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INTERVENING TO PREVENT PRENATAL ALCOHOL AND DRUG EXPOSURE: THE MANITOBA EXPERIENCE IN REPLICATING A PARAPROFESSIONAL MODEL

Cathe Umlah & Therese Grant

Nor'West Mentor Program & University of Washington

Intervening with substance using women who are pregnant and at high risk for giving birth to an alcohol or drug affected child presents considerable challenges to the helping profession. These women may feel considerable shame and guilt related to their substance use, and in order to avoid judgement and criticism, they often distance themselves from the very help they need. These women typically come from families where substance abuse, neglect, and abuse are prevalent, and they lead lives characterized by poverty, domestic violence, and loss. They have been labeled as unmotivated, resistant, and incapable of making meaningful changes in their lives, and in turn these high-risk women are often mistrustful of professionals and the systems designed to help them.

The impact of substance use on pregnant women and their children is considerable. Heavy use of alcohol and/or drugs during pregnancy can cause permanent damage to the developing fetus leading to conditions such as Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), and fetal drug effects. The central nervous system damage characteristic of FAS and FAE can have lifelong effects on affected individuals including learning problems, developmental delays and behaviour problems (Institute of Medicine, 1996). In addition, a mother's continued use of alcohol and/or drugs can lead to a dysfunctional and compromised home environment for the child. In many cases, children born to women who abuse substances are apprehended at birth or subsequently removed from the home due to the risk associated with parental substance use.

The Stop FAS Initiative

The Stop FAS initiative was developed in Manitoba in 1998 to address the growing concern regarding maternal use of alcohol during pregnancy, as well as the increasing number of children being formally diagnosed with FAS in the province. The purpose of this article is to describe the program model, discuss the unique features that enhance intervention with high-risk women, and present early evaluation outcomes from the Winnipeg sites that demonstrate the effectiveness of this model in the prevention of prenatal alcohol and drug exposure in children.

The Stop FAS program model is a replication of the Parent-Child Assistance Program (PCAP, formerly known as the Birth to Three Project) developed in 1991 at the University of Washington School of Medicine in Seattle, Washington (Ernst, Grant, Streissguth & Sampson, 1999; Grant, Ernst & Streissguth, 1999; Grant, Ernst, Streissguth, Phipps & Gendler, 1996). Stop FAS is part of an overall government strategy designed to prevent the births of children with FAS. The program is funded by the provincial government, initially through the Children and Youth Secretariat, which evolved into Healthy Child Manitoba in 2000. The prevalence of FAS in Canada is estimated to be similar to that of the United States, ranging from 1-2 per 1000 live births, depending on factors such as ethnic background and socio-economic status (Canada's Drug Strategy Division, Health Canada, 2000). The true prevalence of FAS in Manitoba is unknown, but prevalence is estimated to be higher among isolated and disadvantaged groups in our province. Fetal Alcohol Effects is a less easily identifiable condition because the characteristic FAS facial features and growth deficiency may not be present. However, FAE is considered to be just as damaging as FAS because the central nervous system damage is permanent and affects the brain's executive functioning. The combined prevalence of FAS and alcohol-related neurodevelopmental disorders is estimated to be 9.1/1000 live births (Sampson et al., 1997).

Theoretical Background

The Stop FAS model is based on a theoretical framework originally conceptualized in the Parent Child Assistance Program/Birth to Three. The critical component of the program is the meaningful and supportive relationship that develops between the client and her mentor. The personalized and caring support offered over a long enough period of time allows for gradual and enduring changes to occur in the woman's life. This aspect of the program model is based on relational theory that recognizes the importance of interpersonal relationships in women's addiction, treatment and recovery. Because a woman's sense of connectedness to others is central to her growth, development and definition of self, positive relationships within the intervention and treatment setting are critical (Amaro & Hardy-Fanta, 1995; Finkelstein, 1993; Miller, 1991; Surrey, 1991). The use of paraprofessional mentors can enhance the opportunity for relationship with clients, as the mentors do not experience the distance that professionals or experts often encounter. Clients can relate to mentors because they have both experienced challenging life experiences and because of mentors' down to earth style and empathic approach.

Overview of the Model

This is an intensive one-on-one outreach model designed to intervene with highrisk substance using women; who are either pregnant or who have just given birth. Paraprofessional mentors offer a wide range of services for a three-year period. They work intensively with a caseload of 12-15 families to assist them in addressing program and individual goals. The services are flexible and personalized based on individual needs. See the accompanying table "Features of the Stop FAS Model" for further details.

Table 1

Features of the Stop FAS Model

This is a three year home visitation model, implemented by well trained and closely supervised paraprofessional mentors. Caseloads never exceed 15 active client families per mentor. Features of the model include:

- Mentors never give up on a woman; women are never asked to leave the program because of relapse or setbacks.
- Mentors develop a network of relationships with everyone involved in a woman's life and provide advocacy for other family members as needed.
- The program continues to advocate for both mother and target child, as appropriate, regardless of custody issues.
- Mentors connect a woman's service providers with each other and facilitate development of an effective plan; services may include Child and Family Services, probation services, alcohol/drug treatment, health services, etc.
- The program links women with the best available community services, and identifies and actively resolves existing barriers. Although the mentor's role is intensive, it is not intended to provide the 'direct' services needed.
- Women identify and evaluate personal goals every four months, which mentors coordinate with program goals.
- Weekly supervision with each mentor and clinical supervisor is essential.
- Weekly staff meetings, including case reviews with the team are essential to help mentors learn from the progress of each other's clients, and to provide a venue for ongoing program training.
- Ongoing program evaluation generates information used by the program to examine outcomes and to enhance the work of mentoring.

Program Sites / Community Partners

Stop FAS was initially funded out of three community-based health centers in Manitoba. The sites in Winnipeg include the Nor'West Co-op Community Health Centre, and the Aboriginal Health and Wellness Centre. A rural site developed in Norway House withdrew from the delivery of the Stop FAS model one year into the project, primarily due to the poor fit between the program model and the community's needs and characteristics. That community of approximately 6000 people is small and close knit in comparison to Winnipeg and women there were reluctant to participate in a program that

works openly with substances use issues, for fear of being stigmatized. Services to pregnant women in Norway House have since evolved and are more broad based and responsive to the unique needs of their community.

The two Winnipeg sites operate independently, although they maintain strong ties with each other, with Healthy Child Manitoba, and with a number of key community partners. Each site has developed its own identity in the community naming themselves the "Nor'West Mentor Program" out of the Nor'West Co-op Community Health Centre, and the "FAS/E Prevention Program" out of the Aboriginal Health and Wellness Centre. Both sites deliver the same model to the community, however the Aboriginal Health and Wellness site is targeted to Aboriginal women only by offering both contemporary and traditional approaches of support to Aboriginal women based on the medicine wheel and the seven sacred teachings. The Nor'West site offers service to women of all cultures.

The Stop FAS initiative was expanded to northern Manitoba in October 2001, with the development of "The Pas Mentor Program" in The Pas and "The Grassroots Mentoring Program" in Thompson. This expansion was primarily due to the preliminary outcome data from the Winnipeg sites that demonstrated program effectiveness in assisting women to enter treatment, achieve sobriety, and use family planning methods.

Significant partners in this initiative include Healthy Child Manitoba under the guidance of the FAS Coordinator, and the Addictions Foundation of Manitoba (AFM). In collaboration with Healthy Child Manitoba, the AFM developed a Stop FAS Training Manual, and facilitated a 10-day training program on addictions for the sites at the beginning of the program in 1998. The AFM continues to provide ongoing training to the sites and facilitates quarterly joint case reviews with the Winnipeg sites.

Program Goals and Objectives

The overall goal of the Stop FAS program is to prevent prenatal alcohol/drug exposure in future children born to high-risk substance using women. The specific objectives that guide the intervention with women are:

- 1. To assist women in obtaining drug and alcohol treatment, and staying in recovery.
- 2. To support women in their efforts to provide a safe and healthy environment for themselves and their children.
- 3. To link women to community resources in order to help them reduce isolation, to improve access to needed resources, and to become more independent (education/employment).
- 4. To reduce the number of alcohol/drug exposed births through abstinence from alcohol/drugs and improved access to reliable family planning methods.
- 5. To demonstrate to community service providers strategies for working more effectively with this population in an effort to improve the outcomes for both women and children.

The model is based on a principle of harm reduction that recognizes abstinence from alcohol and drugs as an ideal outcome, but accepts alternatives that reduce harm (Marlatt, 1996). Women are accepted into the program as they are, regardless of whether they have made a decision to stop using substances or have made a commitment to sobriety. All efforts that clients make to cut down or stop using substances are encouraged, and women are not asked to leave the program if they are unable or unwilling to achieve sobriety. The theoretical foundation of Stop FAS incorporates the trans-theoretical model of change (Proshanska, DiClemente, & Norcross, 1995), which is used extensively in the addictions field. Within this framework, mentors help clients reflect on their ambivalence about change and offer a concrete approach to assisting them in the change process.

Staffing and Scope of the Program

Initially, the Winnipeg sites staffed one full time coordinator and two full time paid mentors. Within eighteen months, each site had reached its capacity of 25-30 women. As the needs of this population became more visible, and the program became more well known and utilized in the community, women were being turned away at referral due to lack of program capacity. Healthy Child Manitoba addressed this situation in 2001, by providing supplemental funding to each site to hire an additional mentor. Overall the two sites now have the capacity to provide services to 90 women in Winnipeg at any given time. Space availability depends on the rotation of graduates out of the program after three years of service.

The Stop FAS program sites are administered by coordinators who have professional backgrounds in social work. The coordinator is a key link to the community in terms of marketing the program and collaborating with other systems. She determines client eligibility and manages the intake process and evaluation data. She supervises the mentors and their casework and provides ongoing clinical direction and support. Each Coordinator is involved in broader community planning regarding FAS, and issues related to pregnant substance using women. Each site also offers training opportunities for community service providers on FAS and strategies for working with high-risk women.

The mentors are trained paraprofessional staff with work experience in the social services field, particularly with high-risk populations. They are required to have completed a minimum Grade 12 education, however many have additional training or education. They are women who represent diverse ethnic backgrounds, and who may have experienced many of the same difficulties as their clients. Having overcome these difficulties in their own lives, they are positive role models for their clients. Self-disclosure can be a useful tool for mentors. In sharing some of their own life experiences with clients, they can give a hopeful message such as, "If I can do it, so can you!" The mentors have varied styles and approaches, but they all have a common belief in the essential worth of each woman they work with and a hopeful and positive attitude. They also share common characteristics of being tenacious, with creative problem solving skills, and a direct and non-judgmental approach with women.

Recruitment

At program inception in 1998, Winnipeg Stop FAS sites did extensive outreach to the service provider community to spread the word about this unique and specific service available to women, and about the program goal to prevent FAS/E. Developing liaisons

with the service community has been an important, ongoing process in order to be aware of the scope of services available, help clients build connections, and maintain the referral base. Stop FAS recruits clients through the providers who are most likely to interface with this high-risk population, and referral sources include hospitals, prenatal clinics and services, community health centres, child welfare, social assistance, alcohol and drug treatment services, and local community resources. Women also self refer based on word of mouth in the community, or by learning about the program from pamphlets distributed in the community.

After a woman is referred, the coordinator determines her eligibility by gathering information from the referral source and from the woman herself. Once eligibility has been determined, a mentor is assigned and schedules an initial home visit within one week of referral. If a program is temporarily full to capacity, Winnipeg sites may refer to one another as appropriate. When no spaces are available in the city in the foreseeable future, Stop FAS coordinators will assist the woman or the referral source to access other resources that may be appropriate for her. The program is voluntary, and women sign forms indicating informed consent to participate when they decide to enroll.

The Clients

In order to be eligible for this program a woman must meet three criteria: (a) she must be pregnant or up to two months postpartum; (b) she must have used alcohol and/or drugs heavily during her pregnancy; and (c) she must be not effectively connected to existing services (in other words, women who are "falling through the cracks"). Heavy use of alcohol or drugs is determined either by frequent binge episodes or ongoing regular use of substances throughout the pregnancy. Both of these using patterns place the developing fetus at high risk for alcohol/drug effects.

Intake demographic data from the first 60 women enrolled in Stop FAS between September 1998 and December 1999 indicates that Stop FAS is providing service to its intended population. Women enrolled share similar characteristics that are important to understand in terms of designing services that will be the most effective for this population.

At enrollment in Stop FAS (n = 60):

- average age was 26 years;
- 75% of women had at least one biological parent with an addiction problem;
- 100% reported being abused as a child (emotional, physical or sexual abuse);
- average education completed is Grade 8;
- 73% used more than one substance, including alcohol;
- average number of children born is 3 (not including current pregnancy);
- average number of children who were no longer in the care of their mothers was three;
- 48% had an unstable living situation (frequent moves or homelessness);
- 85% relied on social assistance for their income.

The Intervention Model

The intervention model involves four basic components: establishing the relationship, identifying client goals, establishing linkages with service providers, and role modeling and teaching basic skills.

Establishing the Relationship. Mentors begin to get to know the client immediately after enrollment in Stop FAS. Building trust in this relationship can take months or even longer, given the client's history of abuse and abandonment and overall mistrust of systems. During this initial phase, mentors help to address the client's immediate needs such as food, shelter or transportation to important appointments. The mentor's outreach and follow through, particularly in this phase, is critical to establishing trust and demonstrating to the client that she is cared about. Mentors meet regularly with each client, depending on the client's needs and provide emotional and practical support on an ongoing basis. Contact can range from weekly visits and/or phone calls to daily contact during periods of crisis. Additional efforts to reach out to the client's family include building relationships with their children, significant others and extended family. These connections serve to further strengthen the bond with the client and provide a vehicle to stay in touch if she disappears or loses touch with her mentor in the future.

Mentors are persistent and creative in their efforts to engage clients and stay connected. Staying in touch over time can pose a significant challenge, particularly when clients are transient or involved in gang or drug cultures, or when they stop reaching out for support because they believe their situation is hopeless. Mentors do a great deal of field work, including scheduled appointments, as well as dropping in on clients at home or dropping in at scheduled visits with their children in foster care. The use of notes and letters that contain friendly, caring and positive messages are particularly effective in letting clients know that the mentors are still thinking of them and ready to get to work whenever the woman is ready. Mentor's efforts have paid off in many situations where women had initially given up on themselves, but who now have begun to turn their lives around and have hope for the future.

Identifying Client's Goals: Assessment and Planning. Within one week after enrollment, the mentor meets with her client to assess the family situation and consider her plan to assist them. Mentors administer a number of user friendly assessment tools with clients to collect baseline information for evaluation and assist with planning. The woman has an opportunity to identify her own goals using "The Difference Game", a unique card-sort assessment instrument that assists her in identifying realistic goals she feels would make a difference in her life (Grant, Ernst, McAuliff, & Streissguth, 1997). Goals are recorded and the mentor and client identify specific steps that need to be taken to achieve these goals. Every four months throughout the program, the client and her mentor evaluate the goals, and the woman may choose new goals on which to work, reflecting changes that may have occurred in her situation or within herself (or she may keep the same goals over time). This process is a dynamic, fun and empowering way to teach women about goal setting. It is a concrete strategy that provides the foundation and the "work" for the program service. Mentors challenge women to achieve their goals, always with a strong belief in the woman's ability to improve her life. **Establishing Linkages with Service Providers**. Mentors are in a key position to coordinate the multidisciplinary systems involved with the client and advocate on her behalf. Beginning at enrollment, the mentor contacts the various service providers with whom the client is involved, provides information about Stop FAS, and identifies her role as a support to the client and case manager (as appropriate). In reality, the child welfare system often takes on the role of case manager and the mentor's role becomes that of team member acting as client advocate. Service agencies with which the mentors typically work include child welfare, employment and income assistance, health, child development/diagnostic services, drug and alcohol treatment, educational, housing, mental health and judicial systems. The mentor uses a team approach to ensure that a comprehensive service plan is developed for each client and that the roles and responsibilities of each team member or agency are clearly stated. This helps to avoid duplication of services and ensures that the client has a workable and consistent plan.

Mentors do extensive resource matching with clients to services that will best meet her needs. They then help her to negotiate the steps needed to make use of the resources. For example, mentors assist women in finding the most appropriate alcohol and drug treatment facility or resource for her circumstances, assist her with completing application forms, advocate on her behalf to reduce time on a waiting list, prepare her to enter treatment, and arrange transportation. They also help women negotiate child care, store their belongings and eventually make arrangements for aftercare treatment and transitional housing. The practical assistance and emotional support offered by the mentor in these circumstances is vital to breaking down the barriers that prevent women from accessing the help that they need.

In an effort to maintain confidentiality, clients are asked to sign a release of information for all systems with which the mentor needs to be in contact. Clients are advised at enrollment about the mentor's duty to report abuse or neglect of children, and suicidal or homicidal behaviour. Mentors discuss child welfare issues with women on an ongoing basis. When reporting to child welfare is necessary, mentors include the client in the process whenever possible. This approach empowers clients to take responsibility for concerns regarding their children, and sets the stage for more cooperative planning.

<u>Role Modeling: Teaching Basic Skills</u>. Mentors take advantage of every opportunity to teach basic life skills and role model for clients. Mentoring is not a desk job and mentors do frequent home visits, as well as provide transportation for women and their children to important appointments. They find that time spent in the car with the client is extremely valuable as they can talk with few distractions.

Women enrolled in Stop FAS often come from chaotic and neglectful childhood backgrounds, where they did not learn basic skills such as relating to others, organizing themselves or even taking care of their basic needs. In addition, many women came from homes where alcohol and drug use was prevalent. Some of the women are alcohol or drug affected themselves due to prenatal exposure, and therefore are also impeded with a developmental disability. Mentors are respectful and helpful in their approach, and look for opportunities to demonstrate and teach women about day to day living. The most effective strategies are those that are very explicit and concrete and are reinforced over time.

Evaluation Framework and Preliminary Outcomes

Evaluation is an important component of the Stop FAS model. Healthy Child Manitoba administers the evaluation framework, which has been adapted from the Seattle PCAP model, and includes program outcomes and implementation measures. Beginning at intake, the coordinator administers an adaptation of the standardized 5th Edition Addiction Severity Index (ASI) interview to all clients to collect baseline data against which to assess program outcomes (McLellan, Cacciola, Kushner, Peters, Smith, & Pettinati, 1992; McLellan, Luborsky, Cacciola, & Griffith, 1985). Mentors evaluate each client's ongoing progress biannually using the Six Month Assessment tool. At the end of the three years, the coordinator administers an Exit Interview, which is a shorter version of the ASI. Together, these three measures provide information on the overall success of the program as outlined in the program objectives. In addition, ongoing evaluation measures focus on the process of the intervention. Process measures include case notes and time summaries that describe and quantify mentors' contact with each client. The "Progress Towards Goals" sheets are used in conjunction with the Difference Game; these are completed every four months to allow the mentor and client to keep track of the goals being worked on.

Preliminary Results

Outcome evaluation among the first 60 women enrolled in the demonstration phase of Stop FAS is complete. Preliminary findings indicate that the program is having an important impact on the well being of both the clients and their children. Among the initial 60 women, 17 (28.3%) moved out of the service area permanently prior to completing the 3 year program. Among the 43 women who graduated from the program by December 2002:

- 26 (60%) were not at risk of delivering a child with FAS because they have either been abstinent from alcohol (and drugs) for 6 months or more <u>or</u> were using a family planning method regularly;
- 28 (65%) had completed an addictions treatment program;
- 21 (49%) were abstinent from alcohol and drugs at exit from the program; of these, 11 (26%) had been clean and sober for six months or more;
- 21 (49%) were using a reliable family planning method (13 [30%] Depo Provera injections; 5 (12%) tubal ligation; 3 (7%) regular pill or condom use};
- 12 (28%) had completed an educational/training program;
- 27 (63%) of target children were living with their own families (10 [23%] with their biological mothers, and 17 [40%] with fathers or extended family).

How Stop FAS has Helped: In Our Clients' Own Words

"I am starting to say no to things I would have said 'yes' to in the past, like friends wanting to go out drinking."

"I stand up for myself more now. I voice my opinions instead of hiding them."

"I am more open, it doesn't matter as much what other people think of me."

"Instead of putting myself in bad situations, I check it out first."

"I am taking more responsibility for myself."

"I am making choices for myself, not letting a man do it for me."

"I like being a mom. I like doing things for my son, being there for him, keeping him safe."

"I saved all the cards and notes my mentor sent me."

"I learned how to talk for myself with other agencies. My mentor would encourage me to call and speak for myself. She followed up and made me call her back."

"My mentor got me to look into FAS/E more and pay attention to my son's needs."

"My mentor said things like...if you can't do it now, you can work on it and it will come."

Conclusion

The Stop FAS model is making a difference in the lives of high-risk substanceusing women and their children in Winnipeg. Preliminary findings reported here demonstrate that a paraprofessional model focused on building positive relationships with women over time is an effective approach that can lead to meaningful change. At exit from the 3-year intervention, over half of these women had completed treatment programs; a quarter had been clean and sober for six months or more; an additional quarter of the women were more recently clean and sober. At entry into the program, none of the women were using contraceptive methods and they did not identify this as a priority in their lives. With assistance from the mentors regarding family planning education and implementation, women are now making informed choices, as evidenced by the substantial increase in the use of family planning methods at the end of the three years. They are beginning to look forward in their lives and get involved in education and/or training programs. Nearly two thirds of the target children are being cared for by their parents or family members. Finally, the data indicates that the program is successful in preventing prenatal alcohol/drug exposure in subsequent children; 60% of our clients are either clean and sober or are using family planning methods at the end of the three years in the program.

These women are worth our efforts. They have hopes and dreams for a good life for themselves and their children, and have the potential to make meaningful changes in their lives. Mentors and coordinators in the Stop FAS program have come to appreciate these clients as strong, capable and resilient individuals, who are also loving mothers to their children. We have learned to never give up on any woman. She may just be the one who is ready to turn her life around.

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About the Authors

Cathe Umlah is a social worker in Winnipeg and Coordinator of the Nor'West Mentor Program. She started this Stop FAS site in 1998 and has a strong commitment to supporting women who are struggling with alcohol and drugs. She is currently completing her Masters Degree in Social Work, Policy Planning and Administration.

Therese Grant is an epidemiologist who has worked in the field of perinatal substance abuse research for 20 years. She is a research assistant professor in the Department of Psychiatry and Behavioral Sciences, adjunct research assistant professor in the Department of Epidemiology, and a research affiliate with the Center on Human Development and Disability at the University of Washington. She has directed the Parent-Child Assistance Program, now operating at five sites in Washington State, since its inception in 1991.