information as a critical part of diagnosis, and explained the four digit diagnostic code currently being used with infants, which examines: growth deficiencies, facial dismorphology, the central nervous system functionality/brain damage, and maternal alcohol use. This system is more beneficial than the meconium test called for in HB 312, and she reiterated the need for doctors to document the prenatal use of alcohol and attach it to the birth record.

4:58:16 PM

MS. CASTO directed the committee's attention to the information page titled "Alaska's FASD Diagnostic Team Network 1/31/2006", which provides a list of 13 [correcting the previous number] diagnostic teams by name, service area, referral criteria, the approximate wait time for a referred client to receive services, and the contact person's information. Due to the demand, she said that the teams are working in a backlog. She pointed out that the average age for diagnosis in Alaska is ten, but the department expects to reduce that to six. The referral criteria does not indicate significant data on adult diagnosis, which she highlighted is a critical area. Finally, she reported on a federal grant which provided in-state training for the four-digit diagnosis method, and also the federally earmarked educational funds which launched last year's well-received media campaign.

5:03:17 PM

REPRESENTATIVE GARDNER moved CSHB 312, Version 24-LS0241\Y, Mischel, 1/23/06. There being no objection, Version Y was before the committee.

5:04:35 PM

CHAIR WILSON provided directions to the committee for the forthcoming CS.

[HB 312 was held over.]

5:06:09 PM

ADJOURNMENT

There being no further business before the committee, the House Health, Education and Social Services Standing Committee meeting was adjourned at 5:06 p.m.