Chapter 13

Prenatal and Postnatal Intervention Strategies for Alcohol-Abusing Mothers in Pregnancy

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Historical Perspective on FAS and Early Prevention/Intervention Efforts.

In 1973, when Fetal Alcohol Syndrome (FAS) came to public awareness with the work of Jones et al (1973) and Jones and Smith, (1973) in the United States, and the work of Lemoine and colleagues (1968) in Nantes, France, questions arose about the link between maternal alcohol abuse and this birth defect in children. By 1977, in connection with a research study at Boston City Hospital, Rosett and colleagues (1976; 1977; 1978; 1981) had developed a “5-Question Screening Interview” for pregnant alcohol-abusing women with the aim of quantifying their alcohol use and helping them have healthier babies. In the same decade, epidemiologic studies were starting to demonstrate adverse offspring effects of prenatal alcohol exposure (Little 1977; Harlap and Shiono 1980; Kline et al 1980).

The Pregnancy and Health Program and other FAS prevention programs.

By 1978, the National Institute of Alcohol Abuse and Alcoholism (NIAAA) funded two FAS prevention programs, including one in Seattle to conduct a community-wide program to address the problem of female alcohol abuse during pregnancy and to prevent Fetal Alcohol Syndrome: The “Pregnancy and Health Program,” or “PHP” (Little et al 1980). Throughout its two years of operation, the main message was “When you’re pregnant, the best drink is no drink at all.” The community was alerted with posters, public service announcements on radio and television, and signs in all Seattle buses (Figure 1). We developed a 24-hour, 7-day per week prenatal alcohol hotline, “5-HEALTH” staffed by professionals and highly trained volunteers, to which one in every 44 pregnant women in Seattle phoned in for help or information (Little et al 1984).

Fliers were inserted into all purchases of alcoholic beverages at Washington State Liquor Stores, and made available at other public venues such as libraries. A team of professional colleagues were trained as trainers, who then educated 6,300 similar professionals who might encounter a pregnant woman or her child (physicians, nurses, alcoholism counsellors, social workers, psychologists, and teachers). We distributed 220,000 informational brochures and posters from nearly 5,000 locations in the area, and provided free evaluations for 151 children who were alcohol-exposed in utero, and made recommendations to their families. We screened at two Seattle hospital prenatal clinics for women drinking at risky levels, and found two simple questions that identified 92% of the women we believed to be at general risk in terms of pregnancy outcome: “Did you ever during the pregnancy drink 5 or more drinks on any occasion?” and “Did you ever feel you should cut down on your drinking?” We also provided risky-drinking mothers with feedback and up to three brief interventions, followed by referrals to alcohol-counselors, whom we had also trained (Little et al 1985). A total of 304 pregnant women were personally seen and given information and/or treatment for alcohol problems as needed. For these women, entry into the program was associated with a significant decrement in drinking, and this, in turn, was related to healthier infants.
at birth. Intervention in drinking during pregnancy was found to be feasible and to provide positive results (Little and Streissguth 1987).

Community surveys conducted on 474 King County residents, before PHP (1979) and after PHP (1981), revealed a high level of awareness of the risks of drinking during pregnancy even before the program began (Little et al 1981; 1984). Initially, obstetricians were the only group surveyed who had less than 90% awareness; but by 1981 their awareness of risks of drinking during pregnancy had risen from 76% to 96%. Belief in abstinence during pregnancy in the King County sample increased from 16% to 21% during PHP, while health professionals’ belief in abstinence during pregnancy (other than doctors) increased from 43% to 56%. In another aspect of the study, we obtained permission from local obstetricians (n = 41 pre and 47 post) to also query over 300 of their patients. To our surprise, at the outset of PHP, more pregnant women (47%) believed in abstaining from alcohol during pregnancy than did their own obstetricians (12%) (Little et al 1983). These data validated the importance of direct public education.

Although a comprehensive model program had been established for detecting and helping babies born to risky-drinking mothers, there was not enough lead time to incorporate the program into the ongoing health care delivery system before a new federal administration was installed, federal funding ended, and the program came to an abrupt halt. Although the basic ingredients of a comprehensive community FAS prevention program were outlined, it was not until a decade later that it was possible to develop another demonstration-intervention program, this time targeting very high risk, alcohol-abusing mothers, picked up in hospital after delivery: the Parent-Child Assistance Program (PCAP) originally known as Birth-to-3. This second time, we had a better understanding of the importance of working very closely with the community to develop a program that could fit into the existing public health structure and would continue after the termination of federal demonstration funds.

After these early prevention programs were developed in conjunction with research projects in Boston and Seattle, there was little formal activity on the prevention front until the late 1980’s, when May and Hymbaugh (1989) and Masis and May (1991) published an inexpensive, macro-level FAS prevention program for Native Americans and Alaskan Natives that educated trainers in local communities across the United States in comprehensive prevention skills and provided technical assistance for developing local programs. For little more than $300,000, May and Hymbaugh trained almost 2,000 people in 92 Indian Health Service Units. Using 8-hour workshops and resource materials developed and provided by a central source, the prevention program capitalized on local talent, enthusiasm, and commitment.

In 1980, Shaywitz and colleagues published data on a white middle class population in New Haven, Connecticut. The 10 mothers of these 15 children were all alcoholic at the time of the pregnancy. At the time of the study, when the children ranged from 6.5 to 18 years, 2 of the 10 mothers were dead; 4 of 8 were undergoing treatment for alcohol-related disabilities, and 5 of 8 were divorced. Although the children had a mean IQ
score of 98 (range 82 to 113) all were heavily alcohol-exposed *in utero*, all had experienced early school failure, and all but one was hyperactive. This was one of the earliest reports of increased mortality among mothers of children with FAS.

**International programs for prevention of FASD**

In 1980, NIAAA funded the first International Workshop on Alcohol and Pregnancy, held May 2-4, in Seattle (Streissguth et al 1981). The concept of “fetal alcohol effects” was introduced in addition to classical FAS: “One finds every gradation from FAS to milder effects of alcohol on the developing fetus,” (Smith 1981). In Sweden, Olegård, who began diagnosing newborns in the mid-1970’s, the prevalence is reported at 1 per 300 women for the partial FAS and 1 per 600 for the full FAS (Olegård et al 1979). Majewski (1981) reported 108 children with “alcohol embryopathy,” (AE) from a German population, which he rated on a point system of severity. He found that the degree of AE was related to the stage of maternal alcoholism, and that, with siblings, the younger was more severely affected than the elder. (Dehaene et al 1981 in France, had published the same with respect to decreasing birthweight among later siblings of alcoholic mothers). Eight Seattle children were presented at this meeting who were diagnosed in infancy (Darby et al 1981). Of these, four had been diagnosed at birth and the mothers of all four were dead by the follow-up exam between 4 and 6 years later, possibly a reflection of advanced stages of alcoholism. Silva et al (1981) demonstrated that women from the favelas of São Paulo, Brazil who drank “pinga” (sugar cane alcohol) heavily during pregnancy had more babies with fetal alcohol effects (short palpebral fissures, microcephaly, and small size for gestational age) than comparable women from the same impoverished environment who drank moderately or not at all.

In Finland, the first child with FAS was diagnosed in 1979, and by 1983, Finnish researchers had begun a major campaign to counsel women in antenatal clinics to reduce their drinking during pregnancy. Thus began a series of studies on the children of these mothers (Halmesmäki 1988; Autti-Rämö, 2000) and the conclusion that decreasing alcohol use in the first trimester was the most efficacious for offspring. Of the 41 children located at 12 years, 8 of the mothers were dead and 4 had been in prison. Studies were now showing the toll of maternal alcoholism on the mothers as well as the offspring.

As a result of these findings abstinence was recommended officially in the US by the Surgeon General in 1981 (Figure 2). “Women who are, or plan to become, pregnant are advised to abstain; health professionals who care for them are urged to ask routinely about alcohol consumption and enter this information into the medical record.” His statement followed publication of a summary paper reviewing the available evidence at the time (Eckardt et al 1981). France followed suite in 2004.

**Study of adolescents and adults with FAS/FAE and their mothers**

To obtain information on the long term implications of FAS and FAE, our Seattle team examined 61 adolescents and adults who had been diagnosed earlier by the
dysmorphologists in Seattle, Vancouver B.C., and on Indian Reservations of the South West, and reviewed their medical records. The findings had important public health implications: 31% of these patients had never been cared for by their biologic mothers and among those who were initially cared for by their mothers, the average age they stopped living with their mothers was 3 1/2 years. A surprising 69% of the biologic mothers were known to be deceased (Streissguth, Aase, et al 1991).

We now know that women get drunk faster, become addicted quicker, and die of alcohol-related disorders after fewer years of drinking than do men (Schenker 1997; Wagnerberger et al 2007). Separate treatment facilities for women are now recognized as essential. Yet, according to one 1989 report (the year of most recent data) less than 14% of all women and 12% of pregnant women in the U.S., who needed substance abuse treatment, received it (Califano 2007).

By 1988, there were numerous programs involving public education, professional training, and services to educate women about the risks associated with drinking during pregnancy. They centred around the common theme of abstinence during pregnancy: “No Alcohol for our Baby,” “For Baby’s Sake, Don’t Drink,” “A Pregnant Woman Never Drinks Alone” (Robinson and Armstrong 1988).

In Sweden, with free medical care and a tradition of full prenatal care for all women, FAS prevention programs were quickly built into existing, widely-used, district maternal and child health clinics throughout the country. District social services offices monitored child welfare and provided finances, housing, and psychological support as needed, to 99% of all Swedish women (Olegård 1988). Each regional clinic included a pediatractician, an obstetrician, a child psychologist, and a coordinator responsible for continuing education of professionals. Confidentiality rules, which they believed had perpetuated secrecy and prevented sharing of critical information, were changed to permit professionals and authorities to exchange information in the interest of the unborn child: a huge step forward. Emphasis was placed on providing midwives with plenty of time to discuss alcohol use and abuse patterns with women at their first prenatal visit, and the availability of suitable alcohol treatment programmes. As a result of these initial programmes, Olegård (1988) reported that the estimated incidence of FAS in Sweden had dropped from 1 in 600 in the mid-1970s to 1 in 2,400 infants by the mid-1980s.

A decrease in FAS incidence was also observed in Roubaix, France (Dehaene 1995; Dehaene et al 1991), where systematic diagnoses of newborns with FAS had been ongoing since 1977, and special community programmes for their mothers had been developed (Titran 1993). More recently, Haver and colleagues (2001) have described the successful treatment of 120 women in special woman-oriented inpatient and outpatient treatment programmes in Sweden.

**Warnings about alcohol use by pregnant women**
In the U.S during this period, public policy continued to move forward but not without controversy. In 1988 the U.S. Congress mandated warning labels on all alcohol beverage containers, after an initial failed attempt in the early 1980’s. Finally, cities and states in the U.S. began to post warning signs about not drinking during pregnancy, beginning with New York City in 1988. In 1993, Washington State adopted a state ordinance: three warning signs were approved and each venue selling alcohol by container or by glass, was required by law to post two such signs (Figure 3). Many other states and cities have followed (Streissguth 1997).

In October 2006, France became the first European country to mandate bottle labeling. Figure 4 shows the catchy logo and the clear warning. Earlier, in 2004, France had issued a government warning “La consommation de boissons alcooliques pendant la grossesse, même in faible quantité, peut avoir des conséquences graves sur la santé de l’enfant.” South Africa followed in 2007, after several studies revealed the highest prevalence of FAS yet reported in the world: namely 40.5 to 46.4 per 1000 in a study of children aged 5-9 and their mothers in several wine-growing areas of the Western Cape Province (May et al 2000; 2005).

Changes in alcohol use by pregnant women across time in Seattle

In 1974/75 and 1980/81, we studied two cohorts of pregnant women (approximately 1500 in each cohort) who were interviewed prior to the 6th month of pregnancy by specially trained nurse/interviewers not part of the clinic staff (Streissguth et al 1983). The number of women, who reported any alcohol use around the time of the first prenatal visit, dropped from 81% in 1974/75 to 42% in 1980/81. The number of binge drinkers (≥5 or more drinks on any occasion) prior to pregnancy recognition was 19% and 17%, for the two studies respectively, not a significant difference. But, the number of binge drinkers during pregnancy decreased from 12.2 to 7.5 (highly significant).

Between 1989 and 2004 in the Seattle area, we carried out 3 more screening studies, this time of over 12,000 women in hospital following delivery (Grant et al, 2009). As in our earlier study, we again found a substantial decrease in any alcohol use during pregnancy (from 30% to 12%) across almost all demographic groups. We also found that the rates of binge alcohol drinking (≥5 drinks on any occasion) during pregnancy decreased across studies, 3%, 4%, 1% respectively. However, we found that binge drinking in the month or so before women knew they were pregnant, increased significantly over this time period (among all racial categories except Native American). These data from this latest study calls for increased attention to the concept of stopping alcohol use when you plan to have a baby, rather than after you know you are pregnant, in order to avoid offspring exposure prior to pregnancy recognition.

Postnatal interventions and prevention of intergenerational alcohol abuse.

In Northern France, a neonatologist, Ph. Dehaene, began diagnosing newborns with FAS in the early 1980’s (Dehaene et al 1981), beginning his ongoing documentation of
the birth prevalence FAS in Roubaix (Dehaene et al 1991). M. Titran, a pediatrician, helped organize an early social/rehabilitative program for mothers with young children with FASD and other problems called the “Tuesday Group,” which is still ongoing. The objective was to promote parental competence and behaviour in order to increase the mothers’ capacity to successfully nurture their children. (Titran 1993). These families had high rates of medical and social problems including poverty, violence, exclusion, and alcohol abuse. The program operates through CAMSP (“Centre d’Action Médico-Sociale Précoce” of Roubaix), which provides day care and residential care as needed for such children. The mothers call their group E.S.P.E.R. (“Hope” in English), an acronym from the French words: “Ecoute, Santé, Parents, Enfants, Respect” (Dumaret 2007). Mothers and pregnant women meet weekly as a group with the same professionals, primarily targeting families with transgenerational alcoholism. The key concept is continuously accessible support. In a study of 22 white families assessed 7 years after their participation ended (mandatory when children were age 6) Dumaret and colleagues found that alcohol abuse, violence, and child neglect had decreased significantly (Dumaret, Constantine-Kuntz et al 2009). All but 2 of the maternal grandmothers were alcoholic, 14 mothers had FASD and 8 of their children had FASD. IQ tests administered to mothers and children, revealed an 18 point IQ difference between mothers with and without FASD and between children with and without FASD. Familial alcohol problems predicted school failure even in the absence of FASD. Three quarters of the families lived below the poverty level. Special education and institutionalization were higher for children with FASD, but accumulation of alcohol problems in the family still predicted school failure, even in the absence of FASD (Dumaret, Cousin et al 2009).

In 1996, the French government began ongoing clinical studies to identify children with FAS in the French province of Réunion Island in the Indian Ocean. Lesure had originally reported a rate of FAS at 6 per 1,000 births, and this was confirmed by Maillard et al 1999. As in Roubaix, the identification of numerous babies with FAS spearheaded prevention programs (Lamblin et al 2008) as well as active groups of mothers and pregnant women with alcohol problems, and professionals working together, focused around the CAMSP programs.

It is now clear that the prevention of future infants with FAS requires continuing postnatal intervention with the birth mother following the birth of an exposed index child, and especially following the birth of a child with FASD. High-risk mothers will still need continued help with their lives and their sobriety as they resume life with a newborn baby. They need to continue decreasing alcohol and substance use, engage in successful contraception, and build healthy, meaningful lives for themselves and their children before having future pregnancies. They can’t do this alone, so we developed a specialized program in Washington State to meet their complex needs (Grant et al 2005; 2007).

**The Parent-Child Assistance Program: PCAP**
PCAP (originally known as Birth-to-3 because it’s a 3-year program) is an intensive home-visitation intervention that works with very high-risk mothers who abused alcohol or drugs heavily during pregnancy and are estranged from usual community service providers. PCAP is an advocacy/case management model that offers personalized support over three years, a period of time long enough for the process of gradual and realistic change to occur. The primary aim of the intervention is to prevent future alcohol and drug exposed births among high-risk mothers who have already delivered at least one exposed child. To achieve this aim, highly trained and well supervised PCAP case managers with a caseload of 16, work with clients for 3 years beginning during pregnancy or within six months after the birth of an index child (Grant et al 2003).

**PCAP:**
**Recruiting high risk mothers**

When PCAP first began, we recruited women in hospital, the day after they delivered their babies. We had already developed a one-page Hospital Screening Questionnaire ("HSQ") (Streissguth, Grant, et al 1991) that we had used successfully to screen over 7,000 immediately post-partum mothers. The HSQ is a confidential, self-report instrument distributed to each mother in hospital. It asks about demographic characteristics and use of any alcohol, binge alcohol (5 or more drinks on an occasion), illicit drugs, and cigarettes during two time periods: the “month or so before pregnancy” and “during this pregnancy.” The HSQ can be scored with the Binge Alcohol Rating Criteria (BARC) (Barr and Streissguth 2001). Women who acknowledge binge drinking (5 or more alcohol drinks on an occasion for either time period), or who acknowledge illicit drug use, are invited to participate in PCAP if they are not already effectively engaged with community service providers. Now, after many years of operation, PCAP receives most referrals directly from service providers so hospital screening is unnecessary. We now strive to enroll substance-abusing women as early in pregnancy as possible, so we no longer use the postpartum HSQ to identify potential participants. However, in starting PCAP in a new community, the HSQ would still be useful to routinely identify women who are not known to community service providers and are in need of help, especially those who come to the hospital to deliver, without receiving prenatal care.

**PCAP:**
**The clients**

Most of the mothers in PCAP experienced as children many of the same devastating circumstances their own children are now experiencing, and the same circumstances we find in mothers of children with FASD: chronic familial substance abuse, poverty, violence, and neglect. The typical PCAP client was born to substance abusing parents. She was physically and/or sexually abused as a child, she did not complete high school and began to use alcohol and drugs herself as a teenager. She is now in her late 20s, has been in jail more than once, and has been through drug treatment and relapsed. She does not use birth control or plan her pregnancies, and now has three or more children, with at least one in the foster care system. Her current partner is abusive, her
The critical component of the PCAP model is the personalized, caring support over three years, a period of time long enough for the process of gradual and realistic change to occur.

**PCAP:**
**The model**

The PCAP model draws on concepts of relational theory, which emphasizes the importance of positive interpersonal relationships in women’s growth, development, and definition of self (Miller and Rollnick 1991), and in their addiction, treatment, and recovery (Finklestein 1993). The model puts into operation the idea that paraprofessionals with some shared history and life experiences can play a unique and therapeutic role in two ways: by helping clients become connected to another person in a trusting, healthy relationship for perhaps the first time in their lives; and by bridging the gap between high-risk families and the services they need but are unlikely to obtain without help.

**PCAP:**
**How advocacy works**

PCAP intervention activities are conducted by paraprofessional advocates, who receive intensive, initial, and ongoing training, and are clinically supervised by a professional in social work, mental health, or chemical dependency treatment. The model uses a case management approach to help mothers reduce the spectrum of risk behaviours associated with substance abuse, and to increase protective factors to enhance the health and social well-being of the mothers and their children. PCAP does not provide direct substance abuse treatment or clinical services. Instead, the program offers consistent home visitation and links women and their families with a comprehensive array of existing community resources, with an emphasis on alcohol/drug treatment, family planning, housing, health care, parenting, and legal resources (Figure 5). Advocates visit client homes frequently during the first 6 weeks, and thereafter work with clients and their service providers approximately once a week or so, depending on client needs. They transport clients and their children to important appointments and work actively within the context of the extended family. According to state law, advocates are mandated reporters of child abuse and neglect and abandonment. They monitor the safety of the child in the current home setting, and continue to stay in contact with the client and the child when they are separated. Advocates trace clients who are missing, and stay in touch with the clients’ family members. Clients are never asked to leave the program because of relapse or setbacks.

**PCAP:**
**Goal setting for vulnerable families**
PCAP is organized around helping mothers reach the goals that are meaningful for them. Because PCAP mothers often have difficulty conceptualizing and expressing their goals, we have developed a special protocol to facilitate this process. PCAP advocates use a card-sort assessment strategy called the “Difference Game” (Grant, Ernst, McAuliff et al 1997) to help their clients identify major problems and goals in their lives, and to develop the specific, incremental steps they will need to take to reach those goals. This involves sorting a set of 31 cards with various items and identifying those that would “make a difference” in their lives. PCAP advocates help their clients organize their thoughts and articulate their concerns and goals. They facilitate development of a step-by-step plan that addresses concerns of providers, yet is realistic for the client, and does not impose impossible expectations. For example, one way they help their clients implement their plans, is to arrange meetings or conference calls (with the client present) to bring the client’s service provider network together to help the client cope with her problems, (in British practice, completion of Children’s Assessment Framework (CAF) see chapter 12).

“There were times when I felt like I was going to relapse and my advocate would be there for me, and she’d keep checking on me, and I’d get through it. I’ve learned so much about myself and being responsible again and being a good mother. It was all what she taught me – she changed my life for me.”

PCAP Client

PCAP:
Professional training of advocates

Comprehensive ongoing training of providers is essential to a successful paraprofessional program. Formal training sessions on relevant topics are conducted by professionals at the beginning of the project and throughout the program (Grant et al 1999). PCAP directors arrange training sessions with representatives from key provider agencies (e.g., Child Protective Services; Planned Parenthood). It is important for advocate/case managers to work within, and with knowledge of, the other services in their area. For details of the PCAP case manager training: including, therapeutic aspects of the intervention; establishing the relationship; identifying client goals; assessment and planning; role-modelling; and teaching basic skills; strengthening the mother-infant dyad; interfacing with the child welfare system; strategies for helping mothers enter and complete treatment; strategies for helping mothers choose a family planning method; and a case study demonstrating the use of the difference game with a client: see Grant et al 2007. Advocates/case managers at each site have a weekly individual supervision session on each client, as well as a weekly group staffing meeting.
to collectively discuss their problems with clients, as well as their successes, and to learn from each other (Grant et al 2002)

I look forward to the staff meetings, particularly when I’m stuck on a particular client. I need a lot of positive reinforcement and I get a lot of that at the staff meetings.

PCAP advocate

PCAP case management is not delivered according to a specific model of behavioural intervention. Instead, case managers develop a positive, empathic relationship with their clients, offer regular home visitation, and help the women address a wide range of environmental problems. A foremost task is to assist clients in obtaining alcohol and drug treatment and staying in recovery. Advocates connect women and their families with existing community services and teach them how to access those services themselves, coordinate services among this multidisciplinary network, assist clients in following through with provider recommendations, and assure that the children are in safe home environments and receiving appropriate health care.

When we ask former clients what made the program work for them, we consistently hear “persistence”:

“My case manager never gave up on me.
She kept believing in me until I finally started to believe in myself.”

PCAP client

**PCAP:**
**Measured outcomes and cost effectiveness**

Future alcohol and drug -exposed births can be prevented in one of two ways: by helping women avoid alcohol and drug use during pregnancy, or by helping them avoid pregnancy if they are using alcohol or drugs. To evaluate our progress in PCAP, we compared PCAP intervention findings from two different cohort experiences in Washington State: the original demonstration (1991-1995) and the Seattle/Tacoma replications (1996-2003) (Grant et al 2005). Compared to the original demonstration program, outcomes at the replication sites were either improved (alcohol/drug treatment completed; abstinence from alcohol/drugs; subsequent delivery unexposed to alcohol or drugs) or maintained (regular use of contraception and use of a reliable method; number of subsequent deliveries during the program).

In studying mothers completing the 3-year PCAP replication programs (Grant et al 2005), we found that 65% of the 78 enrolled prenatal binge drinkers were no longer at
present risk of having another alcohol or drug exposed pregnancy, either because they were using a reliable contraceptive method (31%), or had been abstinent from alcohol/drugs for at least 6 months (23%), or both (12%). Based on local subsequent birth rates and the estimated incidence of FAS among heavy drinkers, we estimate that PCAP prevented at least one and up to three new cases of FAS. The cost of the PCAP program is approximately $15,000 per client for the 3-year program including intervention, administration and evaluation. If PCAP prevented just one new case of FAS, the estimated lifetime cost savings is equivalent to the cost of the PCAP intervention for 102 women (Grant et al 2005). A 2004 independent economic analysis by the Washington State Institute for Public Policy found an average net benefit of $6197 per client among selected well researched home visiting programs, including PCAP, for at-risk families in the U.S. (Aos et al 2004).

Between July 2005 and 2008, we had 240 PCAP graduates: 91% had completed alcohol/drug treatment or were in progress; 84% were abstinent from alcohol and drugs for 6 months or more; 82% of the index children were living with their own families; 72% had attended or completed a GED (high school diploma), college, or work training. Changes during the program were as follows: 62% using a reliable family planning method vs. 9% at enrolment; 74% in permanent housing, vs. 38% at enrolment; 46% now receiving TANF (state funds) vs. 71% at enrolment; 37% now employed vs. 2% at enrolment. At the present time, PCAP serves 675 families in 9 Washington counties and operates programs in provinces throughout Canada.

PCAP: Intervention with women who themselves have FASD

While neuropsychological deficits and other adverse outcomes associated with prenatal alcohol exposure have been well documented for over 30 years, interventions for adults with FASD have not been systematically developed and evaluated. In 1999 PCAP expanded its eligibility criteria to enroll a sample of women with FASD. In 2001 we conducted a 12-month pilot study to examine more specifically how these women could be helped within the existing framework of PCAP (Grant et al 2004). A total of 19 clients with either FASD (n = 11) or prenatally exposed to heavy alcohol and suspected FASD (n = 8) were enrolled in the pilot study. Their average age was 22 years, most were unmarried (84%) and poorly educated (47% had a 9th grade education or less), and almost all had been physically or sexually abused as children (94%). Among the 15 who were mothers, the mean number of children was 2.3 (range 1-6); on average, only half of the children were living with their biologic mothers. All reported many unmet basic service needs. Without special community care, we find that the quality of life and levels of psychiatric distress of adults with FASD living, unrecognised in our communities, is very poor (Grant, Huggins, et al 2005). Mothers with FASD are among the most difficult mothers with whom we have worked.

Adults and adolescents with FASD also have a high rate of suicide attempts (Lemoine & Lemoine 1992). In a separate study, we found that adults with FASD who had attempted suicide differed from those without suicide attempts in terms of more mental
health disorders, more substance abuse disorders, a history of trauma or abuse, more financial stress, and unstable social support, (Huggins 2008).

The cognitive deficits of people with FASD necessitate specific strategies to increase their connection to community services and to improve the quality of services they receive. Our community intervention for mothers with FASD consisted of delivering the standard PCAP model enhanced in two ways: 1) by modifying PCAP in order to accommodate the special cognitive needs of clients with FASD; and 2) by educating community service providers about FASD so they could better accommodate our clients (Grant et al 2007; Grant, Huggins et al 2004).

A Public Health Approach to Fetal Alcohol Syndrome

First published in 1996 by the Institute of Medicine (Stratton et al 1996) in conjunction with the National Institute on Alcohol and Alcohol Abuse (NIAAA), and recently updated by the U. S. Department of Health and Human Services (USDHHS 2009), the public health approach to FAS has described three activities.

Universal Prevention Activities promote general knowledge and social conditions that reduce substance abuse and promote healthy pregnancy practices. Warning signs, public health messages, bottle labels, newspaper articles and so forth continue to inform each new generation about the risks of drinking during pregnancy. An excellent example is the work of Kaskutas and Graves (1994) who found that it took three different types of warnings before a pregnant woman really changed her behaviour regarding alcohol use in pregnancy. Another is the work of Dufour et al 1994, who found a statistically significant increase between 1985 and 1990 in the number of respondents able to correctly identify FAS as a birth defect. However, in 1990, the same survey found that 60% of those who had heard of FAS, thought it referred to an alcohol-addicted baby, and only 29% could correctly identify it as a birth defect.


Indicated Preventions are applied to individuals at highest risk for adverse outcomes: a woman or a couple with alcohol or substance abuse problems, as well as those who have already given birth to a child with FAS. Our PCAP is such an example, and has already been applied to that highest-risk group of all: Mothers who, themselves, have both alcohol problems and/or FASD (Ernst et al 1999; Grant et al 1997; 2004).

Collaborative public health approaches for preventing alcohol exposed pregnancies

Preventing alcohol-exposed pregnancies requires many steps. Countries contemplating the broader problem of reducing alcohol exposed pregnancies would do well to consider steps that we have found useful in the U.S. and in Washington State, involving many
types of public health actions. However, implementation in countries with an existing universal health care system should be easier, (See ‘Hidden Harm’ in Chapter 12).

Government warnings regarding “no safe level of alcohol use during pregnancy” are an effective first step, warranted by the compelling animal and human research published in the past 35 years. At the national level, bottle-labelling of all alcohol-containing beverages can be an important step, as well as well as point-of-purchase warning signs at all local venues where alcohol is sold in any form.

The commission of national funds for research and policy implementation, increased funding for female alcohol problems (for example, protocols for how to detoxify a pregnant woman) and development of guidelines for routine screening for alcohol use and abuse during pregnancy are all important.

Enlisting the support of professional organizations can also be extremely important. At the national level, the American Medical Association (AMA 1999) endorsed universal alcohol screening for all patients over the age of 14 years, and the American College of Obstetricians and Gynecologists (ACOG 2004) outlined the ethical rational for using a consolidated alcohol protocol including universal screening, brief intervention, and referral to treatment. The American Academy of Pediatrics (Pediatrics 2000) endorses the Surgeon General’s recommendation for abstinence during pregnancy and additionally recommends federal legislation requiring the inclusion of health and safety messages in all print and broadcast alcohol advertisements as well as providing information about FAS and not drinking during pregnancy in marriage licenses.

Coordinating efforts with parent organizations and advocacy organizations can be extremely effective in raising public awareness, providing hope and help to families of people with FASD, and developing and raising funds for needed programs. One such advocacy organization with international connections is NOFAS (the National Organization on Fetal Alcohol Syndrome). There is now a NOFAS-UK, with Web access.

Finally, an essential component of each evidence-based research demonstration program is the ultimate incorporation of successful strategies into the ongoing public health programming of the country. Comprehensive prevention efforts are more cost-effective for countries, than managing the costs to society, families and children of raising future generations of alcohol-effected children.
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