Preventing Fetal Alcohol Spectrum Disorders

by Joel Schwarz

In these days of budget shortfalls and budget cutting, it is unusual to find a state program that has not had its funding slashed. One striking exception is the Parent-Child Assistance Program (PCAP) directed by Therese Grant, a University of Washington associate professor of psychiatry and behavioral sciences and a Center on Human Development and Disability (CHDD) research affiliate who has been helping high-risk mothers who abuse alcohol and drugs during pregnancy.

Today, more than two decades after PCAP was developed and launched at the UW as a federally funded research demonstration project, it is serving clients in 10 locations throughout Washington state and operating at near-capacity. In addition, there are two similar PCAP programs in California, one in Michigan and more than 40 throughout Canada. Grant and her staff also are assisting Australian health care providers in an effort to start a similar program in that nation.

PCAP is designed to reduce the incidence of fetal alcohol spectrum disorders (FASD), a range of lifelong neurodevelopmental disorders that includes fetal alcohol syndrome (FAS), a disorder caused by heavy prenatal exposure to alcohol. The program is an intensive, three-year intervention with high-risk mothers who have a history of heavily abusing alcohol or drugs during pregnancy and are isolated from service providers in the community. PCAP’s goal is basic – preventing alcohol and drug exposure to the future children of these women. FAS is the leading known cause of preventable intellectual and developmental disabilities and is estimated to occur between 0.2 and 1.5 times per 1,000 live births in the United States, according to the Centers for Disease Control. FASD is estimated to occur eight times as often. “Alcohol affects a fetus throughout pregnancy. It also affects growth, but the dangerous part, the effects on the brain, occurs throughout pregnancy,” said Grant. “The evidence from animal studies that alcohol causes brain damage is compelling and alcohol causes more birth defects than cocaine or marijuana use.”

Today, PCAP serves clients in nine Washington counties – King, Pierce, Yakima, Spokane, Cowlitz, Clallam, Grant, Skagit and Kitsap – plus the Spokane Tribe of Indians. The program works because it has a solid theoretical foundation, according to Grant. Specifically, it is based on three key elements: the relationship between a case manager and the client, harm reduction, and stages of change. PCAP also has a two-pronged approach. A PCAP case manager works with a woman and her entire family as well as with service providers at other agencies such as housing, treatment and child welfare services who often don’t talk with each other. “The women we work with don’t have the skills to bring service providers together, but our case managers do. Each manager has a small case load of 15 or 16 families so managers have enough time to foster a positive, trusting relationship with each family. We try to have case managers who have had some of the same life experiences as the women we serve.” Grant said. “Having case managers with this experience shows women in the program that they can succeed and also prevents manipulation.
by clients. Our research has demonstrated that the more time a case manager spends with a client the more the client improves. There is a dose response effect.”

Although the ultimate goal of PCAP is to foster recovery and abstinence from alcohol and drugs, it relies on harm reduction. This approach stresses cutting back on destructive behaviors rather than immediate and absolute cessation. “We don’t kick women out of the program if they relapse or if they lose a job,” said Grant. “We all have setbacks. The idea is to help the client figure out what went wrong and not blame.” PCAP also acknowledges that change comes in stages and not at any predetermined timetable. “The intervention looks different for all of our clients. Some are totally resistant for one year, but they get consistent messages from their case manager that we are ready to help whenever they are ready.”

Grant describes the women in the program as “tough.” Eighty percent of them have served jail time and 70 percent have been sexually abused as a child. A typical client is in her mid to late 20s, is a school dropout, not married, on welfare, has two children and is either pregnant or has just given birth to her third child. Most ran away from home around the age of 12, became substance abusers, and have looked for help but have failed in treatment programs two or three times. Referral to PCAP comes from a variety of sources including social workers, judges and child welfare offices. Participation is voluntary. “The first step,” said Grant, “is to get a client out of crisis mode and then slowly help her learn how to begin to live a normal life.”

“We try to teach them parenting skills. These women are trying to be the mother they never had, but they don’t have a template for what good parenting is. They have to be taught. Good parenting is not a biological trait,” said Grant. She added that many of these women come from families where their parents were substance abusers and they are now doing what their mothers did. Many don’t want to be reached and are partying until their baby is born. “But these women really do want to be good mothers, they dream of it, but they have little idea about how to do it. That’s where we step in. The main thing our clients learn is to believe in themselves. PCAP is not a handout program. These women have to do the work themselves, with someone standing next to them to provide guidance and support,” said Grant.

The turnaround in the lives of women who have completed the three-year intervention is remarkable. Most women complete the program and, despite occasional stumbles, data shows that nearly 70 percent have been clean and sober for one year during the program and a similar percentage have received mental health counseling. Ninety percent are in an ongoing alcohol/drug support group and the majority have custody of their PCAP baby, are living in permanent stable housing, and are working, at job training, or furthering their education. Grant said PCAP makes good economic sense. It costs $15,000 per client for PCAP, but the estimated lifetime costs for treating one child born with FAS is $1.5 million.

In a recent paper, Grant has advocated for physicians to screen their women patients of child-bearing age for their substance use and their family planning methods to reduce the chances of having a child with FASD. “We need to motivate women to either stop drinking before and during pregnancy or help those who can’t stop drinking to avoid becoming pregnant. Screening is not done routinely. And some women report getting bad advice from their doctor who says that drinking is okay without knowing her alcohol usage. Most women stop or cut back drinking once they know they are pregnant. But there is a small group of heavy drinkers who produce FASD babies. Some alcoholic women are told it is okay to have one drink every other day and then they will skip a few days saving up those drinks so they can binge drink on the weekend,” said Grant.

Research remains a secondary, but important, component of PCAP. Grant and her colleagues are currently analyzing data from a mother-infant mental health study of women who were methamphetamine users during pregnancy. They are now waiting to learn about funding to test the effectiveness of trauma therapy and PCAP with 150 mothers and their children in a residential treatment setting that will include male case workers working with fathers for the first time.