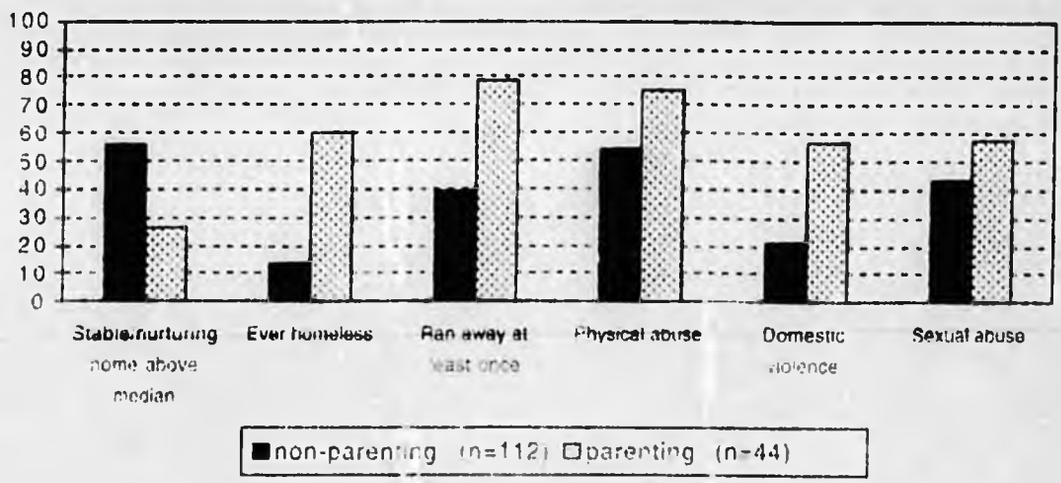
16 Problems with Parenting (PWP)

Of the 253 clients who were over 12 years old at the time of the LHI, 44 (17%) had become parents; 30 females and 14 males (28% of females 12 years and over and 10% of males). For females, the mean age of the first pregnancy was 18 years, for males, the mean age of first fathering of a child was 20 years. The youngest age at which a client with FAS or FAE had a child was 13 years. The maximum number of children born to a mother was four (Only children known to the respondent were reported on the LHI, as clients were not interviewed themselves).

In order to compare clients who became parents with those who did not, a subset of "non-parenting clients" was selected from the database, based on age of client at interview. There was little difference in the average IQ of the two groups. Average IQ was 84 for parents, ranging from borderline mental retardation (IQ 70) to above average (IQ 117). Parents had a slightly higher VABS Adaptive Behavior score than non-parents (66 versus 60).

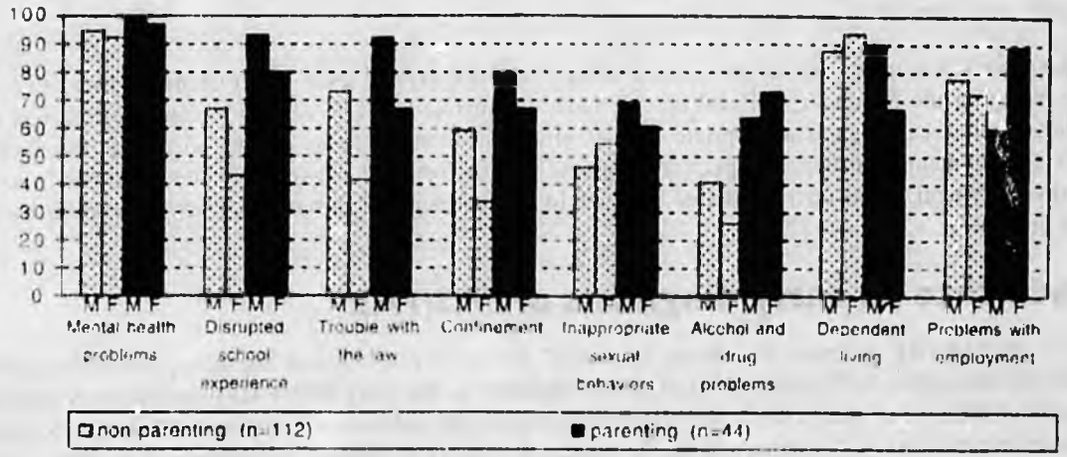
Compared to the non-parenting clients, clients who became parents had a higher rate of history of living in unstable homes. They were much more likely to have been homeless, more likely to have run away from home, and experienced over twice the rate of domestic violence (Figure 16.1).

16.1 Prevalence of risk and protective factors by parenting status



Parenting clients had more Disrupted School Experience, more Trouble with the Law, more Confinement, and more Alcohol and Drug Problems, compared to non-parenting clients (Figure 16.2). They were over two times more likely to have dropped out of school (66% versus 26%).

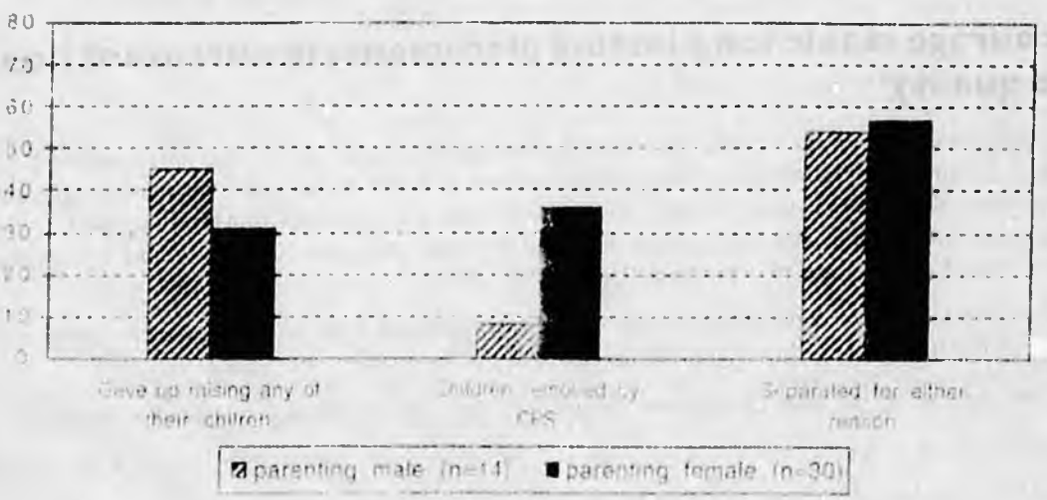
16.2 History of Secondary Disabilities: Comparing non-parenting and parenting clients



Fifty-nine percent of the parents were diagnosed FAS or FAE after they had become parents; 30% before they became parents and for the rest, the two ages were too close to evaluate in this regard. The 44 parents had produced 76 children, at least half of whom were no longer being cared for by the client (Figure 16.3). Thirty six percent of female clients had their children removed from their care by CPS, whereas 45% of male clients had given up raising their children.

Parenting clients were more likely to be married (23% versus 4%). They were more likely to have ever been on welfare (81% versus 48%), but somewhat less likely to have ever received SSI than non-parents (44% versus 50%). 10% of the parents had applied for and received eligibility for DDD versus 20% of the non-parents.

16.3 Separation of parent from child among parenting clients: Comparing male and female clients



An alarming 10% of the female parents were drinking during pregnancy, 17% had a child who had been diagnosed FAS or FAE, and another 17% had children that the respondents suspected of being fetal alcohol affected.

17 Recap and Recommendations

In this chapter, we summarize some of the main findings from this report, draw conclusions, and make recommendations for overcoming the Secondary Disabilities we have documented. While causation can't be inferred from these data, they nevertheless can suggest appropriate courses of action. First we focus on the "extrinsic" risk factors—those that suggest environmental influences, specific programs and so forth. Then we go to the "intrinsic" risk factors—those that reveal typical client characteristics that would demand special protection or consideration by caretakers and service providers.

17.1 Facilitate an early diagnosis of FAS/FAE

Although an early FAS/FAE diagnosis is a strong "universal" protective factor for all Secondary Disabilities (Figures 6.1), only 11% of the clients had a diagnosis prior to age 6 (Table 6.1). An early FAS/FAE diagnosis may help the family better understand the root of their child's developmental delays and behavioral problems and empower the family to advocate for appropriate services particularly in the crucial first years at school. A diagnosis is an effective communication tool that enables caregivers to educate others about the special needs of alcohol-affected individuals.

Many actions could be taken to foster an early diagnosis. These include:

- A statewide network of FAS Diagnostic Clinics such as is already underway in Washington State through the University of Washington Medical School (Clarren & Astley, 1997).
- A referral network system whereby children at risk of having FAS/FAE are screened during infancy and the preschool period for possible FAS/FAE. Those children identified at risk (i.e., from those being adopted from alcohol-abusing mothers, those who are under the supervision of Children's Protective Services for neglect or abuse, and those entering the foster care system) are referred to their local FAS Diagnostic Clinics. A foster care screening program is presently underway in King County, Washington.
- Routinely obtaining prenatal exposure information at each point at which the child and family are evaluated by the system (prenatal care, delivery, and pediatric care school entry, criminal justice, mental health, and so forth).
- Training school nurses to screen for FAS/FAE as part of the school entrance examination. The effectiveness of this program in two counties of Washington State has already been demonstrated.

17.2 Encourage stable long-lasting placements in nurturant homes of "good quality"

Desirable characteristics of the client's home life (stability, nurturance, "good quality") are universal protective factors for all Secondary Disabilities (Figures 6.1). This common sense protective factor is a fundamental right for the well being of all children. The fact that many alcohol-affected individuals have come from dysfunctional, transient, and abusive living situations demands that we reiterate the need for more effective community and family support services, perhaps modeled on the Birth to 3 program (Grant et al., 1996).

Environmental risk factors for secondary disabilities that must be modified if we are to prevent or decrease secondary disabilities are exemplified by the following problems revealed by this study:

- Half of our clients over 12 years of age have *not* lived at least 72% of life in a stable and nurturant environment.
- Half have *not* lived in a home with at least 10 of 12 positive qualities between the ages of 8 and 12 years.
- Half had *not* stayed in each living situation for an average of more than 2 years, and
- Half of our clients 12 years and older, had *not* had their basic (food and shelter) needs met for more than 72% of life.

By identifying environmental risk factors, service providers can work together with the family to prevent secondary disabilities in alcohol affected individuals.

- Early identification of children born to "high risk" women with alcohol and drug problems should draw community resources to these children and their families, ideally during the prenatal period, the postpartum period, and onward into infancy and childhood.
- Advocates/case managers in close personal contact with high risk families can work to improve the quality of the home. When the child's safety in the home cannot be safeguarded, the child should be moved to an alternative long-term home or placed for permanent adoption as early as possible.
- An early diagnosis can identify children with FAS/FAE living in high risk homes, so that biological families can obtain the same state resources that should be available for foster and adoptive families (family support services, medical coverage, home visits, respite care, and case management opportunities and so forth).
- On a policy level, requiring state personnel to disclose the full medical/mental health background history before placing a child in foster care or adoptive placement should insure that the parents will know about the special needs of their children with FAS/FAE from the onset of parenting.
- A better system for educating and training parents about children with FAS/FAE is needed, so that parents and all caregivers can use their energies most efficaciously on behalf of their children.
- Group homes providing stable, long-term residences with personal and job supervision appropriate to the special needs of youth and adults with FAS/FAE are urgently needed. As a start, a model program should be funded, implemented, and evaluated.

17.3 Improve the circumstances of children in alcoholic/drug abusing homes

Living with people who have alcohol/drug problems was a risk factor for five of the eight Secondary Disabilities studied: Alcohol and Drug Problems, Confinement, Disrupted School Experience, Trouble with the Law, and Inappropriate Sexual Behavior.

Half of the clients who were 12 years old and older, had spent at least 30% of their lives living with a person who had an alcohol/drug problem.

Based on our findings, we recommend that efforts be focused on:

- Detecting high risk alcohol and drug abusing mothers and providing appropriate services (during prenatal care, at delivery, at FAS Diagnostic Clinics, and at community treatment centers).
- Expanding alcohol and drug treatment services for women so that they can keep their children with them and their families intact during inpatient treatment.
- Developing advocacy services for alcohol/drug abusing mothers and using advocates as a liaison with CPS for monitoring the safety of children in alcohol/drug-abusing homes (as has been successfully accomplished in the Seattle Birth to 3 Program: Grant et al, 1996).

17.4 Intervene to prevent violence against people with FAS/FAE

Violence against the client is almost a universal risk factor for all Secondary Disabilities, impacting six of the eight studied (Figure 6.1). It is alarming to find that 72% of the clients with FAS/FAE who were 12 years and older have experienced violence (either physical or sexual abuse, and/or domestic violence), and that many have experienced several types of violence in their lifetimes.

Clients' experienced violence is by far the strongest risk factor for Inappropriate Sexual Behavior. At 45%, Inappropriate Sexual Behavior is the second most prevalent Secondary Disability in people with FAS/FAE across the lifespan (Figure 7.1). Regardless of age, between 46% and 52% of clients in the three main age groups studied had engaged in Inappropriate Sexual Behavior. In turn, Inappropriate Sexual Behavior has the strongest relationship to two other Secondary Disabilities, namely, Trouble with the Law and Confinement. These latter are the most costly, serious, and disruptive societal responses to unacceptable, misunderstood, or problem behaviors (Figure 7.2). Clearly, there are strong economic and humanistic reasons for reducing all of these Secondary Disabilities and the risk factors related to them.

Both children and adults with FAS/FAE are vulnerable to being victims of violent physical and sexual behavior, perhaps as a result of both their prenatal brain damage and the high risk environments in which they often live.

Based on our findings, we recommend the following efforts be made to prevent violence against these vulnerable clients:

- Advocates, such as those described in the Birth to 3 program, can serve as an effective liaison with Children's Protective Services (CPS) for monitoring the safety of children and adults with FAS/FAE in high risk homes.
- Several groups of professionals must be informed about the presence of people with FAS/FAE among their client populations, so that the most efficacious treatment models can be developed and implemented. These groups include: sexual deviancy counselors, the sexual abuse treatment field, and those dealing with domestic violence.
- The possibility of prenatal alcohol exposure should be explored (along with a history of physical and sexual abuse) among all patients coming into trouble with the law, mental health, or judicial confinement settings.
- Further research on the most effective response of the criminal justice system to the expression of Inappropriate Sexual Behavior by people of all ages with FAS/FAE is urgently needed. Sentencing alternatives, methods of enhancing familial supervision, and programs to enhance social skills and job skills are needed.

17.5 Develop, evaluate, and implement methods to detect subgroups of people with FAS/FAE who are in special need of interventions

The recommendations in 17.1–17.4 pertain to environmental influences resulting from the discoveries in this study about the "extrinsic" risk factors for secondary disabilities. This study has also addressed the relationship of "intrinsic" characteristics of certain subgroups of people with FAS/FAE that might put them at special risk of developing secondary disabilities. These include:

- people with FAE, who do not have the full facial stigmata of FAS and thus may not readily qualify for services,
- people with FAS or FAE whose IQ level is above 70 and who consequently often fail to qualify for special services,
- people with FAS/FAE who have a marked discrepancy between their IQ levels and their level of Adaptive Behavior, and
- people with FAS/FAE who have a particular cluster of characteristic behaviors as identified by a high FABS score on the Fetal Alcohol Behavior Scale.

Recommendations follow:

- Further research is urgently needed to quantify the prenatal brain damage from alcohol in people who do not have the physical signs of FAS and/or who do not have an IQ score permitting classification as mentally retarded (i.e., IQ below 70).
- The identification and evaluation of new quantification methods should facilitate diagnosis as well as permitting the development of more appropriate guidelines for providing needed services.
- One promising new scale developed for this study that needs further evaluation is the Fetal Alcohol Behavior Scale (FABS). As a high FABS score is a risk factor for numerous secondary disabilities, providing specialized services for this subset of clients might be particularly cost effective.
- Another promising marker derives from the "IQ/Adaptive Behavior Discrepancy" score which is also associated with secondary disabilities. Further study of this and the use of other techniques for evaluating specific cognitive, linguistic, and neuropsychological problems in people with both FAS and FAE, particularly those with IQ scores too high to readily qualify for services, should be a high priority for future research.
- Finally, of course, effective strategies for remedial interventions appropriate to the needs of people with FAS/FAE need to be developed, evaluated, and implemented.

17.6 Promote communities, families, and clients with FAS/FAE working together

Just as all children need immunizations against diseases, people with FAS/FAE appear to need special "immunization" against many inadequacies and dangers in our society. Their functioning is often far below their apparent intelligence. Many people with FAS/FAE appear to learn only inadequately through normal channels about their environment and how to interact with it. Working around the disabilities that these clients are born with is not the family's responsibility alone, but neither is it solely the government's or community's responsibility. Communities, families, and clients working together toward this mutual goal of reduction of Secondary Disabilities may foster better optimization of quality of life for both people with FAS/FAE and their communities.

The Secondary Disabilities data indicate that clients with FAS/FAE come in contact with many different community professionals and agencies. For example: over 90% deal with Mental Health professionals, 60% with the criminal justice system, 23% with alcohol and drug treatment personnel (Figures 8.1, 10.1, 13.3), and 100% with school personnel. The finding that an early diagnosis is a universal protective factor against *all* Secondary Disabilities suggests that information about the diagnosis is useful to have in responding appropriately to a child's problems. People with FAS/FAE and their families could facilitate more beneficial and humane services by sharing the diagnostic information with professionals they work with.

Half of the clients 12 years and older display Inappropriate Sexual Behavior (Figure 12.1). Although the rates of these behaviors are about the same for females and males, the outcome is very different. Thirty nine percent of the males 12 years and older with Inappropriate Sexual Behaviors are "in Trouble with the Law" over these behaviors, while about 10% of the females go to treatment. The inappropriate sexual behavior that gets males into trouble with the law is "inappropriate touching". Females most frequently go to treatment for promiscuity, compulsions, and sexual advances. People with FAS/FAE and their families should know that Inappropriate Sexual Behavior does not just begin in adolescence. Among 6-11 year olds, approximately 37% of girls and 41% of boys are already exhibiting these behaviors. Families, criminal justice, and mental health professionals need to work together to develop new intervention strategies that will truly reduce rather than increase the level of Secondary Disabilities.

Alcohol problems occur in 33% of clients with FAS/FAE over the age 12 (Figure 13.1)--of these, 65% have gone on to abuse street drugs, at an average of two years after the onset of alcohol abuse. Early parental recognition and intervention of alcohol problems among youth with FAS/FAE could result in the prevention of other drug abuse problems. Families should also be apprised that female clients have as high a rate of alcohol problems as male clients, and that females are much less likely to receive treatment for their alcohol problems. Clients with FAS/FAE and their families should be aware of the special vulnerability to alcohol problems that is carried by all children of alcoholics, and develop appropriate early family practices to guard against the onset of alcohol problems among alcohol-affected individuals.

Approximately 80% of the adults with FAS/FAE in this study do not appear to be achieving either an independent living status or problem-free employment (Figures 14.1, 15.1). People with FAS/FAE, their families, school personnel, and mental health professionals need to start planning long before adulthood for a lifetime involving some degree of support. Training of appropriate living and working skills needs to start long before adulthood.

Many recommendations have been made regarding what the government agencies can do to help lower the rates of secondary Disabilities observed in this client sample. Families can do a lot too. Certainly, communities also need better education about people with FAS/FAE. But it is the cooperation among families, communities, government agencies, and clients that permits a focusing of combined energies toward solutions that are beneficial to all.

18 References

Aase J.M., Jones K.L., & Clarren S.K. (1995). Do we need the term "FAE"? *Pediatrics, 95*(3), 428–30.

Alcoholic Beverage Labeling Act of 1988. (1988). Public Law 100–690, 100th Cong. 2d. sess. Nov. 18, 1988.

American Psychiatric Association. (1994). *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, DSM-IV.* Washington, D.C.: American Psychiatric Association.

Aronson, M. & Olegård, R. (1987). Children of Alcoholic Mothers. *Pediatrician, 14*, 57–61.

Centers for Disease Control and Prevention. (1992). *Monthly Vital Statistics Report: Advance Report of New Data from the 1989 Birth Certificate*, vol. 40(12, suppl). National Center for Health Statistics, Centers for Disease Control, Atlanta.

Chernoff, G.F. (1977). The fetal alcohol syndrome in mice: An animal model. *Teratology, 15*(3), 223–229.

Clarren, S.K. & Smith, D.W. (1978). The fetal alcohol syndrome. *The New England Journal of Medicine, 298*(19), 1063–1067.

Clarren, S.K. & Astley, S. (1997). The development of the Fetal Alcohol Syndrome Diagnostic and Prevention Network in Washgton State. In Streissguth A.P., & Kanter, J. (Eds.). *Selected Papers From: Overcoming and Preventing Secondary Disabilities in FAS & FAE.* Seattle: University of Washington Press.

Faustman, E.M., Streissguth, A.P., Stevenson, L.M., Omenn, G.S., & Yoshida, A. (1992). *Role of maternal and fetal alcohol metabolizing genotypes in fetal alcohol syndrome.* Society of Toxicology, 1992 Annual Meeting, Seattle Convention Center, Seattle, Washington, February 23–27, 1992.

Grant T.M., Ernst C.C., Streissguth A.P., Phipps P., & Gendler B. (1996). When case management isn't enough: A model of paraprofessional advocacy for drug- and alcohol-abusing mothers. *Journal of Case Management, 5*(1), 3–11.

Hanson JW, Streissguth AP, Smith DW. (1978). The effects of moderate alcohol consumption during pregnancy on fetal growth and morphogenesis. *Journal of Pediatrics, 92*(3), 457–460

Institute of Medicine. Stratton, K.R., Howe, C.J., & Battaglia, F.C. (Eds.). (1996). Fetal alcohol syndrome: diagnosis, epidemiology, prevention and treatment. Washington, D.C.: National Academy Press.

Jones, K.L. & Smith, D.W. (1973). Recognition of the Fetal Alcohol Syndrome in early infancy. *Lancet, 2*(836), 999–1001.

Jones, K.L., Smith, D.W., Ulleland, C.N., & Streissguth, A.P. (1973). Pattern of malformation in offspring of chronic alcoholic mothers. *Lancet, 1*(815), 1267–1271.

Jones, K.L., Smith, D.W., Streissguth, A.P. & Myrianthopoulos, N.C. (1974). Outcome in offspring of chronic alcoholic women. *Lancet, 1*(866), 1076–1078.

LaDue, R.A., Streissguth, A.P. & Randels, S.P. (1992). Clinical considerations pertaining to adolescents and adults with Fetal Alcohol Syndrome. In Sonderegger, T. B. (Ed.), *Perinatal Substance Abuse: Research Findings and Clinical Implications* (chapter 4, pp. 104–131). Baltimore: The Johns Hopkins University Press.

Lemoine, P., Harousseau, H., Borteyru, J.-P. & Menuet, J. C. (1968). Children of Alcoholic Parents: Abnormalities observed in 127 cases. *Selected Translations of International Alcoholism Research (STIAR)*. Rockville, MD: National Institute on Alcohol Abuse and Alcoholism. [Translation from the French of: Les enfants de parents alcooliques: Anomalies observées, à propos de 127 cas. *Ouest Medical (Paris), 21*:476–482.] (Available from the National Clearinghouse for Alcohol and Drug Information, P.O. Box 2345, Rockville, MD 20847–2345, 1-800-729-6686.)

Lemoine, P. & Lemoine, Ph. (1992). Avenir des enfants de mères alcooliques (Etude de 105 cas retrouvés à l'âge adulte) et quelques constatations d'intérêt prophylactique [Outcome in the offspring of alcoholic mothers (study of one hundred and five adults) and considerations with a view to prophylaxis]. *Annales de Pediatrie (Paris), 39*, 226–235.

Majewski, F. (1979). Alcohol embryopathy: Experience in 200 patients. *Developmental Brain Dysfunction, 6*, 248-265.

NIAAA (1981). *Sixth Special Report to the U.S. Congress on Alcohol and Health*. U.S. Department of Health and Human Services. National Institute of Alcoholism and Alcohol Abuse.

Randall, C.L. (1977). Teratogenic effects of in utero ethanol exposure. Blum, K., Bord, D. & Hamilton, M. (Eds.), *Alcohol and Opiates: Neurochemical and Behavioral Mechanisms* (pp. 91-107). New York: Academic Press, 1977.

Sattler, J.M. (1988). *Assessment of Children*(3rd edition). San Diego: Jerome M. Sattler, Publisher.

Sparrow, S.S., Bella, D.A. & Cicchetti, D.V. (1984). *Vineland Adaptive Behavior Scales, Interview Edition Survey Form Manual*. Circle Pines, MN: American Guidance Service.

Spohr, H.L., Willms, J. & Steinhausen, H.-C. (1993). Prenatal alcohol exposure and long-term developmental consequences. Lancet, 341(8850), 907-910.

Spohr, H.L., Willms, J. & Steinhausen, H.-C. (1994). The fetal alcohol syndrome in adolescence. *Acta Pediatrica Supplement, 404*, 19-26.

Steinhausen, H.C., Willms, J. & Spohr, H.-L. (1993). Long-term psychopathological and cognitive outcome of children with fetal alcohol syndrome. *Journal of the American Academy of Child and Adolescent Psychiatry, 32*(5), 990-994.

Steinhausen, H.C., Willms, J. & Spohr, H.-L. (1994). Correlates of psychopathology and intelligence in children with fetal alcohol syndrome. *Journal of the American Academy of Child Psychology and Psychiatry, 35*, 323-331.

Streissguth, A.P., Aase, J.M., Clarren, S.K., Randels, S.P., LaDue, R.A. & Smith, D.F. (1991a). Fetal alcohol syndrome in adolescents and adults. *Journal of the American Medical Association, 265*(15), 1961-1967.

Streissguth, A.P., Barr, H.M., & Press, S. (1996). A Fetal Alcohol Behavior Scale (FABS) for describing children and adults affected by prenatal alcohol exposure. *Alcoholism: Clinical and Experimental Research, 20*(2), 73a.

Streissguth, A.P., Clarren, S.K., & Jones, K.L. (1985, July). Natural history of the Fetal Alcohol Syndrome: A ten-year follow-up of eleven patients. *Lancet, 2*, 85-91.

Streissguth, A.P., Herman, C.S. & Smith, D.W. (1978a). Intelligence, behavior, and dysmorphogenesis in the Fetal Alcohol Syndrome: A report on 20 patients. *Journal of Pediatrics, 92*(3), 363-367.

Streissguth, A.P., Herman, C.S. & Smith, D.W. (1978b). Stability of intelligence in the Fetal Alcohol Syndrome: A preliminary report. *Alcoholism: Clinical and Experimental Research, 2*(2), 165-170.

Streissguth, A.P. & Kanter, J.W. (in press). *Selected Papers From, Overcoming and Preventing Secondary Disabilities in FAS & FAE*. Seattle: University of Washington Press.

Streissguth, A.P., Kogera-Frye, K. & Barr, H.M. (1994). A preliminary report on primary and secondary disabilities in patients with fetal alcohol syndrome: Why prevention is so needed. Paper presented at the 1994 NIAAA FAS Prevention Conference.

Streissguth, A.P., LaDue, R.A. & Randels, S.P. (1988). *A Manual on Adolescents and Adults with Fetal Alcohol Syndrome with Special Reference to American Indians* (2nd ed.). Albuquerque, NM: Indian Health Service.

Streissguth, A.P., Randels, S.P. & Smith, D.F. (1991b). A test-retest study of intelligence in patients with the fetal alcohol syndrome: Implications for care. *Journal of the American Academy of Child and Adolescent Psychiatry, 30*(4), 584-587.

Surgeon General's Advisory on Alcohol and Pregnancy (1981). FDA Drug Bulletin, 11(2). Rockville, Maryland: U.S. Department of Health and Human Services.

Yeargin-Allsopp, M., Murphy, C.C. & Spafford, C.S. (1995). Digit span and other WISC-R scores in the diagnosis of dyslexia in children. *Developmental and Medical Child*, 30, 1219-1229.

Wechsler, D. (1967). *WPPSI Manual: Wechsler Preschool and Primary Scale of Intelligence*. New York: The Psychological Corporation.

Wechsler, D. (1974). *WISC-R Wechsler Intelligence Scale for Children-Revised*. New York: The Psychological Corporation.

Wechsler, D. (1981). *WAIS-R Manual: Wechsler Adult Intelligence Scale-Revised*. New York: The Psychological Corporation.

19 Glossary of Terms and Abbreviations

- **ABC score** — Adaptive Behavior Composite—the summary score from the VABS, derived from combining the four domains of adaptivity measured: Communication Skills, Daily Living Skills, and Socialization. The ABC is a standard score, like IQ, which is set to the same parameters as the Wechsler IQ tests: 100=normal and 15=one standard deviation
- **ADP** — Alcohol and Drug Problems
- **Arith** — Arithmetic—subtest of Wechsler IQ tests
- **ARND** — Alcohol Related Neurodevelopmental Disorder
- **Birth to 3** — The Seattle Advocacy Model Program for high risk mothers abusing alcohol and drugs. (See Grant et al., 1996)
- **BlkDes** — Block Designs—subtest of Wechsler IQ tests
- **CDC** — Centers for Disease Control and Prevention
- **CFN** — Confinement
- **CNS** — Central Nervous System
- **Coding** — Coding—subtest of Wechsler IQ tests
- **Comp** — Comprehension—subtest of Wechsler IQ tests
- **CPS** — Children's Protective Services
- **DDD** — Division of Developmental Disabilities
- **DigSp** — Digit Span—subtest of Wechsler IQ tests
- **DK** — Don't Know
- **DPL** — Dependent Living
- **DSE** — Disrupted School Experience
- **DSM-IV** — Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
- **DVR** — Department of Vocational Rehabilitation
- **Dx** — Diagnosis
- **Extrinsic RPF** — A Risk and Protective Factor that describes something in the client's environment or something that has happened to the client
- **FABS** — Fetal Alcohol Behavior Scale—The FABS is a list of 36 behaviors (selected out of 72 items on a Personal Behaviors Checklist) that parents and caretakers have frequently used to describe people with FAS. The 36 items are characteristic of people with FAS irrespective of age (except infants and the elderly) and IQ (except the profoundly retarded). (See Streissguth, Barr and Press, 1996)
- **FADU** — Fetal Alcohol and Drug Unit
- **FAE** — Fetal Alcohol Effects
- **FAS** — Fetal Alcohol Syndrome
- **Info** — Information—subtests of Wechsler IQ tests

- **Intrinsic RPF** A Risk and Protective Factor that involves some characteristic of the clients themselves (like IQ)
- **IOM** Institute of Medicine
- **IQ** Intelligence Quotient. This is a standard score, with the population mean=100, and 15=one standard deviation.
- **ISB** Inappropriate Sexual Behaviors
- **LHI** Life History Interview
- **Max** Maximum
- **Med** Median
- **MHP** Mental Health Problems
- **NPCP** National Perinatal Collaborative Project
- **ObjA** Object Assembly—subtest of Wechsler IQ tests
- **Odds Ratio** The ratio of two ratios describing the relation of a two-valued outcome (say, A and B) to a two-valued predictor (say, y and n). It is the ratio (yB/yA)/(nB/nA), or (yB*nA)/(yA*nB). (See Chapter 6 for examples)
- **PFAE** Possible or Probable Fetal Alcohol Effects
- **PFAS** Possible or Probable Fetal Alcohol Syndrome
- **PicA** Picture Arrangement—subtest of Wechsler IQ tests
- **PicC** Picture Completion—subtest of Wechsler IQ tests
- **PIQ** Performance Scale IQ—from the Wechsler IQ tests
- **PWE** Problems With Employment
- **RPF** Risk and Protective Factors
- **SD** Secondary Disabilities
- **Sim** Similarities—subtest of Wechsler IQ tests
- **Specific RPF** A Risk and Protective Factor that only applies to some of the eight Secondary Disabilities studied, or may be Risky for some and Protective for others
- **SS** Standard Score: the rescaling of any numerical variable so it has an easily remembered standard deviation (in the case of Wechsler IQ tests, the WRAT-R and the VABS, the average=100 and the standard deviation around the average is 15 points).
- **SSI** Supplemental Security Income
- **TWL** Trouble With the Law
- **Tx** Treatment
- **Universal RPF** A Risk and Protective Factor which is uniformly protective or risky for all six of the main Secondary Disabilities described in Figure 6.1 and Table 6.1
- **VABS** Vineland Adaptive Behavior Scale
- **VIQ** Verbal Scale IQ—from the Wechsler IQ tests
- **Vocab** Vocabulary—subtest of Wechsler IQ tests
- **WISC-R** Wechsler Intelligence Scale for Children-Revised
- **WPPSI-R** Wechsler Preschool and Primary Scale of Intelligence Revised
- **WRAT-R** Wide Range Achievement Test Revised

Secondary Disabilities

Information | Age Comparison Table | Developing Baby | Secondary Disabilities | FAQ's

Other problems, or secondary disabilities, arise when needs go unmet for children with alcohol-related birth defects.

In a 1996 study of 415 FAS/FAE patients ranging in age from 6 to 51 years, Dr. Ann Streissguth of the University of Washington identified a number of secondary disabilities that a person is not necessarily born with. These include:

- 90% had mental health problems
- 80% of those over 21 were dependent on others for daily needs
- 80% (21 and older) had employment problems
- 60% (12 and older) were expelled or dropped out of school
- 60% (12 and older) had trouble with the law
- 50% (12 and older) inappropriate sexual behavior
- 50% (12 and older) were incarcerated or confined for mental health reasons
- 30% (12 and older) had alcohol or drug problems

This study also identified several universal "protective factors" that - if addressed early on and consistently - helped minimize the secondary disabilities.

- Living in a stable nurturing home for over 72% of life
- Being diagnosed before the age of six years
- Never having experienced violence against oneself
- Staying in each living situation for an average of more than 2.8 years
- Experiencing a good quality home from age six to twelve years
- Having applied for and been found eligible for Developmental Disability Services
- Having a diagnosis of FAS rather than FAE
- Having basic needs met for at least 13% of life

Fetal Alcohol Spectrum Disorders

Fetal Alcohol Spectrum Disorders

Protective Factors for Children with FAS

Several positive factors have been identified that might help reduce secondary conditions that result from fetal alcohol syndrome (FAS). Some of these protective factors are:

Early Diagnosis - Children with FAS who are identified early have an improved prognosis. A child who is identified early in life can be placed in appropriate educational classes and given access to social services that can help the child and his or her family. In addition, early diagnosis helps families and school personnel understand why the child might act or react differently from other children in some situations.

Involvement in Special Education and Social Services - Children who receive special education geared towards their specific needs and learning style are more likely to achieve their developmental and educational potential. Children with FAS show a wide range of behaviors and severity of symptoms. Special education allows for individualized educational programs. In addition, families of children with FAS who receive social services, such as respite care or stress and behavioral management training, have more positive outcomes than families who do not receive such services.

Loving, Nurturing, and Stable Caretaking Environment - While all children benefit from a loving and stable home life, children with FAS can be particularly sensitive to disruptions, transient lifestyles, or harmful relationships compared to children who do not have FAS. Community and family support are needed to prevent secondary conditions in individuals with FAS.

Absence of Violence - Individuals with FAS who live in stable or non-abusive households or who do not become involved in youth violence are much less likely to develop secondary conditions than children who have been exposed to violence in their lives. Children with FAS need to learn and be taught other ways of showing their anger or frustration.

Source:
Streissguth, A.P., Barr, H.M., Kogan, J. & Bookstein, F. L., "Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)," Final Report to the Centers for Disease Control and Prevention (CDC), August, 1996, Seattle: University of Washington, Fetal Alcohol & Drug Unit, Tech. Rep. No. 96-06, (1996).

[Return to Top]

Date: May 2, 2006
Content source: National Center on Birth Defects and Developmental Disabilities

Topic Contents

- Home
- Basics
- FAQs
- Fact Sheets
- Materials
- CDC Activities
- National Task Force

Quick Links

Read about the Science Ambassador Program and available lesson plans on FAS for middle and high school classrooms

FAS Guidelines for Referral and Diagnosis
Click here to view or download the Guidelines. [PDF document]
Find out how to order copies

Surgeon General's Advisory on Alcohol Use in Pregnancy [PDF document]

MMWR Recommendations and Reports - Guidelines for Identifying and Referring Persons with Fetal Alcohol Syndrome

Report on alcohol consumption among women who are pregnant or who might become pregnant

Curricula Available

Contact Info

Fetal Alcohol Syndrome
NCBDDD, CDC
Mail-Stop E-86
1600 Clifton Road
Atlanta, GA 30333
1-800-CDC-INFO (232-4636)

404-498-3040 FAX
Email: cdcinfo@cdc.gov

Thank you for visiting the CDC-NCBDDD Web site. Click here to contact the National Center on Birth Defects and Developmental Disabilities

We are not able to answer personal medical questions. Please see your health care provider concerning appropriate care, treatment, or other medical advice.

Programs & Campaigns

Science Ambassador

Pregnancy Planning Education Program

National Center on Birth Defects & Developmental Disabilities

Centers for Disease Control and Prevention, 1600 Clifton Rd, Atlanta, GA 30333, U.S.A.
Public Inquiries: 1-800-CDC-INFO (232-4636); 1-888-232-6348 (TTY)

USA.gov | Department of Health and Human Services

Attachment B

Fetal Alcohol Spectrum Disorders, The Basics
U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration

CS

2/27

Tim Kelley

AK Medical Association

- concerned w/ line 9810 of SB 267
- gave number for Jim Jordan 562 0304 AK State Med Assoc.
- claims doctors are already doing it 244-4487

- ~~[redacted]~~ age of majority + 2 (20yrs)

586-4273 = fax #

SB25

Call Cissna

Jim Jordan

- charting
- med. record is property of med. professional
- ~~[illegible]~~ "that's the best practice"
- can't write a letter

- allerted to hearing on Mon

fax: 561-2963

Alaska State
Legislature
State Capitol
[redacted]
907 465-3756 fax
From the Office of Senator Bettye Davis

To: Legal Services **Fax:** 465-2029; phone: 465-2450

From: Thomas S. Obermeyer **Date:** 3/3/2008

Re: Request for CS for SB 267, 25-LS1471\A **Pages:** __3_ pages including cover

CC:

Urgent ☐ For Review ☐ Please Comment ☐ Please Reply ☐ Please Recycle

RUSH PLEASE – HEARING AT 1:30 TODAY

Note: To Whom It May Concern:

Please prepare a CS for Senate Bill 267 per attached amendment prepared by Jan Ruthdale, Dept. Law, and approved by Senator Davis.

Copies of original and changes in "Amendment" are attached.

Please call if you have any questions.

Thomas S. Obermeyer
907-465-3762

DRAFT

25G-2
2/27/2008
2:04 pm)

AMENDMENT

OFFERED IN THE SENATE HEALTH, EDUCATION AND SOCIAL SERVICES COMMITTEE

BY _____

TO: SB 267

Page 1, lines 5 - 14:

Delete all material and insert:

"**Sec. 08.64.364. Health care professionals to document an infant's prenatal exposure to alcohol.** (a) For the purpose of screening for fetal alcohol spectrum disorder, a person licensed under this chapter attending or making a postnatal examination of a mother and infant shall document observations, medical history, and other available information of the infant's prenatal exposure to alcohol in the infant's medical file. Information described in this section that was obtained from statements of the mother made during the mother's examination that is confidential medical information of the mother may not be released without the consent of the mother, except upon court order, or as required by AS 47.17.024. The documentation must be in the form or format required by the board.

(b) Except as provided in AS 47.17.024, information received under this section may not be used except for the purposes of providing medical diagnosis, treatment, or care of the child.

(c) In this section, "infant" means a child who is less than 12 months of age."

Thomas Obermeyer

From: Rutherdale, Jan A (LAW) [jan.rutherdale@alaska.gov]
Sent: Sunday, February 24, 2008 4:01 PM
To: Thomas Obermeyer
Cc: Laughlin, Wilda J (HSS); Sen. Bettye Davis
Subject: DOL comments to SB 267

Tom,
As noted in my earlier email to you, I understand from Mike Ford that you would like an outline of what concerns the Department of Law has with SB 267. Below is a recap of what the bill is trying to accomplish and our position that it does not accomplish that result; in practice, it may accomplish the opposite. In addition, since this issue has already been addressed in a 2006 addition to the reporting statutes, we don't believe that there is a need for this bill.

1. Problem sought to be addressed:

SB 267 requires that a health care professional record an infant's pre-natal exposure to alcohol, if the mother so consents, in the infant's medical file. According to the sponsor statement, "This information is desired to assist with early FASD diagnosis's when applicable . . . A documentation of pre-natal alcohol exposure in the child's medical file will assist medical professionals in making more accurate diagnoses. . . . This legislation comports with the FAS Surveillance Project recommendations found in Fetal Alcohol Syndrome Prevalence in Alaska: "Health care providers should be encouraged to document the details of maternal alcohol use during pregnancy in the child's medical chart."

There is no question that documentation is important in diagnosing FASD. In my experience, the FASD evaluators will not even begin an assessment of a child or adult suspected to have FASD unless there is some sort of documentation that the mother of the person to be evaluated drank during pregnancy. For example, if someone saw the mother drinking during pregnancy or if the mother admits to drinking during pregnancy, the evaluators would want this fact documented, such as in a letter or records of some kind, including medical, police or OCS records.

Usually, FASD symptoms don't appear until the child is in school or older. The biggest problems of documentation arise when the child is an adult and 20-30 years have passed since the pregnancy. This bill tries to ensure that a health professional documents drinking behavior when the child is still an infant.

2. This bill does not solve the need for increased documentation because it allows the mother to prevent such documentation:

Instead of providing more documentation, this bill may have the unintended effect of making it more likely that the documentation of pre-natal exposure to alcohol exposure will not be made. If, as the sponsor statement states, it is important that the documentation is made in the first place, asking the mother and giving her veto power over this documentation creates a possibility that the documentation will not be made. The file is the infant's and this would prevent the doctor to do what is best for the infant. In other words, if making the documentation is good medical practice, the documentation should be made regardless of the mother's wishes.

3. AS 47.17.024 already addresses this issue:

AS 47.17.024, enacted in 2006, requires a "practitioner of the healing arts" (which includes a doctor) involved in the delivery or care of an infant to make a report to OCS if the practitioner determines that the infant has been exposed to alcohol. If the doctor makes a report of harm the doctor

will undoubtedly note this fact in the infant's file. Therefore, there is no need for this bill, since the documentation is already being made. In addition, given the reporting statute, OCS is going to have this prenatal exposure documented in their files, which will be helpful in later making an FASD diagnosis (at least when OCS is involved, which is often the case).

4. This bill may create confusion for doctors who are trying to follow AS 47.17.024.

If the mother objects to any documentation about prenatal exposure in the infant's file, the doctor is still obligated to make a report of harm under AS 47.17.024. but if the mother refuses to allow documentation, the doctor may be under the false impression that he/she does not have to comply with AS 47.17.024. Alternatively, the lack of documentation due to mother's refusal may make it more likely that the doctor will forget to make a report to OCS, or it will require the doctor to create a filing system apart from the infant's file so that the doctor can honor the mother's request but still keep a record that he made the report of harm pursuant to AS 47.17.024.

5. This bill is a departure from normal licensing requirements.

Normally, the state does not legislate best practices for a doctor. If it is good practice for doctors to document exposure to alcohol, the doctors will probably already be doing this. If more education is needed for doctors, there are better ways to satisfy this need than by legislation.

Thank you for providing this opportunity to share my concerns about this bill. Please feel free to call or email me if you have any questions are wish to discuss this matter further.

Jan Rutherdale
Deputy Section Chief
Child Protection Section
Attorney General's Office
(907)465-3608
Fax: (907)465-3019

25-LS1471\A
Bullard
2/11/08

SENATE BILL NO.

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-FIFTH LEGISLATURE - SECOND SESSION

BY SENATOR DAVIS

Introduced:
Referred:

A BILL

FOR AN ACT ENTITLED

"An Act requiring certain persons licensed by the State Medical Board to document an infant's prenatal exposure to alcohol in the infant's medical file."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

*** Section 1.** AS 08.64 is amended by adding a new section to article 3 to read:

Sec. 08.64.364. Health care professionals to document an infant's prenatal exposure to alcohol. (a) For the purpose of screening for fetal alcohol spectrum disorder, a person licensed under this chapter attending or making a postnatal examination of a mother and infant shall document the infant's prenatal exposure to alcohol in the infant's medical file, if the mother provides her consent to the inclusion of the information in the infant's medical file. The documentation must be in the form required by the department.

(b) Information received under this section may not be used except for the purposes of providing medical diagnosis, treatment, or care.

(c) In this section, "infant" means a child who is less than 12 months of age.

LEGAL SERVICES

DIVISION OF LEGAL AND RESEARCH SERVICES
LEGISLATIVE AFFAIRS AGENCY
STATE OF ALASKA

(907) 465-3867 or 465-2450
FAX (907) 465-2029
Mail Stop 3101

State Capitol
Juneau, Alaska 99801-1182
Deliveries to: 129 6th St., Rm. 329

MEMORANDUM March 3, 2008

SUBJECT: Legal and practical issues relating to the requested CSSB 267(HES) (Work Order No. 25-LS1471\C)

TO: Senator Bettye Davis
Chair of the HESS Committee
Attn: Thomas Obermeyer

FROM: Alpheus Bullard TGB
Legislative Counsel

You requested a committee substitute for SB 267 based on an amendment prepared by Jan Ruthdale of the Department of Law. I have several comments.

1. The requested committee substitute directed a person making a postnatal examination of a mother and infant to document "*observations, medical history, and other available information of the infant's prenatal exposure to alcohol in the infant's medical file.*" This is unclear. Whose "observations," whose "medical history," and what is "available information"? I redrafted this to read, "the person's observations," the mother's pertinent medical history" and other "information relevant" to the infant's prenatal exposure to alcohol.

2. The language you requested provides that *"[i]nformation described in this section that was obtained from statements of the mother made during the mother's examination that is confidential medical information of the mother may not be released without the consent of the mother, except upon court order, or as required by AS 47.17.024."* The committee substitute you requested makes changes to a provision that directs that certain information be recorded in an infant's medical file. This means that the mother's information is released to the infant's medical record. Any future provider of medical services to the infant will encounter the information provided by the mother in the infant's file. If the information obtained from the mother by a medical provider is not confidential, this is something of which she should be made aware. I'm not sure what the sense of "release" is supposed to be, but it does not seem to make sense in the context of what the bill requires.

Note too, that the concept of doctor-patient confidentiality would not apply just to "*confidential medical information of the mother*" but all noncriminal information shared by the mother in seeking the advice, care, and/or treatment of a physician for herself or her child. It is a generally accepted principle that individuals seeking medical help or

advice should not be inhibited by any fear that their medical concerns or conditions will be disclosed to others. Patients entrust personal knowledge of themselves to their physicians, which creates an uneven relationship in that the vulnerability is one-sided. There is usually an expectation that physicians will hold that special knowledge in confidence and use it exclusively for the benefit of the patient. See Alaska Rule of Evidence 504(b) which provides:

> **General Rule of Privilege.** A patient has a privilege to refuse to disclose and to prevent any other person from disclosing confidential communications made for the purpose of diagnosis or treatment of the patient's physical, mental or emotional conditions, including alcohol or drug addiction, between or among the patient, the patient's physician or psychotherapist, or persons who are participating in the diagnosis or treatment under the direction of the physician or psychotherapist, including members of the patient's family.

The committee substitute would have such information recorded in the infant's medical file, but not *"released without the consent of the mother, except for court order, or as required by AS 47.17.024."* I don't know how a court would interpret this language, but I believe that it is certainly possible that the changes affected by the committee substitute could be interpreted as an unconstitutional violation of a mother's right to privacy.

3. Senate Bill 267 requires a person licensed under AS 08.64 to document "*an infant's prenatal exposure to alcohol*" in the infant's medical file, and that the information "*may not be used except for the purposes of providing medical diagnosis, treatment, or care.*" AS 47.17.024 imposes a duty on practitioners of the healing arts to notify the Department of Health, Education and Social Services of an infant's condition that the practitioner has determined has been adversely affected by, or is withdrawing from exposure to, a controlled substance or alcohol. The duty imposed by AS 47.17.024 is a different duty than that created under the bill. SB 267 deals only with the documentation of information in an infant's medical file relating to a mother's consumption of alcohol, not a practitioner's determination that an infant has been adversely affected by alcohol. These are legally and practically distinct actions and responsibilities.

If you have any questions, please do not hesitate to contact me.

ALB:lmb
08-051.lmb

Enclosure

Don Burnell

From: Marilyn Dodd [akafp@gci.net]
Sent: Friday, February 29, 2008 2:44 PM
To: Sen. Bettye Davis
Subject: sb267

Attachments: ATT00001.htm; sb267.doc

RECEIVED
MAR 0 3 2008

ATT00001.htm (4 KB) sb267.doc (31 KB)

Maryann Roland, MD
President Elect, Alaska Academy of Family Physicians

Dear Senator Davis:

The Board of Directors of the Alaska Academy of Family Physicians represents over 365 primary care physicians who practice throughout Alaska. We oppose Senate Bill No. 267. This bill requires documentation in an infant's medical record any prenatal exposure to alcohol, but only with the mothers consent.

We believe this bill is unnecessary and has unintended legal consequences. Practitioners already have a statutory and ethical duty to report suspected alcohol or drug abuse affecting a child. The Medical Practice Act requires all pertinent information to be entered into a medical record. Furthermore, to restrict use of any information only for the purpose of providing medical diagnosis or treatment limits its use in any potential legal case. Since this would affect how evidence may be used, it may require a more wide-reaching change in court rules.

The benefits of early diagnosis and treatment for Fetal Alcohol Syndrome Disorder are undeniable. However, we do not believe this bill adds any encouragement to better document a medical history. It would not help with either early diagnosis or treatment. Therefore, we strongly urge that SB267 be defeated.

Sincerely,

Maryann Roland, M.D.
President Elect, AKAFP

Alaska Academy of Family Physicians

35565 Spur Highway #266, Soldotna, AK 99669 akafp@gci.net www.alaskaafp.org 907 258-2255 office 530 326-5612 fax

Maryann Foland, MD
President Elect, Alaska Academy of Family Physicians

Dear Senator Davis:

The Board of Directors of the Alaska Academy of Family Physicians represents over 365 primary care physicians who practice throughout Alaska. We oppose Senate Bill No. 267. This bill requires documentation in an infant's medical record any prenatal exposure to alcohol, but only with the mothers consent.

We believe this bill is unnecessary and has unintended legal consequences. Practitioners already have a statutory and ethical duty to report suspected alcohol or drug abuse affecting a child. The Medical Practice Act requires all pertinent information to be entered into a medical record. Furthermore, to restrict use of any information only for the purpose of providing medical diagnosis or treatment limits its use in any potential legal case. Since this would affect how evidence may be used, it may require a more wide-reaching change in court rules.

The benefits of early diagnosis and treatment for Fetal Alcohol Syndrome Disorder are undeniable. However, we do not believe this bill adds any encouragement to better document a medical history. It would not help with either early diagnosis or treatment. Therefore, we strongly urge that SB267 be defeated.

Sincerely,

Maryann Foland, M.D.
President Elect, AKAFP

25-LS1471\C
Bullard
3/3/08

CS FOR SENATE BILL NO. 267(HES)

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-FIFTH LEGISLATURE - SECOND SESSION

BY THE SENATE HEALTH, EDUCATION AND SOCIAL SERVICES COMMITTEE

Offered:
Referred:

Sponsor(s): SENATOR DAVIS

A BILL

FOR AN ACT ENTITLED

"An Act relating to requiring certain persons licensed by the State Medical Board to document an infant's prenatal exposure to alcohol in the infant's medical file."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

*** Section 1.** AS 08.64 is amended by adding a new section to article 3 to read:

Sec. 08.64.364. Health care professionals to document an infant's prenatal exposure to alcohol. (a) For the purpose of screening for fetal alcohol spectrum disorder, a person licensed under this chapter attending or making a postnatal examination of a mother and infant shall document the person's observations, the mother's pertinent medical history, and other information relevant to the infant's prenatal exposure to alcohol in the infant's medical file. Information described in this section that was obtained from statements of the mother made during the postnatal examination that is confidential medical information of the mother may not be released without the consent of the mother, except by court order, or as required by AS 47.17.024. The documentation must be in the form or format required by the

New Text Underlined [DELETED TEXT BRACKETED]

department.

(b) Except as provided in AS 47.17.024, information received under this section may not be used except for the purposes of providing medical diagnosis, treatment, or care of the infant.

(c) In this section, "infant" means a child who is less than 12 months of age.

permission for release

Jan - child in need of aid - exception of confidentiality

Michael Baldwin - Family clinician - Anchorage

Tim Kelley - concerns w/ original
forwarded copy to attorney

* Diane Casto
FAS administration
465-3033
Testify for SB 267
No parental consent

Rick Ionnoino 463-7373
Juneau

Don Burrell

From: Susan Hargis
Sent: Friday, February 01, 2008 2:02 PM
To: Sen. Bettye Davis
Cc: Thomas Obermeyer; Rep. Andrea Doll
Subject: FASD Bill
Attachments: HB0300A.pdf; HB300 FASD Sponsor Stmt.doc

Senator Davis,

Here's the bill and sponsor statement for the FASD bill. Rep Doll asked me to send it to you and your staff per your discussion.

Thanks for your support on it!

Regards,
Sudie Hargis
Office of Representative Andrea Doll
susan.hargis@legis.state.ak.us
(907) 465-3744

Leg liaison office SB 267
4021
Wilda

Alaska State Legislature
Representative Andrea Doll
House District 4

Sponsor Statement
HB 300 Documentation of Prenatal Alcohol Exposure

HB 300 requires certain health care practitioners making a post-natal examination to document information in an infant's medical record about the mother's alcohol consumption, if the mother provides consent. This information is vital for use in later diagnosis when children begin to show symptoms of abnormal development, and can help doctors determine whether or not the child may have Fetal Alcohol Spectrum Disorder (FASD).

The scope of the bill is purposely limited to alcohol and does not include drug use. The bill specifies that information related to a mother's use of alcohol can only be used for diagnostic and medical purposes, not as evidence against the woman's fitness or in an attempt to remove her custodial rights.

State Capitol, Juneau, AK 99801-1182 Phone: 907-465-3744 Fax: 907-465-2273
Rep_Andrea_Doll@legis.state.ak.us www.akdemocrats.org/doll

HOUSE BILL NO. 300

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-FIFTH LEGISLATURE - SECOND SESSION

BY REPRESENTATIVE DOLL

Introduced: 1/15/08
Referred: Labor and Commerce, Health, Education and Social Services

A BILL

FOR AN ACT ENTITLED

"An Act requiring certain persons licensed by the State Medical Board to document an infant's prenatal exposure to alcohol in the infant's medical file."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

*** Section 1.** AS 08.64 is amended by adding a new section to article 3 to read:

Sec. 08.64.364. Health care professionals to document an infant's prenatal exposure to alcohol. (a) For the purpose of screening for fetal alcohol spectrum disorder, a person licensed under this chapter attending or making a postnatal examination of a mother and infant shall document the infant's prenatal exposure to alcohol in the infant's medical file, if the mother provides her consent to the inclusion of the information in the infant's medical file. The documentation must be in the form required by the department.

(b) Information received under this section may not be used except for the purposes of providing medical diagnosis, treatment, or care.

(c) In this section, "infant" means a child who is less than 12 months of age.

SENATE BILL NO. 267

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-FIFTH LEGISLATURE - SECOND SESSION

BY SENATOR DAVIS

Introduced: 2/13/08
Referred: Health, Education and Social Services, Finance

A BILL

FOR AN ACT ENTITLED

"An Act requiring certain persons licensed by the State Medical Board to document an infant's prenatal exposure to alcohol in the infant's medical file."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

*** Section 1.** AS 08.64 is amended by adding a new section to article 3 to read:

Sec. 08.64.364. Health care professionals to document an infant's prenatal exposure to alcohol. (a) For the purpose of screening for fetal alcohol spectrum disorder, a person licensed under this chapter attending or making a postnatal examination of a mother and infant shall document the infant's prenatal exposure to alcohol in the infant's medical file, if the mother provides her consent to the inclusion of the information in the infant's medical file. The documentation must be in the form required by the department.

(b) Information received under this section may not be used except for the purposes of providing medical diagnosis, treatment, or care. of the child

(c) In this section, "infant" means a child who is less than 12 months of age.

reports can be made up to the age of 6
– birth defects registry

AMA Alaska, Medical Board

impl. is on educ. of med. professionals

title 18–

pre-existing condition? for insurance

Thomas Obermeyer

From: Rutherdale, Jan A (LAW) [jan.rutherdale@alaska.gov]
Sent: Friday, February 29, 2008 9:59 AM
To: Thomas Obermeyer
Cc: Sen. Bettye Davis; Laughlin, Wilda J (HSS)
Subject: SB 267 proposed amendment
Attachments: SB 267 amendment 022708

Hello Tom,
As we spoke on the phone, attached is a proposed amendment to the bill. The changes from the first version are in lines 6-12 and line 15. I'm hoping this amendment is self explanatory. It keeps the original bill's limitation to postnatal examinations, but, in our opinion, it cures the problem in the original bill – giving the mother veto power over information that the doctor gleans outside of the mother's statements (such as the doctor's observations or information from others) or the mother's statements made when the infant, not the mother, is the patient.

If you have any questions about this amendment or wish to discuss further, please let me know.
Jan

Jan Rutherdale
Deputy Section Chief
Child Protection Section
Attorney General's Office
(907)465-3608
Fax: (907)465-3019

Jana – Let's discuss.
Tom

MEMORANDUM
(Confidential)

DATE: February 25, 2008
TO: Senator Bettye Davis
FROM: Thomas S. Obermeyer
RE: SB 267 – Concerns by Department of law per attached notes by Asst. A.G., Jan Rutherdale, 2/24/08

Summary of Attorney Rutherdale's Comments

1. The bill may have the unintended result of requiring the physician or health practitioner, to act contrary to the best interests of the infant.
2. This bill, contrary to normal licensing practices, legislates "best practices" for a physician, with a new licensing section, AS 8.64.364, "Health care professionals to document an infant's prenatal exposure to alcohol."
3. AS 47.17.024, "Child Protection," already requires a "practitioner of the healing arts" to report to the department (OCS) if he/she determines the infant has been exposed to fetal alcohol. It follows that if the health practitioner reports harm, this information routinely is placed in the infant's file.
4. If OCS investigates and makes a finding of FAS, the mother's prenatal alcohol use may still wind up in the infant's file, regardless of this bill which addresses licensing and documentation of health care professionals.
5. This bill allows the mother to refuse documentation of her prenatal alcohol consumption in the infant's file, which is the only file that is permanent and will be forwarded with the child's history to other providers or institutions, or routinely called into question in evidentiary matters or discovery in legal proceedings for child custody, etc. concerning mother's prenatal alcohol use.
6. The file is the INFANT'S, not the mother's, not the doctor's. It is made for the benefit of the infant, not the mother, or doctor.
7. The doctor still must report to OCS under this bill, and if he/she cannot make a report to the infant file, he/she may wish to keep his/her own private separate file for protection from liability for malpractice. This auxiliary file serves no purpose but to protect the doctor, not the infant.

SB

279

MEMORANDUM

SENATOR FRED DYSON

Date: February 27, 2008

To: Senator Bettye Davis, Chair
Senate Health, Education, and Social Services Committee

From: Senator Fred Dyson

Sub: Request for Hearing – SB 279 – Notice and Consent for a Minor's Abortion

---

This memo is a request that you schedule SB 279 – "Notice and Consent for a Minor's Abortion" for a hearing in your committee at the earliest possible date.

I have attached a copy of the bill, a sponsor statement and bill packet for your use. Please contact Jeremy in my office if you have any questions (ex. 4729).

Thank you for your consideration. It is greatly appreciated.

ALASKA STATE SENATE

Contact:
Interim Address:
10928 Eagle River Road
Eagle River, AK 99577
(907)-694-6683
Fax# (907)-694-1015

Session

(907)-465-2199
FAX# (907)-465-4587
State Capitol
Room 121

Senator Fred Dyson

SPONSOR STATEMENT

SB 279 Parental Notification and Consent for a Pregnant Minor Aborting an Unborn Child

The issue of parental consent and the eleven-year struggle for protecting parental rights requires this complete picture for the legislature to address this subject.

On November 2, 2007 in *State of Alaska v. Planned Parenthood of Alaska*, the Alaska Supreme Court, in a 3 – 2 decision, has once again undermined a long line of case law, the intent of the Constitution, and the overwhelming support of the people of Alaska. SB 279 is a direct response to an active judiciary and an attempt to put this issue to rest once and for all.

Overriding the Governor's veto, the legislature passed the Parental Consent Act (PCA) in 1997. In July of that same year, Alaska Superior Court Judge Sen Tan ruled the law was unconstitutional because "the privacy clause of the Alaska Constitution protects minors as well as adults." The Superior Court did not address whether or not the PCA violated the privacy clause. The State appealed the decision and the Supreme Court ruled that the privacy clause extends to minors unless there is a compelling state interest using the least restrictive means available. The Supreme Court remanded the case back to Sen Tan to hold an evidentiary hearing to determine if PCA furthered a compelling state interest.

In January 2003 the Superior Court held a bench trial spanning almost three weeks to hear evidence regarding the constitutionality of the PCA. In October 2003, Judge Sen Tan ruled the PCA was unconstitutional because it did not further a compelling state interest while using the least restrictive means available. In January 2004 the Superior Court enjoined the State from enforcing the PCA declaring the PCA was unconstitutional under the equal protection and privacy clauses of the Alaska Constitution.

The primary purpose of the right to privacy is to protect Alaskans from **"unwarranted intrusions by the State"** (*Ravin,* P.2d 514). State law already requires parental consent for tattoos, immunization, school use of student information, body piercing, school travel for extra-curricular activities, marrying, entering the military, and all medical procedures except abortion. In the mental health profession, this is recognized as cognitive dissidence.

In its November 2, 2007 decision, the court agreed with the State that *"protecting minors from their own immaturity and aiding parents in fulfilling their parental responsibilities"* are *"compelling interests."* Therefore, the issue at hand for the court was whether the PCA was the least restrictive means of achieving the State's compelling interests.

SB 279 addresses the legal issues of parental consent in a practical manner based on the historical beliefs of our forefathers. The Parental Consent Act of 1997 was fully compliant with the U.S. Supreme Court precedent *Bellotti v. Baird,* (443 U.S. 622 1979). In essence, the Alaska Supreme Court in its November 2, 2007 decision struck down a decision of the U.S. Supreme Court. Justice Carpeneti eloquently wrote the dissenting decision stating the following:

> *"Because this court's rejection of the legislature's thoughtful balance is inconsistent with our own case law and unnecessarily dismissive of the legislature's role in expressing the will of the people, I respectfully dissent."*

The dissent opinion brought to light the lack of consideration or recognition in case law that *"children are not generally considered competent to consent to medical procedures."* It brought to light the four exemptions in the PCA, *"married minors, ... minors who have been legally emancipated, ...minors who have entered the armed services of the United States .and ...who have become employed and self-subsisting."* For those pregnant minors who did not fall into the four exempt categories a judicial bypass provision was provided for appropriate circumstances. It was a process designed to be speedy and cost-free to the child. The PCA called for a five-day response of the court; SB 279 calls for a three-day response. Failure by the court to respond in time would be construed as an act constructive authorization. The judicial bypass requires a sworn statement from the pregnant minor and an adult family member or state agent such as an Office of Children's Services caseworker or law enforcement officer.

Carpeneti discussed the fact that the Court quickly recognized that there was a compelling State interest but failed *to "look closely at the nature of the state's and parents' interests"* leaving *"its constitutional 'balance' one-sided."* Carpeneti continues in his dissent to outline case law that creates a judicial history of *"treating minors differently from adults," "protecting twelve-year-olds from older teenagers and from their own immaturity in choosing to participate in harmful activity,"* prohibiting minors from making contract to *"smoke cigarettes or drink alcoholic beverages or consent to sexual intercourse. Without a parent's consent they may not become licensed drivers or get married or obtain general medical or dental treatment."*

> *"In sum, the Alaska Parental Consent Act appears to be the product of a concerted effort to make certain that those pregnant girls who are sufficiently mature to make the decision to obtain an abortion on their own are allowed to do so while those who are not sufficiently mature either obtain a parent's consent or, in the case of parental abuse, a judicial determination that the procedure is in their best interest."*

In his dissenting opinion, Carpeneti uses the litmus test for parental consent that is required for participation in school field trips to demonstrating the extent to which the State must go to terminate parental rights is his argument:

"In addition to society's interest in protecting children from their own immaturity, we have long held that parents have a fundamental right in raising of their children."

Carpeneti's dissenting opinion determines that the State's compelling interest does outweigh the equal protection and privacy clauses because:

"In sum, the norm in American, and Alaskan, life and law is that the parents are a child's first and most important resource for assistance in decision-making. For that reason, the state's interest in protecting children from the consequences of their own immaturity, and in so doing protecting the health of its children, and its interest in supporting parents' right and duty to guide the upbringing of their children is particularly compelling."

SB 279 enacts the notification process that the Court determined is the least restrictive means of achieving the State's compelling interest but further continues to require parental consent unless the minor chooses a judicial bypass. It leaves intact the four exemptions from parental consent: *married minors, minors who have been legally emancipated, minors who have entered the armed services of the United States, and minors who have become employed and self-subsisting.*

I believe parental consent should be a part of Alaska Public Policy that recognizes the State's compelling interest in *"protecting minors from their own immaturity and aiding parents in fulfilling their parental responsibilities."* In addition to **parental consent**, SB 279 provides for a judicial bypass for sexual abuse cases using a ***lower standard than the 1997 PCA Act's clear and convincing*** provision, and a **provision prohibiting the parents from coercing a pregnant minor to have an abortion**.

In an era where government intrusion continues to be an issue with infr. gement on parental rights, it is time to reverse the trend and protect those principles our forefathers rooted in government to preserve our freedom and support traditional and essential parental rights.

ALASKA STATE SENATE

Contact:
Interim Address:
10928 Eagle River Road
Eagle River, AK 99577
(907)-694-6683
Fax# (907)-694-1015

Session:
(907)-465-2199
FAX# (907)-465-4587
State Capitol
Room 121

Senator Fred Dyson

SB 279 Penalties, Parental Notice, Parental Consent, and Judicial Bypass for an Abortion

SECTIONAL ANALYSIS

*** Section 1.** Adds a notice requirement to the consent requirement in AS 18.16.010(a). Section 3 sets out specific requirements for notice and consent

***Sec. 2.** AS 18.16.010(g) is reenacted to shift the burden of proof for prosecution of a physician who performs an abortion to the State. With the new statutory language all it takes to determine the standard for whether or not an abortion is required because of a medical emergency is the doctor's good faith, clinical judgment. The doctor should make one of the following findings:

(1) an immediate abortion of the minor's pregnancy is necessary to avert the minor's death; or

(2) a delay in providing an abortion will create a serious risk of medical instability due to a substantial and irreversible impairment of a major bodily function of the pregnant minor.

***Sec. 3.** Requires the physician performing the abortion or the referring physician to give actual notice to one legal parent or the legal guardian or custodian of the possible abortion. Is notice must be in person or by telephone. If in person, the parent or guardian must provide a government issued I.D. and provide documentation of their legal relationship with the minor requesting an abortion. If the notice is by telephone, the call must be initiated by the physician and the physician must take reasonable steps to verify the true identity of the person receiving notice and his or her relationship to the minor.

If the physician has exhausted efforts for notice in person or by phone, the physician can send written notice to the parent or guardian at the last known legal mailing address. This bill adjusts the waiting period to 48 hours after actual notice or 48 hours after the letter is deemed received. A letter is deemed received 48 hours after it is mailed, so that would be 96 hours. If the doctor actually talks to a parent, the waiting period would only be 48 hours.
One of the minor's parents or the minor's legal guardian or custodian has consented in a notarized writing to the performance or inducement of the abortion

Notice and consent is not required if the minor and a brother or sister of the minor who is over the age of 21, or a law enforcement officer, or a representative of state Child Protective services, or a grandparent, or a stepparent specified by the minor signs a notarized written statement certifying their personal knowledge of the abuse against the minor by a parent or guardian or sexual abuse by another person.

The other exceptions to notice and consent would be if a court issues an order under AS 18.16.030 authorizing the minor to proceed with the abortion without notice to the parent, guardian, or custodian or if a court, by its inaction under AS 18.16.030, constructively has authorized the minor to proceed with the abortion without notice to the parent, guardian, or custodian.

If the physician proceeds with the abortion proceeds after receiving notarized declarations of abuse, the physician performing or inducing the abortion must certify in the patient's medical record that he or she has received the written declarations of abuse or neglect abuse to and must report the abuse to OCS. Any physician who relies in good faith on written statements declaring abuse and who reports the abuse to Child Protection authorities shall not be civilly or criminally liable for failure to give notice to or to obtain consent from a parent, guardian or custodian. If the minor's pregnancy was the result of a sexual assault on the minor, the physician performing or inducing the abortion must retain, and take reasonable steps to preserve, the products of conception following the abortion for use by law enforcement authorities in any subsequent criminal prosecution of the assailant.

*** Sec. 4.** This amends AS 18.16.030, **Judicial bypass for minor seeking an abortion.** (a) A woman who is pregnant, unmarried, under 17 years of age, and unemancipated who wishes to have an abortion without notice to and without the consent of a parent, guardian, or custodian may file a complaint in the superior court requesting the issuance of an order authorizing the minor to proceed with the abortion without notice to the parent, guardian or custodian and/or to consent to the performance or inducement of an abortion without the consent of a parent, guardian, or custodian.

In the interest of shortening any delays in the process of obtaining the judicial bypass, subsection (c) reduces from five to three days the time in which Superior Court must render a decision on a judicial bypass. If the court does not issue a decision in three days the inaction will be considered a constructive order.

*** Sec. 5.** Adds notice to process for filing for judicial bypass without notice to and the consent of a parent, guardian, or custodian.

***Sec. 6.** Requires the court to hold a hearing not later than the third business day after a judicial bypass complaint has been filed. This reduces the deadline from five to three days for expediency purposes.

Sec. 7. Amends provisions for an appeal to a dismissed complaint for judicial bypass by adding notice language and reducing the timeline from four to three days the superior court has to deliver a copy of the appeal to the supreme court.

Sec. 8. Provides for a minor requesting a judicial bypass can request the superior court issue an order directing the minor's school allow the minor to attend a judicial bypass hearing and prohibits the school from notifying the parents, guardian, or custodian

***Sec. 9.** This is a new section of the law prohibiting a parent, guardian, custodian, or any other person from coercing a pregnant minor to have an abortion performed. If a minor is denied financial support by the minor's parents, guardian, or custodian due to the minor's refusal to have an abortion performed, the minor shall be deemed emancipated for the purposes of eligibility for public assistance benefits, except that such benefits may not be used to obtain an abortion. As used in this Section, "coercion" means restraining or dominating the choice of a minor female by force, threat of force, or deprivation of food or shelter.

Requires physicians to submit monthly reports to the Department Health and Social Service on forms prescribed by the department reporting the following:

1. the number of consents obtained under this law
2. the number of times in which exceptions were made to the consent requirement under this law
3. the type of exception, the minor's age
4. the number of prior pregnancies and prior abortions of the minor

No patient names are to be used on the forms. The Department is required to make a compilation of the data reported available to the public on an annual basis.

***Sec. 10.** Direct court rule change adding notice to consent provisions of Rule 220(a) Rules of Appellant Procedure, scope of judicial bypass appeals. It also contains language cleanup from revisor that replaces "parental consent" with consent of a parent, guardian, or custodian.

***Sec. 11.** Direct court rule change adding notice to consent provisions of Rule 220(c)(1) Rules of Appellant Procedure, notice of judicial bypass appeals. It also contains language cleanup from revisor that replaces "parental consent" with consent of a parent, guardian, or custodian.

***Sec. 12.** Direct court rule change amending Rule 220(a) Rules of Appellant Procedure, constructive order of judicial bypass appeals. It reduces from five to three days the deadline for the appellant to receive a constructive order because the court did not enter an order on an appeal.

***Sec. 13.** Direct court rule change adding "notice" to consent language in Rules of Probate Procedure Rule 20(a), Petition for Judicial Bypass Procedure to Authorize Minor to Consent to an Abortion.

***Sec. 14.** Direct court rule change adding notice to consent provisions of Rule 20(e) Rules of Probate Procedure, Findings and Order of Judicial Bypass Procedure to Authorize Minor to Consent to an Abortion.. It also contains language cleanup from revisor that replaces "parental consent" with consent of a parent, guardian, or custodian.

***Sec. 15.** Direct court rule change adding notice to consent provisions of Rule 20(f) Rules of Probate Procedure, Findings and Order of Judicial Bypass Procedure to Authorize Minor to Consent to an Abortion. It reduces from five to three days the deadline for the appellant to receive a constructive order because the court did not enter an order on an appeal.

***Sec. 16.** Indirect court rule amendment of Rules of Civil Procedure Rule 24(a) Right to Intervention by providing of a legislative right to intervention in Section 18.

***Sec. 17.** Severability clause.

***Sec. 18.** This new provision of law allows the Legislature, by joint resolution or by and through the Legislative Council, to appoint one or more of its members who sponsored or co-sponsored this Act, as a matter of right and in his or her official capacity, to intervene to defend this law in any case in which its constitutionality is challenged.

***Sec 19.** The enactment of Section 18, legislative right to intervention, is contingent on a two-thirds vote approval on indirect court rule amendment of Rules of Civil Procedure Rule 24(a) Right to Intervention.

***Sec. 20.** This Act takes effect within thirty (30) days of its enactment.

SB

280

SENATE COMMITTEE REPORT
First Committee of Referral

DATE: 2/19/08

FURTHER: Labor and Commerce
Finance

Date of 5-Day Notice: 3/6/08
(in accordance with Uniform Rule 23)

DATE TURNED IN TO OFFICE: 3/26/08

Health, Education and Social Services Committee considered SENATE BILL NO. 280

SB 280 MEDICAID/ INS FOR CANCER CLINICAL TRIALS

"An Act requiring health care insurers to provide insurance coverage for medical care received by a patient during certain approved clinical trials designed to test and improve prevention, diagnosis, treatment, or palliation of cancer; directing the Department of Health and Social Services to provide Medicaid services to persons who participate in clinical trials; relating to experimental treatments; and providing for an effective date."

and recommends:

[✓] be **replaced** with [ ] **SCS** or [✓] **CS** SB 280 (HES)

[ ] adopt **previous** [ ] **SCS** or [ ] **CS** ____ CS · Forthcoming ____)

[ ] attached amendment(s)

[ ] adopt _____ Letter of Intent

[ ] further referral to _____ Committee

SENATE BILL:
[ ] Same Title
[ ] New Title

HOUSE BILL:
[ ] Same Title
[ ] Technical Title Change
[ ] New Title w/ SCR #____

NEW FISCAL NOTE(S):

Department	Date	Fiscal		
HSS	3/6	✓		

PREVIOUS FISCAL NOTE(S):

Department	Date	Fiscal	Index		SCR #

[ ] **APPROPRIATION - no fiscal note**

SIGNATURE AND RECOMMENDATION	PRINT LAST NAME	DO PASS	DO NOT PASS	NO REC	AMEND
	Elton			✓	
	Thomas	✓			
	Coe[illegible]			✓	
	Dyson			✓	
CHAIR: Betty Davis	Davis	✓			

Alaska State Legislature

Interim: (May - Dec.)
716 W. 4th Ave
Anchorage, AK 99501
Phone: (907) 269-0144
Fax: (907) 269-0148

Session: (Jan. - May)
State Capitol, Suite 30
Juneau, AK 99801-1182
Phone: (907) 465-3822
Fax: (907) 465-3756
Toll free: (800) 770-3822

Senator_Bettye_Davis@legis.state.ak.us
http://www.akdemocrats.org

Senator Bettye Davis

CS for Senate Bill 280, 25-LS1464\C (3/6/08)

"An Act requiring health care insurers to provide insurance coverage for medical care received by a patient during certain approved clinical trials designed to test and improve prevention, diagnosis, treatment, or palliation of cancer; directing the Department of Health an Social Services to provide Medicaid services to persons who participate in clinical trials; relating to experimental procedures; and providing for an effective date."

SPONSOR STATEMENT

Clinical trials are research studies that test how well new medical approaches work in patients. Each study answers scientific questions and tries to find better ways to prevent, screen for, diagnose, or treat disease. Patients who take part in cancer clinical trials have an opportunity to contribute to the knowledge of, and progress against cancer. They also receive state-of-the art treatment from experts in the field. The National Cancer Institute, as part of the U.S. National Institutes of Health, reports 6,000 cancer trials in the United States any one time. They include trials in prevention, screening, diagnosis, treatment, quality-of-life, and genetic studies.

SB 280 removes important barriers to the participation of patients in cancer clinical trials in Alaska. It requires that all health care plans, including Medicaid, cover routine patient care costs for patients enrolled in all phases of clinical trials, including prevention, detection, treatment, and palliation (supportive care) of cancer. Currently Alaska health plans can exclude coverage for routine patient-care costs while a patient with cancer is enrolled in a clinical trial. Providers of health care plans often conclude that money is saved by excluding care while patients participate in clinical trials. But these patients, if not enrolled in clinical trials, will continue to receive conventional therapy at roughly the same or slightly increased costs in the short-run.

Studies have shown that only 2-3 percent of eligible adult patients enroll in clinical trials with a 6.5% increase in costs for clinical trial participants compared to nonparticipants. (National Conference of State Legislatures, www.ncsl.org/programs/health/clinicaltrials.htm, accessed 2/27/08) Without in-state facilities and support of clinical trials participants in Alaska currently have to travel out of state, increasing the cost of non-emergency transportation which is about 3% of total Medicaid costs.

In FY 2007 an estimated 4,600 patients received cancer treatments through Alaska's Medicaid program at a cost of $21.5 million. The average payment per beneficiary was about $4,675. The federal government reimburses the state at about 50% of the total costs. Based on an estimated 2.5% participation rate per above, about 115 patients are expected to participate in clinical trials each year. A 6.5% increase for 115 persons would add $35.00 per year to Medicaid for cancer treatments. Non-emergency transportation costs for the same group are estimated to add another $15.00 per year. The fiscal note adds an estimated $50,000 per year with the federal government paying half of this.

Twenty-three states have passed legislation or instituted special agreements requiring health plans to pay the cost of routine medical care patients receive while participating in clinical trials. Passage of SB 280 will result in more successful outcomes in cancer treatments in Alaska, increase retention of patients in Alaska for their cancer care, and also, after full implementation, result in cost savings in the short and long term.

25-LS1464\C
Bailey
3/6/08

CS FOR SENATE BILL NO. 280( )

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-FIFTH LEGISLATURE - SECOND SESSION

BY

Offered:
Referred:

Sponsor(s): SENATOR DAVIS

A BILL

FOR AN ACT ENTITLED

"An Act requiring health care insurers to provide insurance coverage for medical care received by a patient during certain approved clinical trials designed to test and improve prevention, diagnosis, treatment, or palliation of cancer; directing the Department of Health and Social Services to provide Medicaid services to persons who participate in those clinical trials; relating to experimental procedures; and providing for an effective date."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

*** Section 1.** AS 21.42 is amended by adding a new section to read:

Sec. 21.42.410. Coverage for clinical trials related to cancer. (a) A health care insurer that offers, issues for delivery, delivers, or renews a health care insurance plan in the state shall provide coverage for the costs of medical care incurred by a patient enrolled in an approved clinical trial related to cancer, including the costs of prevention, detection, treatment, and palliative care of cancer. The coverage to be

provided must include leukemia, lymphoma, and bone marrow stem cell disorders. For purposes of this subsection, 'approved clinical trial related to cancer" means a scientific study using human subjects designed to test and improve prevention, diagnosis, treatment, or palliative care of cancer, or the safety and effectiveness of a drug, device, or procedure used in the treatment of cancer if the study is approved by

(1) an institutional review board that complies with 45 CFR Part 46; and

(2) one or more of the following:

(A) The United States Department of Health and Human Services, National Institutes of Health, or its institutes or centers;

(B) The United States Department of Health and Human Services, United States Food and Drug Administration;

(C) The United States Department of Defense;

(D) The United States Department of Veterans' Affairs; or

(E) a nongovernmental research entity abiding by current National Institute of Health guidelines.

(b) The cost of medical care required under (a) of this section includes payment for the costs of medical care regardless of where treatment in a clinical trial is administered.

(c) This section does not apply to a fraternal benefit society.

(d) In this section, "cost of medical care"

(1) means the amount paid for

(A) diagnosis, care, mitigation, treatment, or prevention of disease; or for the purpose of affecting any structure or function of the body, including the use of a drug, device, or procedure and the medically necessary services required to administer the drug or use the device;

(B) a drug or device approved for use by the Food and Drug Administration regardless of whether the Food and Drug Administration has approved the drug or device for use in treating the patient's particular condition and the medically necessary services to administer the drug or to use the device; and

(C) transportation primarily for and essential to medical care described in this paragraph;

(2) does not include amounts paid for

(A) an item that is the subject of investigation in a clinical trial that does not meet the criteria set out in (1)(B) of this subsection; or

(B) the costs incurred by the sponsor of a clinical trial for data collection or analysis.

*** Sec. 2.** AS 21.55.140(a) is amended to read:

(a) A state plan may not provide benefits for charges for the following:

(1) care for an injury or disease either

(A) arising out of and in the course of an employment subject to a workers' compensation or similar law or where the benefit is available to be provided under a workers' compensation policy or equivalent self-insurance to a sole proprietor, business partner, or corporation officer; or

(B) to the extent benefits are payable without regard to fault under a coverage statutorily required to be contained in a motor vehicle or other liability insurance policy or equivalent self-insurance;

(2) treatment for cosmetic purposes other than surgery for the prompt repair of an accidental injury sustained while covered or for replacement of an anatomic structure removed during treatment of tumors;

(3) travel, other than transportation covered under AS 21.55.110(17);

(4) private room accommodations to the extent it is in excess of the institution's most common charge for a semiprivate room;

(5) services or articles to the extent that the charge exceeds the reasonable charge in the locality for the service;

(6) services or articles that are determined not to be medically necessary, except for the fabrication or placement of the prosthesis as specified in AS 21.55.110(12) and (2) of this subsection;

(7) services or articles that are not within the scope of the license or certificate of the institution or individual rendering the services or articles;

(8) services or articles furnished, paid for, or reimbursed directly by or

under any law of a government, except as otherwise provided in this chapter;

(9) services or articles for custodial care or designed primarily to assist an individual in the activities of daily living;

(10) service charges that would not have been made if no insurance existed or that the covered individual is not legally obligated to pay;

(11) eyeglasses, contact lenses, or hearing aids or the fitting of them;

(12) dental care not specifically covered by this chapter;

(13) services of a registered nurse who ordinarily resides in the covered individual's home, or who is a member of the covered individual's family or the family of the covered individual's spouse;

(14) experimental procedures**, except during an approved clinical trial related to cancer; in this paragraph, "approved clinical trial related to cancer" has the meaning given in AS 21.42.410(a)**; and

(15) services and supplies for which the patient was not charged.

*** Sec. 3.** AS 47.07.030 is amended by adding a new subsection to read:

(e) The department shall provide the services set out in (a) and (b) of this section to an eligible person, notwithstanding the person's participation in an approved clinical trial related to cancer. In this subsection, "approved clinical trial related to cancer" has the meaning given in AS 21.42.410(a).

*** Sec. 4.** This Act takes effect January 1, 2009.

LEGAL SERVICES

DIVISION OF LEGAL AND RESEARCH SERVICES
LEGISLATIVE AFFAIRS AGENCY
STATE OF ALASKA

(907) 465-3867 or 465-2450
FAX (907) 465-2029
Mail Stop 3101

State Capitol
Juneau, Alaska 99801-1182
Deliveries to: 129 6th St., Rm. 329

MEMORANDUM February 18, 2008

SUBJECT: Sectional summary relating to mandatory insurance for clinical trials (Work Order No. 25-LS1464\A)

TO: Senator Bettye Davis
Attn: Tom Obermeyer

FROM: Dennis C. Bailey
Legislative Counsel

You have requested a sectional summary of the above-described bill.

As a preliminary matter, note that a sectional summary of a bill should not be considered an authoritative interpretation of the bill and the bill itself is the best statement of its contents.

Section 1. Requires a health care insurer to provide coverage for approved clinical trials related to cancer.

Section 2. Amends the restrictions on state plan benefits, which otherwise prohibit a benefit for experimental procedures, by creating an exception for approved clinical trials related to cancer.

Section 3. Directs the state Medicare program to provide services to persons who participate in approved clinical trials related to cancer.

Section 4. Provides for an effective date.

DCB:med
08-106.med