

A Pilot Community Intervention for Young Women with Fetal Alcohol Spectrum Disorders

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ABSTRACT: Fetal Alcohol Syndrome, a permanent birth defect caused by maternal alcohol use during pregnancy, is a leading preventable cause of mental retardation. Neuropsychological deficits have been well documented, however interventions developed have not been evaluated. We describe a successful 12-month community pilot intervention with 19 young women with Fetal Alcohol Spectrum Disorders (FASD). Improved outcomes (including decreased alcohol and drug use, increased use of contraceptives and medical and mental health care services, and stable housing) were obtained by implementing a community intervention model of targeted education and collaboration with key service providers, and by using paraprofessional advocate case managers as facilitators.

KEY WORDS: fetal alcohol syndrome; intervention; prevention; community.

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INTRODUCTION

Fetal Alcohol Syndrome (FAS), a permanent birth defect caused by maternal alcohol use during pregnancy, is the leading preventable cause of mental retardation in the Western World (Abel & Sokol, 1987). The term Fetal Alcohol Spectrum Disorders (FASD) has been proposed to encompass the formal diagnoses of FAS and Alcohol-Related Neurodevelopmental Disorder (ARND) (Institute of Medicine, 1996), and the broad range of central nervous system effects related to alcohol exposure in utero (O'Malley & Hagerman, 1998; Streissguth & O'Malley, 2000).

The neuropsychological deficits and other adverse outcomes associated with prenatal alcohol exposure have been well documented over 30 years of research (Mattson & Riley, 1998; Roebuck, Mattson, & Riley, 1998; Streissguth, et al., 1991; Streissguth, Bookstein, Barr, Sampson, O'Malley, and Kogan Young, 2004). Children and adults with FASD characteristically demonstrate impairment in executive functioning (Bookstein, Streissguth, Sampson, Connor, & Barr, 2002; Connor, Sampson, Bookstein, Barr, & Streissguth, 2000; Kodituwakku, Handmaker, & Cutler, 1995; Mattson, Goodman, Caine, Delis, & Riley, 1999). Executive function skills are cognitive abilities that include sequencing of information and behavior, cognitive flexibility, response inhibition, planning, and organizing behavior. Because these skills are critical for appropriate decision-making and self-regulation, deficiencies can have an impact on multiple aspects of functioning, such as work and school performance, social interactions, parenting, and daily living skills.

However, interventions for individuals with FASD have not been systematically developed and evaluated (Carmichael Olson & Burgess, 1997; Coles & Lynch, 2000; Institute of Medicine, 1996; Randall, 2001). In 1999, the Parent-Child Assistance Program (PCAP) at the University of Washington expanded its evidence-based and widely replicated intervention model in order to enroll a sample of women diagnosed with FAS or FASD. The PCAP 3-year home visitation model was designed originally in 1991 to work with high-risk alcohol and drug-abusing pregnant women, with the primary goal of preventing future births of children prenatally exposed to alcohol and drugs (Ernst, Grant, Streissguth, & Sampson, 1999; Grant, Ernst, & Streissguth, 1999). As part of a research unit at the University of Washington (UW) that has conducted FAS research since the 1970s, we hypothesized that our combined expertise on FAS and on interventions with high-risk women could be applied to the FASD population for whom interventions had not

been developed, by enrolling some young women with FASD into the existing PCAP. In 2001 we undertook the 12-month pilot study reported here with the aims of assessing and better understanding specifically how women with FASD could be helped within the existing framework of PCAP. In consideration of 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 purpose of this paper is to:

- describe how PCAP and community service providers collaborated to better understand and serve clients with FASD;
- describe demographic and psychosocial characteristics of the 19 PCAP clients with FAS or FASD and enrolled in this pilot study;
- compare client connection to key services at baseline vs. at conclusion of the 12-month pilot intervention.

METHODS

Two events converged to bring about the study described here. In July 1999 the Washington State Legislature approved additional funds to enroll a small number of young women with FASD into PCAP (in addition to those already enrolled). In 2001, the Washington Chapter of the March of Dimes funded a small grant to develop a pilot community training and evaluation project for young women in PCAP with FASD who themselves had children or were at risk of having children.

The Pilot Community Intervention

This pilot community intervention for young women with FASD consisted of delivery of the standard PCAP model, enhanced in two ways: (1) by modifying PCAP in order to accommodate enrollment of clients with FASD; (2) by educating community service providers to accommodate clients with FASD.

The Standard Parent–Child Assistance Program (PCAP) Model

The pilot intervention was based within two existing PCAP programs in Seattle and Tacoma in Washington State. Both programs are based on a model that has been described elsewhere (Ernst, Grant, Streissguth, & Sampson, 1999; Grant, Ernst, & Streissguth, 1999; Grant, Streissguth, & Ernst, 2002; Institute of Medicine, 1996). In brief, trained and supervised PCAP paraprofessional advocate case managers with a caseload of approximately 15 families each, work with clients for 3 years beginning during pregnancy or shortly after the birth of a child. PCAP case management is not delivered according to a specific model of behavioral intervention. Instead, advocates develop a positive, empathic relationship with their clients, help them address a wide range of environmental problems, 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.

Modifying PCAP to Accommodate Clients with FASD

The 1999 expansion of PCAP to enroll clients with FASD from the community required concomitant staff training and development. These steps were also necessary to alert PCAP advocates to the possibility that some of the high-risk mothers they were already working with might be fetal alcohol affected. UW research scientists and clinicians educated PCAP advocate 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 advocates had encountered in working with clients with FASD who were among their PCAP clients. PCAP staff observed the diagnostic process at the UW FAS diagnostic clinic, and administrators coordinated to streamline the lengthy intake process for obtaining a true medical diagnosis for our clients. With assistance from a social work visiting scholar, PCAP advocates took responsibility for helping 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 could facilitate the diagnostic process by evaluating clients, and negotiated with state agencies to pay for these exams. As FASD enrollment got underway, PCAP advocates 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.

The Pilot Study Phase

Subjects were initially enrolled in the standard 3-year PCAP intervention between August 1999 and August 2001, and at entry were assigned to a PCAP advocate case manager who delivered home visitation and intervention services. Participants were recruited through community referral, with sources including hospital and welfare social workers, the judicial system, substance abuse treatment facilities, child protective services workers, and from the fetal alcohol follow-up study on our research unit. Participants in the nested FASD 12-month pilot study were recruited from among enrolled PCAP subjects who themselves had FASD. Women were considered eligible for the pilot study who: (1) had a documented medical diagnosis of prenatal alcohol damage, or had a suspected diagnosis because they had characteristics of prenatal alcohol damage in the presence of prenatal alcohol exposure; (2) had at least one year remaining in the 3-year PCAP program. The pilot study was conducted from June 2001 through May 2002.

Educating the Community to Accommodate Clients with FASD

Current clinical practice recommendations call for coordinated, multi-systemic management for FASD patients (Carmichael Olson & Burgess, 1997; Clarren, 2002; FAS/E Support Network of B.C., 2003; Hagerman, 1999; Institute of Medicine, 1996;

Smith & Coles, 1991; Streissguth, 1997). However, as we began our work we found, as others have, that providers knew very little about FAS and its implication for practice, and had little direct experience with this patient population. With that in mind, as part of the pilot community intervention we identified key providers who we believed could deliver quality service to our clients with FASD, who were interested in the problem of prenatal alcohol abuse and its effects, and who were willing to work with one of our clients as a case study in close collaboration with her PCAP advocate. We provided an initial educational session on FASD to the agencies with which each provider was affiliated, using a slide presentation and materials on FASD we developed. We also provided back-up consultation for individual providers as questions or problems arose in treating PCAP clients with FASD in the community.

Community providers and this study's paraprofessional advocates brought distinctly different but complementary skills to the intervention. The experienced advocates helped the providers understand the relationship between the organic brain damage sustained in utero by clients with FASD 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.

In working with community providers, advocates recommended strategies to communicate more effectively with FASD clients. For example, when giving instructions, they advised providers to talk in concrete terms, avoid using words with double meanings or idioms, and say exactly what they mean. They asked physicians to give simple step-by-step instructions, and then have the patient demonstrate understanding of the directions by showing a skill, rather than relying on a verbal affirmation that she understands. They recommended that simple (5th grade level) written instructions be given, with illustrations if possible. For advocates and professional providers alike, it was critical to re-teach and repeat important points at each visit, and to remember that instructions were unlikely to generalize to a similar situation. In their work with providers, advocates emphasized the importance of consistency both in the environment and in the people providing care. If the primary provider must change (as it may in community clinics and agencies where staff turnover is high), they suggested a transition period in which the current provider could introduce the new provider. Finally, advocates emphasized that the aim of treatment should be to stabilize presenting problems rather than to pursue a cure for permanent disabilities in reasoning, judgment and memory.

Measurements

The Addiction Severity Index 5th Edition (ASI) and a PCAP ASI addendum were administered to all subjects at intake into PCAP by one of the clinical supervisors (JP or NW, both master's level mental health specialists). The ASI is a face-to-face, semi-structured one-hour interview assessment of problem severity in seven domains: medical, employment, legal, family/social, psychiatric/emotional, alcohol, and other drug use. It has been widely used in clinical and research settings with a variety of populations (McLellan, et al., 1992, 1985; McGahan, Griffith, & McLellan, 1986; Zanis, McLellan, Canaan, & Randall, 1994). In 1997 PCAP adapted the ASI for use with high-risk pregnant

and parenting women by supplementing it with questions about childhood history characteristics, contraceptive methods, community service utilization, and service needs (identified by client self-report in conjunction with interviewer assessment).

Institutional Review Board approval was obtained from the University of Washington and informed, signed consent was obtained from all subjects. A certificate of confidentiality was obtained from the federal Department of Health and Human Services, to further protect subjects' privacy.

RESULTS

Community Trainings

During this 12-month pilot study, we conducted FASD training with providers at 15 major clinics and agencies (six medical clinics, five mental health clinics, and four substance abuse treatment agencies) and linked each of our 19 clients with a specific provider whose services they needed but had not previously received.

Subjects

A total of 19 PCAP clients who had FASD ($n = 11$) or suspected FASD ($n = 8$) were enrolled in the pilot study. When they enrolled in the pilot study, subjects had been participating in the PCAP 3-year intervention for varying lengths of time (an average of 10.7 months, range = 1–22).

The average age of subjects was 22.3 years (range 14–36), most were white (63%), unmarried (84%), poorly educated (47% had a 9th grade education or less), and almost all had been physically or sexually abused as children (94%) (Table 1). Among the 15 (79%) 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.

Forty seven-percent reported having a serious, chronic medical condition such as a seizure disorder or kidney failure. Sixty eight-percent reported having been incarcerated (jailed) in the past. On the ASI, 12/17 clients (71%) reported having had a psychiatric evaluation, and 10 of these knew their diagnosis: bipolar disorder ($n = 5$), depression ($n = 3$), and one each with post-traumatic stress disorder (PTSD) and schizophrenia.

Outcomes Among Clients with FASD

At the start of the pilot, only 3 clients (16%) reported that their medical and/or mental health care needs were being adequately met. For the

TABLE 1

**Demographic and Psychosocial Characteristics of Women
with FASD or Suspected FASD (N = 19)**

<i>Characteristic</i>	<i>n (%) or Mean (SD)</i>
Age (yrs)	22.3 (5.7)
Race	
White	12 (63.2%)
American Indian	4 (21.0%)
African American	3 (15.8%)
Unmarried	16 (84.2%)
Education (yrs)	9.9 (1.9)
≤9 years	9 (47.4%)
Physical/sexual abuse as child	17/18 (94.4%)
Parity (among 15 with children)	2.3 (1.8)
# Children living with mother	1.2 (0.68)
Alcohol/illegal drug use ¹	
None	3 (15.8%)
Any alcohol	13 (68.4%)
Binge alcohol	4 (21.0%)
Any illegal drugs	15 (78.9%)
Cigarettes	15 (78.9%)
Chronic medical condition ²	9 (47.4%)
History of incarceration (jail)	13 (68.4 %)
Ever had psychiatric evaluation	12/17 (70.6%)
Primary diagnosis	
Bipolar	5/12 (41.7%)
Depression	3/12 (25.0%)
PTSD	1/12 (8.3%)
Schizophrenia	1/12 (8.3%)
Diagnosis unknown	2/12 (16.7%)

¹Defined as any use in the 10 months prior to the intake ASI interview.

²Includes medical problems such as seizure disorder, kidney failure, asthma.

other 16, medical/mental health care was identified as a specific unmet need (8 medical health care only; 4 mental health care only; 4 both). All 16 women began receiving these services during the pilot intervention by a

provider educated about FAS (although PCAP staff assessment indicated services were still insufficient for 4 of the 8 with mental health needs).

At intake into standard PCAP, 9 of the 19 young women (47%) were living in stable housing, and 10 reported housing as a specific need. By the start of the pilot, 2 more had obtained adequate housing as part of standard PCAP intervention (58%). At the conclusion 12 months later, 16 (84%) had secured stable housing. Among the 3 who were not housed by the end of the pilot, 2 had fluctuated for months between being incarcerated and homeless; the third was "couch surfing," but had affiliated with her tribe and begun receiving outpatient substance abuse treatment.

One of the primary aims of the PCAP intervention is to prevent the birth of yet another generation of alcohol/drug affected individuals. To this end, beginning at enrollment, advocates helped substance abusing clients enter treatment, helped those who were not problematic users to avoid or minimize use, or motivated them to choose a reliable family planning method. At intake into PCAP, only 3 of the 19 young women (16%) had not used alcohol or illegal drugs in the previous 10 months. By the start of the pilot, 14 women (74%) were not using, having either received alcohol/drug treatment as part of standard PCAP ($n = 6$), stopped using as a result of advocate and natural supports, without undergoing formal treatment ($n = 5$), or maintained their abstinence ($n = 3$). At the end of the pilot, 14 women were not using; 11 of these had maintained their abstinence throughout the pilot (7 had continued in treatment), and 3 were newly in recovery. Among the 5 women still using either alcohol or drugs or both, 3 were using a reliable contraceptive (2 tubal ligations, 1 Depo Provera injection).

At intake into standard PCAP, only 3 of the 19 young women (16%) were using a regular family planning method. During the pilot, the number of women using a reliable contraceptive increased from 8 (42%) at the start to 14 (74%) at the conclusion (7 Depo Provera, 3 tubal ligation, 2 intrauterine device (IUD), and 2 pills). Four women were not using any form of contraception (2 had been clean and sober for 8 and 24 months, respectively, when the pilot concluded, and 2 were using alcohol and/or drugs). One woman became pregnant during the pilot, and was clean and sober for the last 6 months of her pregnancy.

DISCUSSION

In this study we found that young women who have FASD or suspected FASD reported a troubled life history profile and had many unmet

basic service needs. Over this 12-month pilot study, we demonstrated a method for providing individualized intervention to connect the FASD clients with systems of care, resulting in outcomes clinically relevant for the women themselves and for the prevention of future births of children with FASD. These outcomes include decreased alcohol and drug use, increased housing and use of contraceptives, and improved medical and mental health care services.

The effect of prenatal alcohol exposure on the developing brain varies greatly depending on timing, frequency, and duration of exposure, and as a result the affected individuals' cognitive capacities, potential to learn, and behavior will also fall along a wide continuum (Alcohol Research and Health, 2000). The highly skilled PCAP advocates found the impact of the neuropsychological deficits on their FASD clients was obvious, and required that advocates modify their traditional intervention approaches. Advocates had to assume a far more directive role as they introduced clients to community services and helped them comply with appointments and recommendations. In addition, the advocates handled many of the usual barriers to treatment such as repeat scheduling, transportation, and childcare problems that would otherwise have hindered successful service delivery.

Working with FASD clients was far more difficult than working with the typical PCAP clients for whom the intervention was designed, i.e. high-risk substance-abusing women with complex problems. 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 from the advocate or they learned them very slowly. As one advocate said, "She just does not get it," referring to the client's lack of comprehension, poor memory, and difficulty executing a plan even with assistance. Therefore, while the pilot did not necessarily result in FASD clients developing the ability to access services independently, advocates' 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.

A serious impediment experienced by the FASD clients was stringent and narrow institutional eligibility criteria that sometimes prevented them from receiving or being able to pay for services. For example, although a client had poor adaptive living skills that prevented her from living independently (a typical characteristic of FASD clients), because she had an IQ above 70 she was not eligible for developmental disabilities services and financial support.

We demonstrated in this pilot study that an experienced and clinically supported advocate, working in collaboration with her client and a network of educated providers, might reasonably expect to accomplish a number of important steps over the course of a 12-month intervention. These steps, not necessarily sequential, include the following:

1. 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 Protective Services (CPS) and the courts.
2. Assisting clients in obtaining inpatient or outpatient treatment and supportive aftercare, for those actively abusing alcohol or drugs.
3. 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.
4. Establishing an educated network of service providers who will continue to work with clients after the advocate's services are no longer available.
5. Obtaining DDD (Division of Developmental Disabilities) status for clients as appropriate in order to secure a measure of financial stability for the future.
6. 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 an advocate has helped a client stabilize.

Although we assessed client utilization of key services during the 12 months, we do not have data on frequency of contact with providers, nor did we assess provider behavior with clients after our training. Our intention in this pilot study was to draw attention to the complexity of the problems faced by people with FASD, and to demonstrate pragmatic approaches to educating providers about working with this clientele with multiple co-morbidities. Follow-up studies with this population will include more extensive data collection to measure client and provider behavior change.

We cannot alter the permanent organic brain damage associated with 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. 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 fetal alcohol affected individuals, improve their quality of life, and ultimately prevent the births of future alcohol-damaged children.

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