The Role of Therapeutic Intervention with Substance Abusing Mothers:

Preventing FASD in the Next Generation

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INTRODUCTION

Maternal alcohol and drug abuse during pregnancy is a serious public health problem that incurs risk for both mother and child. For the mother, substance abuse is associated with increased risk of prenatal complications, sexually transmitted diseases, depression, and domestic violence. For the child, prenatal exposure carries the potential for neonatal complications, lifelong neurodevelopmental damage, and the likelihood of a compromised home environment.

Alcohol is legal and widely available, so it is not surprising that among pregnant women alcohol drinking is more prevalent than illicit drug use. In population-based studies, approximately 10.1% of pregnant women reported drinking any alcohol during the previous month (Centers for Disease Control and Prevention [CDC], 2004), compared to 3.7% reporting drug use (Substance Abuse and Mental Health Services Administration [SAMHSA], 2002). The irony is that alcohol is a known teratogen whose neurobehavioral effects are more harmful than cocaine and other illicit substances of abuse (Jacobsen, Jacobson, & Sokol, 1994; Jacobson, Jacobsen, & Sokol, 1994; Coles, Platzman, Smith, James, & Falek, 1992; Institute of Medicine [IOM], 1996). Prenatal alcohol exposure puts children at risk for fetal alcohol syndrome (FAS), a permanent birth defect and a leading cause of mental retardation and neurodevelopmental disorders. FAS and related fetal alcohol spectrum disorders (FASD) are tragedies that know no socioeconomic, race, or age boundaries.

FAS and FASD are entirely preventable, a fact that was a compelling impetus for us as we developed the Parent-Child Assistance Program (PCAP). The purpose of this chapter is to describe the PCAP intervention, and examine how PCAP therapeutic strategies help prevent births of alcohol and drug exposed children in the next generation.

Background

PCAP began in 1991 at the University of Washington as a federally-funded research demonstration designed to test the efficacy of an intensive, 3-year advocacy/case management
model with high-risk mothers and their children. The primary aim of the model was to prevent subsequent alcohol and drug exposed births among birth mothers who abused alcohol and/or drugs during an index pregnancy. Research findings demonstrated the model’s efficacy (Ernst, Grant, Streissguth, & Sampson, 1999; Grant, Ernst, & Pagalilauan, 2003), and the Washington State legislature subsequently funded PCAP to develop sites in six counties, creating a capacity to serve 450 families statewide. The model has been replicated at numerous other sites in the United States and Canada.

In 1999 PCAP broadened eligibility criteria to enroll a limited number of women who themselves have FASD, and who have surprisingly poor access to even the most basic community amenities. Access to services is critical because individuals with FASD are at risk for a host of adverse life outcomes (including homelessness, untreated mental illness, physical/sexual abuse, domestic violence) unless environmental risk factors are decreased and protective factors enhanced (Streissguth et al., 2004). Women with FASD who become pregnant have a high likelihood of drinking during pregnancy and delivering a next generation of children with this same birth defect, particularly if their lives are impaired by these kinds of dire life circumstances (Grant, Ernst, Streissguth, & Porter, 1997; Streissguth, Porter, & Barr, 2001).

A Profile of the Mothers

Women are eligible to enroll in PCAP who: 1) are pregnant or up to six months postpartum; 2) abused alcohol and/or drugs heavily during the pregnancy; and 3) are ineffectively engaged with community service providers. Enrollment in PCAP does not require that a woman have confirmed or suspected FASD.

At enrollment, most PCAP clients’ lives are characterized not only by substance abuse, but by problems that result from a dysfunctional upbringing and chaotic lifestyle. 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. She is abused by her current partner, her housing situation is unstable, and her main source of income is welfare.

Women who fit this bleak description have been vilified in a social and political climate suggesting that alcohol/drug-addicted mothers are responsible for a variety of social ills (Greenhouse, 2000; Nelson & Marshall, 1998; Paltrow, Cohen, & Carey, 2000; Will, 1999). They have been labeled unmotivated and difficult to reach, and many professionals have come to view them as a hopeless population. Not surprisingly, chronic substance-abusing women become distrustful of “helping” agencies. Yet alienation from community resources only exacerbates the problem. The result is that those women at highest risk for delivering children with serious medical, developmental and behavioral problems are the least likely to seek and receive prenatal care and other assistance from community resources designed to help them.

Some suggest the real victims of maternal substance abuse are the children, and question the wisdom of investing scarce resources on mothers who are unlikely to change. The PCAP model was developed because we understand that these mothers were themselves the abused and neglected children of just a decade or two ago. They were born into troubled families, and grew into young women who used alcohol and drugs and delivered babies born into the same circumstances as their mothers had been. Social welfare, medical, and educational systems, if available, were not able to break this ongoing cycle of deprivation. Turning our backs on mothers because they are difficult to work with does not make their problems go away. It does ensure that these women will continue to experience a host of problems associated with intergenerational
substance abuse, and continue to bear children who suffer in turn. PCAP undertook the challenge to find a way to connect with this population.

Co-occurring Disorders among Birth Mothers

Substance abuse among American women co-occurs with mental disorders at high rates. In 2002, almost 6 percent of adult women (6.4 million) were estimated to have a substance use disorder in the past year. Of these, approximately 30% (almost 2 million) had both a substance use disorder and a serious mental disorder as defined by DSM-IV (SAMHSA, 2004). The most common psychiatric conditions co-morbid with substance abuse are anxiety and affective disorders, primarily major depression (Kessler et al., 1997). Substance abusing pregnant women similarly have a high incidence of co-occurring psychological distress (Miles, Svikis, Kulstad, & Haug, 2001) and depressive symptoms (Burns, Melamed, Burns, Chasnoff, & Hatcher, 1985; Marcenko & Spence, 1995). The burden of mental health problems coupled with substance abuse makes the treatment prognosis worse than for either problem alone (Bobo, McIlvain, & Leed-Kelly, 1998; Greenfield et al., 1998; Driessen et al., 2001).

Among people who have FASD or suspected FASD there is an even higher prevalence of mental health problems (Famy, Streissguth, & Unis, 1998; Streissguth et al., 2004). Among PCAP clients statewide, 129/445 (29%) reported that their mothers were heavy drinkers during their pregnancy with them (11 had obtained an actual FASD diagnosis). Among the 129, all had a substance abuse disorder (the condition that made them eligible for PCAP), and 61/129 (47%) reported having received a diagnosis of a co-occurring mental health disorder in the past. The eleven young women with diagnoses of FASD had a mean IQ of 82. Ten had been sexually abused and seven physically abused. Six reported having a formal psychiatric diagnosis: bipolar disorder (4), depression (1), or schizophrenia (1). The clients were assessed by the Brief Symptom Inventory (BSI), a screening for psychiatric illness. Mean BSI scores for the group were greater than 1.0 SD above standardized means on six of nine primary symptom dimensions, and six of the
women had a total score suggesting the need for more extensive psychiatric assessment (Grant, Huggins, Connor, & Streissguth, 2005).

The PCAP Intervention

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, trained and supervised PCAP case managers with a caseload of 15 to 20 families each, work with clients for 3 years beginning during pregnancy or within six months after the birth of an index child.

PCAP case management is not delivered according to a specific model of behavioral 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. Case managers 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 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 becoming pregnant if they are using alcohol or drugs. We compared PCAP intervention findings from two different cohort experiences in Washington State: the original demonstration (OD) (1991-1995) and the
Seattle/Tacoma replications (1996-2003) (Grant, Ernst, Streissguth & Stark, 2005). Compared to the OD, 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) (Table 2).

Insert Table 2 about here

On program exit, at PCAP replication sites we found that 65% of the 78 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 state subsequent birth rates and the estimated incidence of FAS among heavy drinkers, we estimate that PCAP prevented at least one and up to 3 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. The estimated average lifetime cost for an individual with FAS is $1.5 million (Harwood, Fountain, & Livermore, 1998; Rice, 1993). 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. 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, Lieb, Mayfield, Miller, & Pennucci, 2004).

THEORETICAL FOUNDATIONS AND
CORRESPONDING INTERVENTION STRATEGIES

Relational Theory
The PCAP model draws on the concept of relational theory, which emphasizes the importance of positive interpersonal relationships in women’s growth, development, and definition of self (Miller, 1991), and in their addiction, treatment, and recovery (Finkelstein, 1993). The relationship aspect of intensive intervention—“having a person to talk to who really cared”—may be more critical to improvement than the concrete services received (Pharis & Levin, 1991).

Building on this concept, PCAP hires ethnically diverse case managers with shared history and cultural experiences, who understand clients in a way that allows them to gain access and build rapport with women who might otherwise be unapproachable. PCAP case managers have each faced at least one significant obstacle to well-being, for example, domestic violence, poverty, single parenting, an alcoholic parent, or personal alcohol or drug abuse. More importantly, each has overcome the obstacle and achieved significant success, for example, by going back to school or maintaining steady and meaningful employment. When a PCAP clinical supervisor assigns a new client to a case manager, she does not necessarily make the assignment based on race or ethnicity in common. Instead, it is the case managers’ life struggles and successes that enable them to be positive and credible role models, offering their clients hope and motivation grounded in reality. For example, among the statewide PCAP staff, approximately 60% formerly used or abused alcohol or drugs, but all had been clean and sober for at least 6 years at the time they were hired.

PCAP case managers are paraprofessionals in the sense that they are uncredentialed in helping professions such as nursing or social work. However, the model requires more of its case managers than most programs that use paraprofessionals. Prior to hire, PCAP case managers must have at least four years of community-based experience related to prenatal substance abuse or associated problems, or the equivalent combination of education and experience.

“I know what it’s like to be a single parent, homeless, and on welfare. I share a common ground with my clients as far as those things go. The
difference is that I saw what the obstacles were, and overcame them. I just kept moving ahead and learned that where there's a will, there's a way”. — PCAP Case Manager

*Stages of Change*

PCAP incorporates stages-of-change paradigms and motivational interviewing strategies. The approach recognizes that clients will be at different stages of readiness for change at different times, and that ambivalence about changing addictive behavior is normal (Miller & Rollnick, 1991).

The constructs of stages-of-change and self-efficacy dovetail (Olds, Kitzman, Cole & Robinson, 1997; Sherman, Sanders & Yearde, 1998). Self-efficacy is the belief in one’s ability to perform in ways that will produce desired outcomes, and expectations about self-efficacy are influenced most powerfully by an individual’s own past accomplishments (Bandura, 1977). A client’s self-efficacy determines whether she will begin a behavior, put the required effort into it, and maintain her efforts.

PCAP case managers understand that for clients who have never experienced competence and accomplishment, each small step toward rebuilding her life is a risk the woman takes deserving of attention and encouragement. Case managers have a positive influence on clients’ efficacy expectations, motivational states, and, ultimately, behavior by:

- providing clients with concrete, practical opportunities to accomplish goals of abstinence, recovery, and social adjustment;
- helping clients recognize and celebrate each step toward performance achievements;
- offering ongoing verbal and emotional encouragement regardless of temporary setbacks or relapse;
- role-modeling, as someone who has achieved personal goals similar to those the client may be aiming toward; and
- helping clients learn daily coping strategies, including compliance with mental health recommendations and medication regimens in order to avoid negative emotional mood
“You wait for that tiny indication that the client sees the way and is ready to change. Then you reach out at the right time to help her move along. I have hope and faith in people. I really believe they want to change if they say they do.” — PCAP Case Manager

**Harm Reduction**

The framework of the PCAP intervention was influenced by harm reduction theory. Harm reduction is based on the assumption that alcohol and drug addiction and the associated risks can be placed along a continuum, with the goal being to help a client move along this continuum from excess to moderation, and ultimately to abstinence, in order to reduce the harmful consequences of the habit (Marlatt & Tapert, 1993). In this view, “any steps toward decreased risk are steps in the right direction” (Marlatt, Somers & Tapert, 1993, p. 148).

In practice, case managers focus attention not simply on reducing alcohol and drug use, but on reducing other risk behaviors and addressing the health and social well-being of the clients and their children. For example, an important PCAP goal is to reduce the incidence of future drug and alcohol-exposed births. While not every client will be able to become abstinent from alcohol and drugs, harm can be reduced by encouraging the woman to use effective family planning methods to avoid becoming pregnant if she is still using.

**Case Manager Training**

Comprehensive ongoing training 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, Ernst, & Streissguth, 1999). PCAP directors arrange training sessions with representatives from key provider agencies (e.g., Child Protective Services, Planned Parenthood) so case managers can learn the dynamics of the agencies and work more effectively with them, and for agency staff to be introduced to the role of the case managers. Their
familiarity with the PCAP model and with individual staff members enhances our ability to address specific service barriers encountered by clients and resolve them more quickly. Case managers attend community trainings offered by health and social services agencies in the area in order to increase their knowledge-base and to establish contacts and share strategies with providers who encounter similar issues working with a substance-abusing population.

**Therapeutic Aspects of the Intervention**

The PCAP intervention is a therapeutic process between case managers and their clients that develops and grows over the course of the program. The process allows for a client’s gradual transition from initial dependence on the case manager’s assistance and support, to interdependence as they work together to accomplish steps toward goals, to independence as the client begins to trust in herself as a worthwhile and capable person, and learns the skills necessary to manage her life.

**Establishing the Relationship**

Case managers and clients begin by getting to know each other and establishing the trust that will enable them to work closely together for three years. This bonding process sometimes takes months for clients whose lifelong experiences of abuse and abandonment taught them not to trust anyone. They find that time spent in the car with a client is valuable because they can talk together at length with relatively little distraction; they do not have to make eye contact if a woman is uncomfortable with that, and silences are not uneasy.

At the first home visit, the case manager identifies and addresses immediate problems such as obtaining clothes and diapers for the newborn or locating temporary housing; activities that demonstrate from the beginning that the case manager cares and can be trusted to follow through. Within the first few weeks, the case manager sets the ground rules, or defines the nature of the relationship. She may explain:

- “We’ll have a three-year working relationship, not a three-year friendship.”
• “You can trust that I will be with you through ups and downs: there will be times you don’t like me. It’s okay if you disagree with me, but we have to keep communication open.”
• “I’ll always be truthful with you. I won’t lie to you, or for you.”
• “My role is not to continually respond to your crises, but to help you move beyond crisis and toward achieving your goals.”
• “If you take one step, I’ll take two.”

Case managers work within the context of the client’s family, and establish rapport with the other children, the husband or significant other, and members of the extended family. As mothers, our clients are at the center of this network of relationships, in which everyone is involved in some way with her substance abuse and related problems. Family members may have powerful influence over the woman, and they will all be affected by critical changes the woman makes as she attempts to break long established behavioral patterns. Gaining the family's trust is a preliminary step that then allows the case manager access and the opportunity to communicate with this important group throughout the intervention.

Clients sometimes disappear for weeks or months at a time, leaving the children with family members. Having a close relationship with the family allows the case manager to continue to provide services on behalf of the children, as well as to learn the whereabouts of the missing client. Most missing clients inevitably reconnect with their case manager when they experience a crisis event. A client may experience several cycles like this before she begins to recognize that she herself will have to change her behavior, that it’s tremendously beneficial to have the advocate’s help, and that the clock is ticking on her time left in the program.

**Identifying Client Goals: Assessment and Planning**

In treatment planning, the more individualized and accurate the client assessment, the more useful it will be. PCAP developed the “Difference Game” card sort assessment to enable clients and case managers to work together to identify client needs (Grant, Ernst, McAuliff, & Streissguth,
1997). The Game is easy to administer and interpret, is engaging and meaningful, and can be a powerful strategy for intervention when used as a stimulus for identifying client goals. Clients often know what needs to be changed, but because of low outcome expectancy and a poor sense of self-efficacy, they feel helpless and incompetent to begin to solve problems on their own.

The Difference Game is a concrete, hands-on activity. Adapted from a scale developed by Dunst et al. (1988), it consists of a set of 31 laminated cards, on each of which is written an item that is a possible client need (e.g. “housing,” “drug or alcohol treatment,” “more education”) and including a “wild card” representing any additional need the client may choose. The case manager asks the client to sort the cards into two piles, those items that would “make a difference” in her life, and those that “no, would not make a difference.” The client is then asked to select from the “yes” cards the 5 items that represent her most important needs. Finally, she ranks these 5 cards in order of her priorities.

The case manager and client use these top 5 cards as the basis for discussion and for planning a course of action that will “make a difference.” The client identifies specific, meaningful goals that she would like to work on during the next 4 months, and together they come to an agreement about realistic steps they can take toward meeting those goals. They record each goal, the small steps required to reach the goal, and who will be responsible for accomplishing different tasks. It is critical that some of the steps, no matter how small, are attainable by the client in a 4-month period, because it is as she observes herself accomplishing desired behavior that her sense of self-efficacy develops.

Goals are evaluated and reestablished every 4 months because this length of time allows clients 1) to accomplish short-term, concrete tasks (e.g. complete paperwork for housing waiting lists, or enroll in a neighborhood parenting class), and 2) to make progress on long-term goals (e.g., enter long-term residential treatment). It is not unusual for a client to specify a single, major issue (e.g., stay in recovery, or not see a former abusive partner), as a continuous goal every 4
months throughout her PCAP participation.

The effectiveness of the Difference Game is that it requires the client to think about and choose her most meaningful priorities, instead of someone in a professional capacity determining those for her. The focus is on possibilities and desired outcomes as opposed to problems, weaknesses, or negative conditions. The Difference Game, used in conjunction with the development of meaningful goals, is a logical method that illustrates to clients within the context of their own lives the continuum from making a decision, to taking definite steps, to ultimately reaching a goal that makes a difference.

Case Study: Using the Difference Game with a Client

The following event occurred in a family preservation project. A client completed the Difference Game with her therapist, selecting the Wild Card as her top card and designating it as a “need for make-up.” The therapist was less than optimistic about letting this client set the direction for case planning, but she nevertheless returned to the client and asked her to explain the “story” behind each card selected (and particularly the “make up” card, knowing there were more pressing issues in the family). The client's story revealed a problem she had previously been unwilling to talk about. For years her spouse had physically and emotionally abused her, and refused to let her wear cosmetics. The client believed if she could be courageous enough to wear make up, it would be the first step toward leaving the relationship and beginning a new life. The make-up was her symbol for change. The therapist supported the client’s reasoning. The woman made a plan and successfully set it in motion over the following months.

Finding a Voice in the Service Provider Network

PCAP case managers do not provide direct services, such as substance abuse treatment or health care, but instead connect clients with appropriate providers and experts in the community. They provide practical assistance and emotional support to clients in a manner that cannot be duplicated by service providers who have high caseloads, specific agendas, and time constraints.
Professional and agency effectiveness increase when the case manager tackles barriers (e.g., lack of housing, transportation, and/or child care) that could otherwise hinder or defeat a provider’s aims for a client. A physician, for example, can more fully focus on a family’s health care needs when a case manager addresses the family’s environmental issues.

In the initial stages of the intervention, PCAP clients typically have poor negotiating skills. The case manager role models telephone etiquette and interpersonal behavior that is likely to elicit support and help, and practices with the client. She helps the client organize her thoughts and articulate concerns and goals. After releases of information are signed, she arranges meetings or conference calls to bring members of a client’s provider network together, with the client present whenever possible. The case manager functions as a liaison for communication within this network, and works to facilitate development of a service plan that gives voice to the client’s needs, creates realistic expectations, and addresses providers’ concerns. The case manager then helps the client follow through with the plan.

In practical terms, this strategy means that a mother in recovery will not be faced with trying to comply with a court’s stipulation that she attend outpatient treatment five mornings a week in one part of town, while the housing authority assigns her to a unit in a neighborhood requiring her to make two bus transfers to get to treatment, and Child Protective Services grants her reunification with her two children with no contingencies for childcare (a true scenario). When a woman learns to speak up in a way that demonstrates respect for herself and others—and with her case manager as guide and advocate—providers will listen, recognize the realities of her circumstances, and design a plan that will help her succeed in her recovery, rather than set her up for another failure.

In some situations, a “strong arm” in the form of a written contract is beneficial, and clients are more likely to adhere to goals when they participate in establishing the concrete, logical steps of such a document. Case managers may work with clients and providers to draw up agreements that
define explicit responsibilities and timelines. The case manager refers to the contract both in supporting her client and in upholding the position of an agency. Personalized agreements heighten service providers’ awareness of the possibilities of working successfully with this high-risk population.

*Role Modeling, Teaching Basic Skills*

Role-modeling and teaching basic life skills are critical case manager strategies. It is clear that the clients’ bleak backgrounds have done little to prepare them for adult life or parenting. For example, problems with landlords and bill collectors are common. Few of these women have ever lived in a household that was “managed,” nor have they had adequate training to prepare them for basic functioning within an economic system. In addition, they may have cognitive impairment as a result of prenatal exposure to alcohol/drugs and their own years of substance abuse. Case managers find that the most effective teaching techniques with clients are those that are explicit, hands-on, and experiential.

“My case manager handled a lot of situations, and I learned through her how to deal with and talk to people.” — PCAP Client

“My case manager had a big influence on me and how I deal with things in my life.” — PCAP Client

*The Mother/Infant Dyad*

On the most basic level, case managers first help mothers attend to the quality of the home environment, to make it safe and comfortable for children. They help the mother learn to turn away former acquaintances who drop by to party with her, or who need a place to sleep. They help her learn how to reduce the level of stimulation from loud music and other noise, clean the house, and keep potentially harmful items out of the baby’s reach. Because our clients typically live in low-income or substandard housing, case managers are frequently involved in extended negotiations with a landlord to make repairs in electrical wiring or broken windows.
As basic environmental needs are addressed, the case manager begins to give a mother information about her child’s particular developmental stage, and teach her to have appropriate expectations. For example, a baby who is learning to pick up and eat Cheerios from a tray in front of her is likely to scatter the cereal. The case manager helps the mother learn to show the baby and demonstrate delight in her progress, rather than shout or slap because the baby “made a mess.”

An important home visit activity is to simply help the mother observe the baby playing and responding to various stimuli. Case managers teach a mother to pay attention, to observe, and to understand that her baby has a personality and communicates with every facial expression and gesture. They may record with the mother what the baby can do as they observe and interact for 20 minutes, to illustrate to her the diversity and complexity of her baby’s behavior. The case manager may then ask the mother to repeat this again before the next home visit, and will leave with her a notebook for recording.

*Interface with the Child Welfare System*

PCAP staff are mandated to report child abuse and neglect. As regular home visitors, they are in a unique position to identify problems that may place children at grave risk in families who would otherwise have disappeared from notice by health and social service providers. They instigate removal of children from the home when necessary.

The issue of child custody is a recurrent theme in clients’ lives because a majority of the women have had children removed from their care by the state. Regaining custody is a common goal stated by clients in their first year in the program, although case managers do not necessarily concur that reunification is in the best interests of the child/ren. The turning point for successful resolution of child custody issues occurs when the mother realistically comes to terms with her ability to parent, and is willing to consider the best interests of the child. For some mothers this means deciding to relinquish custody to a foster family who has bonded with the child and would like to adopt. For others it means staying in recovery and doing whatever is necessary to resume
or maintain custody of her child/ren. Regardless of who has custody, case managers work on behalf of the child to secure a safe home environment and regular health care.

The following case study illustrates how case managers are able to continue to work with clients after reporting to Child Protective Services (CPS).

C. delivered a medically fragile infant, and had custody of the baby after she was released from the hospital. It soon became obvious to the case manager that C. was using drugs, was not eating for days at a time, and was not capable of keeping the baby on a feeding and medication schedule. Her case manager was open and honest with C. and explained that she was recommending removal of the child by CPS until the mother could provide competent care. The baby was removed, and CPS wrote a contract with the mother stipulating drug treatment and parenting classes specific to medically fragile infants. Although C. was initially angry and distant with her, the case manager offered to help her comply with the CPS recommendations. The case manager attended parenting classes with C., maintained her trust, kept in close contact with the CPS social worker, and kept the client informed. C. completed 90 days of inpatient treatment, followed by six months of outpatient treatment. The CPS worker drafted a permanency plan stipulating that the baby be adopted by the foster mother, but the case manager intervened because C. was complying successfully with the written contract. The baby was ultimately returned to C. Her former boyfriend, a crack user, disappeared now that C. was mothering a special-needs child. C. began to believe in her worth as a person and in her abilities as a mother, fully and gratefully accepting responsibility for her child.

PCAP case managers teach clients about behaviors that are normal and appropriate for children of different ages; they role model alternative ways of responding to a child’s behavior;
they enroll clients in parenting classes and accompany them if necessary. Clients are sometimes impatient and harsh with their children, but case managers rarely observe signs of deliberate injury. If a case manager suspects that someone else in the household (for example, a boyfriend) is abusing a child, they involve the mother and Children’s Protective Services with the immediate aim of stopping harm to the child. The next step is to teach the mother to pay attention and recognize problems, resist pressure from “friends” who pose a risk to her family, and protect her children (or lose them).

In general, PCAP and child welfare services work closely together. However, child welfare recommendations can be inconsistent depending on the social worker if decisions are based on biased attitudes and beliefs, or lack of information and experience (the agency has a high turnover rate). It is not uncommon for a woman to comply with her contract stipulations in order to regain custody of her child, only to learn that her social worker will recommend child removal at a court hearing. As advocates, PCAP case managers help clients comply with their individual contracts and act as liaisons between the agency and the client. They keep careful documentation and maintain releases of information so they can communicate with all parties, verify compliance or non-compliance, and advocate accordingly to uphold agreements made in the contract.

It is not uncommon for PCAP case managers to voice objections to child welfare workers over decisions to not investigate, or to close cases early without adequate follow-up oversight. This is particularly true in cases where the client is an alcoholic mother. Service providers do not necessarily understand that although alcohol is a legal substance not detectable on urine screening, it can be a dangerous drug. We know that a mother who has a chronic, untreated alcohol problem poses a serious risk to children in her care because of the potential for neglect, including malnutrition and accidents. In cases like these, PCAP case managers and/or supervisors make referrals to child welfare and continue to do home visits and maintain a watchful eye while the woman remains in the program. Clearly, our work is made more difficult if we do not have the
strong arm of the civil agency charged with child protection. In extreme cases PCAP asks the police to go to a home and intervene on behalf of the children.

Accepting Setbacks

Any undertaking that requires a person to make fundamental changes in long established behavior patterns (for example, losing weight or quitting smoking) may entail setbacks. Relapse should not be a surprise in the recovery process, particularly among clients with a long history of drug or alcohol abuse. PCAP clients are not asked to leave the program because of noncompliance, setbacks, or relapse. Instead, they are taught to learn from their mistakes. This policy has resulted in clients’ increased likelihood of overcoming shame after relapse, contacting the case manager quickly, resuming recovery (or treatment), and repairing the damage done. Case managers use relapse experiences to help clients examine events that triggered the setback, and to develop resiliency strategies. When a client is able to successfully rebound from a relapse event, she develops self-efficacy as she observes herself coping, overcoming a crisis, and moving on.

Two PCAP Case Studies: Jane and Laurie

Jane

Jane was a Native American woman who enrolled in PCAP when she was 18 years old. Her birth mother had been an alcoholic and it was suspected that she drank heavily during her pregnancy with Jane. Jane was now pregnant with her first child and had been a heavy drinker during the first few months of the pregnancy.

As a baby Jane had been adopted by a middle class white family, and was subsequently raised only by her adopted father. Her youth was not that of a typical middle class child. She had difficulties in school. She frequently ran away and got into fights. By the time she was 14 she was in a group home for juveniles. One day she severely beat another girl, almost killing her. Jane was sent to a juvenile detention center until she was 17. When she was transitioned from there into another group home, Jane began using alcohol and marijuana again. Soon after her release at the
age of 18, she moved in with a man nearly twice her age, became pregnant, and was referred to PCAP.

Not surprising, Jane was slow to trust her PCAP case manager and rarely asked for help. The case manager continued to call and show up at her home, offering help. Eventually, Jane began initiating the calls to ask for help. As a first time mother (and her partner a first time father), they needed assistance with the basics of parenting. The case manager spent a lot of time with both parents, on parenting skills, budgeting, and helping them communicate with each other. It was obvious that Jane had a hard time managing the demands of daily life.

The unexpected happened when Jane had a psychotic break: becoming extremely paranoid, hearing voices, expressing suicidal ideation and even thoughts of hurting her child. Her case manager facilitated Jane’s admission to a psychiatric hospital where she was diagnosed with bipolar disorder. By now the case manager had a strong and trusting relationship with Jane, and had established herself as someone whose advice Jane could trust. This positive and close relationship helped Jane accept the diagnosis more readily, and she began outpatient psychiatric treatment and medications. Even though a Child Protective Services case was opened, she and her partner were able to retain custody of their child. After a year, Jane's mental illness symptoms stabilized. She left the father of her baby and entered art school. PCAP helped her obtain subsidized housing and connected her with a long-term case management program that would work with her after she left our program. At the time she left PCAP, she was continuing the ongoing struggle with her mental health condition, but she had a strong support network in place.

Laurie

Laurie was a typical PCAP client. She came from a family where drug use was the norm. She had been molested as a child. She had been in family placements and foster care. She never knew her father. She had been involved in gangs. Her older brother had been murdered. Her mother and aunt were in prison for drug-related crimes. She herself had served time for a drug-
related crime, and she was facing sentencing for another.

At age 29 she had just given birth to her second child. She had abused cocaine and alcohol throughout the pregnancy. Her 7 year old daughter had been removed from her care the year before, due to neglect. She had had a hard life and didn't trust anyone, but was willing to be in PCAP because she was told it would “look good” to Child Protective Services (CPS). But she didn't really want anyone in her business.

Her PCAP case manager had a very hard time getting involved in Laurie's life. The case manager was only “allowed in” to help with things like clothes and transportation. There were many missed appointments. Still the case manager persisted. She left phone messages and notes, and sometimes visited the home unannounced.

After about a year in PCAP, the client’s life fell apart. She was facing jail time and she became pregnant again. This time she turned to PCAP. With the case manager’s help, Laurie completed inpatient substance abuse treatment for pregnant women. Upon discharge she continued with her outpatient treatment. The judge allowed home detention for her sentence, provided she did not re-offend. Her housing became stable again, she began mental health treatment, and she gave birth to a healthy son. She now recognized when she needed help, and called her case manager before a crisis developed. She entered a welding program at the local community college and graduated. She invited her PCAP case manager to the graduation.

As she leaves PCAP, Laurie is in permanent stable housing, has obtained full-time employment, and is no longer on welfare. She has been clean from drugs and alcohol for over a year. She has regained custody of her older daughter. In addition she now has custody of her two younger sisters, who were being neglected in a family placement, so she is parenting a total of five children.

Had Laurie been enrolled in a typical social services program, she would have been discharged for non-compliance, or program services would have ended long before Laurie had
learned the lessons that took time to learn. She would have lost custody of all of her children and she'd be back in prison. Because her PCAP case manager was a persistent presence in Laurie’s life, she was able to be there at the right time, the moment the client decided she wanted to change and needed help.

*Strategies for Helping Mothers Enter and Complete Treatment*

While it is desirable for a woman to acknowledge her own substance abuse problem and ask for help, it may not happen soon enough. Often the criminal or civil dependency court system will require the client to obtain treatment. Once in a treatment setting, clients have no choice but to hear the stories of other women like themselves, including those who acknowledge their addiction. In this setting they are able to detoxify, begin to listen, and examine their own lives. PCAP case managers sometimes ask the court, with the client's knowledge and trust, to mandate treatment, and find that these formerly resistant clients become some of our most successful.

Unwillingness to be separated from their children is the most common barrier to getting women to enter and stay in treatment. Long-term, gender-specific residential treatment programs are almost always the first choice of PCAP case managers for their clients, and we are fortunate to have these available in Washington State. These residential programs are designed for children to accompany their mothers, and for mothers to learn and practice their parenting for a period of up to 6 months. They give families an opportunity to live in a safe place, free of the chaotic environment to which they are accustomed. The extended length of stay gives mothers and their case managers time to set up the support systems they will need when they leave, particularly clean and sober housing.

PCAP case managers are familiar with the treatment programs in their area and establish good relationships with the administrators and counselors. They can facilitate admitting their client to the program they believe may be best suited to the client's needs. They are instrumental in walking women through the many steps required to become eligible for funding for treatment and
medical care. Case managers find that it is important to gain the cooperation of the client's family and support system because they can be a source of motivation and practical help while the woman is in treatment. Women who are able to build connections with healthy, drug-free family members are most likely to succeed.

While women are in treatment, the PCAP case manager visits regularly to provide emotional support and problem solve any issues that may jeopardize her staying in treatment (for example, by supervising child visitation). They may support the client by helping her obtain clothes and toiletries; they may write letters of encouragement. With the client's permission, they participate in case staffing and discharge planning. They help make plans for the woman’s life after treatment, particularly by exploring options for safe, stable housing.

After leaving treatment, the PCAP case manager works with her client on immediate needs and long-term goals. While engaged in activities together they talk about stressors, relapse triggers, and relapse prevention strategies. Clients are most likely to succeed if they are active in after-care programs, so the case manager will introduce her to groups and will perhaps attend 12-step meetings with her until the client is comfortable attending alone. Through all of this, the message is that the client can succeed. If a relapse occurs, it’s a temporary setback and an opportunity to ask for help in getting back on track.

Strategies for Helping Mothers Choose a Family Planning Method

The family planning objectives of the Parent-Child Assistance program are to reduce the incidence of future alcohol and drug-exposed births, and to reduce the incidence of unintended pregnancies. While we know that one way to achieve this is to motivate clients to use an appropriate family planning method, the choice to do so is entirely the client’s. PCAP is not a pregnancy prevention program. Many clients who achieve a stable and sober lifestyle choose to become pregnant because for the first time they’ll experience a healthy pregnancy and have the opportunity to raise their own child. Case managers help clients understand that sex is a natural
and enjoyable part of life, and that “family planning” means planning her pregnancies to occur at an optimal time.

It is essential that case managers connect clients with family planning clinics or health care providers who provide physical examinations, identify potential contraindications for specific birth control methods, and determine the safest and most appropriate method for the woman. Case managers who accompany their client to these visits can then review the material periodically to make sure the client understands. The necessary knowledge base includes:

- The basics of female and male anatomy and how contraception occurs;
- Personal health condition and how some birth control methods may be contraindicated because of a preexisting health condition;
- The range of birth control options available and what the options require from the client; some options may not be wise choices because of a client’s life style;
- The side effects of various methods;
- The long-term health risks of unsafe sex: e.g., risks of contracting sexually transmitted diseases, hepatitis C.

Introducing the concept of family planning, educating, motivating, and helping a client obtain a method is not necessarily a straightforward process for reasons ranging from the intensely personal and familial, to those imposed by lawmakers or the insurance industry. The process takes time, and may involve setbacks, missed appointments, birth control side effects or failure, or subsequent unintended pregnancy. Understanding this can reduce case manager frustration. The important points are to be sensitive to the client’s perspective, including cultural and religious factors, to follow-up and take the next step, and to be persistent in meeting client and program goals.

The conversation with a client about family planning will be an ongoing one. Case managers use motivational interviewing strategies to help clients examine the reality of their situation and the consequences of another pregnancy. The process is gradual and thoughtful so that
decisions are long lasting, grounded in the client’s own belief system, and based on her individual choices. PCAP case managers don’t argue with clients about family planning because developing resistance and conflict will be counterproductive.

When a case manager introduces the topic of family planning, she often discovers that a client has already been thinking about it, or has tried a method previously. We may hear reservations like the following:

- “I am not sexually active now, so I don’t think I need to use birth control.”
- “I haven’t gotten pregnant for the last 2 years and I haven’t been using birth control, so why would I need it now?”
- “I tried it, but it made me gain weight, so I’m not interested in using birth control.”
- “I don’t like to put chemicals in my body.”

Case managers encourage clients to discuss previous experiences, fears, and expectations. It is especially helpful to acknowledge ambivalence and elicit ideas about the pros and cons of another pregnancy in very concrete terms. Case managers write down the client’s ideas in her own words so the client can recognize her own thought processes when they revisit the topic. By not imposing concepts or suggestions that have no bearing on a client’s beliefs and feelings, she demonstrates respect and avoids creating frustration on both parts.

Role modeling can be an important part of family planning intervention with clients, and particularly with women who have FASD. Case managers may choose to talk with their clients about methods they’ve used in the past, decision-making processes they’ve gone through, and what has worked well for them. In this way clients observe a person they respect taking care of themselves and taking charge of their own fertility.

As the case manager continues goal-setting exercises with the client every four months, they explore how having another child might affect the client’s ability to achieve her objectives.
While neuropsychological deficits and other adverse outcomes associated with prenatal alcohol exposure have been well documented for over 30 years, interventions for individuals 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 FASD (n = 11) or 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 mother. All reported many unmet basic service needs.

In considering the special cognitive deficits associated with FASD, we realized that to meet the needs of these women we would have to develop specific strategies to increase connection to community services and improve quality of services delivered. The pilot community intervention consisted of delivery of the standard PCAP model enhanced in two ways: 1) by modifying PCAP in order to accommodate clients with FASD; and 2) by educating community service providers to accommodate clients with FASD.

Modifying PCAP to Work with Clients with FASD

This adaptation required staff training and development, a process that also served to alert case managers to the possibility that some of the high-risk mothers they were already working with might be fetal alcohol affected. University of Washington researchers and clinicians educated PCAP case managers and supervisors on topics including biologic mechanisms of fetal alcohol exposure, teratogenic effects across gestation, diagnostic characteristics, and central nervous system and behavioral problems across the lifespan. An FAS expert and author trained staff on the day to day management of individuals with FASD, and facilitated a staffing session on
management issues case managers had encountered in working with clients with FASD who were among their PCAP clients. PCAP staff observed the diagnostic process at the university FAS diagnostic clinic. Case managers helped clients assemble documentation required by the diagnostic clinic, including copies of birth or other records verifying extent of prenatal alcohol exposure, early childhood photos, growth charts, and school records. PCAP located a neuropsychologist in the community who facilitated the diagnostic process by evaluating clients, and negotiated with state agencies to pay for these exams. As FASD enrollment got underway, PCAP case managers met in weekly case consultations with supervisors to review assessment data, develop and monitor tailored interventions, address service barriers, and, as necessary, solicit additional consultation from an experienced staff clinical psychologist.

*Educating the Community to Work with Clients with FASD*

Clinical practice recommendations for FASD patients call for coordinated, multi-systemic management. However, as we began our work we found that most providers knew very little about FAS and its implication for practice, and had little direct experience with this patient population. With that in mind, we identified key providers who could deliver quality service to our clients with FASD, who were interested in the problem, and who were willing to work with a client with FASD as a case study in close collaboration with her PCAP case manager. We conducted FASD training with providers at 15 major clinics and agencies, and offered consultation as questions arose in treating these young women.

*Recommendations to Providers*

The community providers and PCAP case managers brought different but complementary skills to the intervention. Experienced case managers helped providers understand the relationship between the clients’ organic brain damage and their sometimes socially inappropriate and otherwise puzzling behaviors, and how to respond in helpful ways. For example, clients with FASD typically experienced difficulties in the following areas as a result of diminished executive function
skills: translating information from one sense or modality into appropriate behavior (e.g., hearing into doing); generalizing information from one situation to another; and comparing, contrasting, sequencing, predicting, and judging events and experiences in their lives. Clients’ poor short-term memory often resulted in information or instructions being quickly forgotten. Although their long-term memory could be fine, their information storage was often disorganized, so information was difficult to retrieve. Their expressive language or articulation was often better than their receptive language or comprehension.

Case managers recommended to community providers the following strategies to communicate more effectively with FASD clients:

• Talk in concrete terms, avoid using words with double meanings or idioms, and say exactly what you mean.
• Give simple step-by-step instructions, and then have the patient demonstrate understanding by showing a skill, rather than relying on a verbal affirmation that she understands.
• Give simple (5th grade level) written instructions, with illustrations if possible.
• Re-teach and repeat important points at each visit, and remember that instructions are unlikely to generalize to a similar situation.
• Provide consistency both in the environment and in the people providing care. If the primary provider must change, create a transition period for the current provider to introduce the new provider.
• The aim of treatment should be to stabilize presenting problems rather than to pursue a cure for permanent disabilities in reasoning, judgment and memory.

Skilled PCAP case managers found that working with FASD clients was far more difficult than working with the typical PCAP clients for whom the intervention was designed, i.e., substance-abusing women with complex problems. The impact of the neuropsychological deficits on their FASD clients was obvious, and required that case managers modify their traditional intervention approaches. Case managers found it helpful to remind these clients that the reason
they had difficulty with memory and daily living functions is because of brain damage caused by their mother’s alcohol drinking during pregnancy. This strategy helped clients understand the importance of not repeating the pattern, and provided motivation for them to abstain from drugs and alcohol and/or use a family planning method.

While typical PCAP clients can be taught how to improve access to services by defining and articulating needs and problems, locating an appropriate provider, making appointments, and using transportation systems, the FASD clients were either unable to learn these skills or they learned them very slowly. Case managers had to assume a far more directive role as they introduced clients to community services and helped them comply with appointments and recommendations. As one case manager said, “She just doesn’t get it,” referring to the client’s lack of comprehension, poor memory, and difficulty executing a plan even with assistance. Therefore, while this pilot project did not necessarily result in FASD clients developing the ability to access services independently, PCAP assistance did result in clients’ increased use of services. By combining education with follow-up hands-on experience, we demystified the FASD disability for the providers, who were then able to deliver services appropriately tailored to the specific needs of FASD patients. In addition, the pilot resulted in relatively stable contacts for clients with providers, a critical step in improving retention and adherence to provider recommendations over time.

FASD Case Study

Michelle came into PCAP the same way most women do. During pregnancy her drug of choice was methamphetamine, and she also drank occasionally. Although she had permanently lost custody of four other children, she was allowed to keep custody of her newborn son because she had made significant progress since relinquishing her parental rights. It was clear from the beginning that Michelle had multiple problems; her case manager was frustrated at her inability to “get it.” The PCAP clinical supervisor suspected FASD at intake and met with Michelle’s mother
to interview her about her pregnancy drinking. Her mother initially denied alcohol use, but readily admitted to using heroin. When the supervisor asked if it were possible that she drank before she knew she was pregnant the mother said yes, she had “partied just like everybody else, and had loved Black Russians.” After alcohol exposure was verified, Michelle had a neuropsychological evaluation. Her IQ was 73 and she had significant problems with memory and processing information.

Within a year and a half of her son’s birth, Michelle gave birth to a second child, a girl, and went to live with her two children in a clean and sober home for women with substance abuse issues. It became clear that Michelle could not keep track of both children at the same time; her son had disappeared on several occasions. Only with the assistance of the group home staff and the other residents was she able to parent as well as she did. A child welfare report was made and she lost custody of the children, not because she was a bad mother, but because she couldn’t manage the two children simultaneously. Michelle’s case manager arranged to have her evaluated at a brain injury clinic at a local hospital, where they formulated a treatment plan including occupational therapy and memory tools. Michelle was able to recognize her own improvement, stating, “Hey! I can multitask now!”

Michelle’s children were eventually allowed to have longer visits at her home, and she appeared to be able to track and process the children’s activities. Unfortunately, Michelle did not get custody of her two youngest children because of her past history. However, the family they were placed in allowed liberal visitation, and Michelle was able to be an active part of their lives. Michelle chose to have a tubal ligation because she knew she would be able to stay in contact with her children, and she could not stand the grief of relinquishing a future child.

Our small pilot study convinced us that an experienced and clinically supported case manager, working in collaboration with her client and a network of educated providers, might reasonably expect to accomplish a number of important steps over a 12-month intervention. These
steps, not necessarily sequential, include the following:

- Securing stable housing, and safe, secure placements for the children; this may include connecting clients with parenting classes, support groups and respite care; helping clients make decisions about their ability to adequately care for all of their children; mediating with child welfare services and the courts.

- Assisting clients in obtaining inpatient or outpatient treatment and supportive aftercare, for those actively abusing alcohol or drugs.

- Assisting clients in evaluating family planning needs and choosing a contraceptive method, keeping in mind that a long-term, more reliable method may be the best option because of memory and judgment impairment.

- Establishing an educated network of service providers who will continue to work with clients after the case manager’s services are no longer available.

- Obtaining DDD (Division of Developmental Disabilities) status for clients as appropriate in order to secure a measure of financial stability for the future.

- Identifying committed, experienced and/or trained mentors for clients, as most individuals with FASD will require long-term support and assistance.

These interventions may not only improve the client’s current quality of life, but may also establish an enduring foundation for preventing crises long after a program’s services are no longer available, thereby mitigating the social and familial burden associated with the long term care of these individuals. Caregivers who have become exhausted or alienated may be willing to resume a supportive mentoring role after a case manager has helped a client stabilize.

We cannot alter the permanent organic brain damage associated with a diagnosis of FASD or the difficult life circumstances these patients have experienced. The formidable challenge remains that these young women, and most individuals with FASD, will continue to need some kind of coordinated assistance across the lifespan.

Gatekeepers of health and social services must recognize when their systems are
ineffective, and examine different approaches to working with challenging clientele. Our experience has demonstrated that with the expertise of a knowledgeable and dedicated staff, and with the commitment of strong community partnerships, we have the potential to serve mothers and children affected by alcohol and drug abuse, improve their quality of life, and ultimately prevent the births of future alcohol-damaged children.

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Will, G.F. (1999, November 1). Paying addicts not to have kids is a good thing. *Baltimore Sun*, p. 15A.

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<td>45/79 (57)</td>
<td>88/155 (57)</td>
</tr>
<tr>
<td>Category</td>
<td>Count 1</td>
<td>Count 2</td>
<td>Count 3</td>
<td>Count 4</td>
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<tr>
<td>Other family</td>
<td>10/54</td>
<td>10/76</td>
<td>13/79</td>
<td>20/155</td>
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<td>Adopted</td>
<td>2/54</td>
<td>10/76</td>
<td>11/79</td>
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<td>State foster care</td>
<td>14/54</td>
<td>13/76</td>
<td>7/79</td>
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<td>Regular well-child care</td>
<td>35/38</td>
<td>51/53</td>
<td>58/61</td>
<td>109/114</td>
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For more information about the Parent-Child Assistance Program (PCAP) contact:

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