# THE ELSIPOGTOG QUEST FOR EXCELLENCE

## THE INSTITUTIONALIZATION OF AN INNOVATIVE, COMMUNITY-BASED PROGRAM FOR THE PREVENTION, DIAGNOSIS AND INTERVENTION OF PREVENTABLE PRE-NATAL BIRTH DISABILITIES.

**By**

**Don Clairmont**

**Dalhousie University**

**November 2010**

**ACKNOWLEDGEMENTS**

This assessment of an interesting and path breaking, multidimensional, community approach to the problems of FASD and related non-genetic birth disabilities was only possible because of the leadership provided in the areas of Health and Justice in Elsipogtog by Claudia Simon, Eva Sock, Ron Brun and Lori Cox. Together they have built an integrated system of prevention, diagnosis and treatment – the Eastern Door - which is directed at major health and social problems and which would do large metropolitan areas proud, never mind a small, relatively poor community such as Elsipogtog. They imaginatively sought and successfully obtained the required resources to create a sophisticated program and also encouraged a rigorous assessment of it. The evaluation received excellent collaboration from all local service providers, provincial officials, and the clients participating in one or more of the central program services.

**TABLE OF CONTENT**


| | |
|---|---|
| EXECUTIVE SUMMARY | p.4 |
| THE TASKS OF THE ASSESSMENT: THE PROBLEMATIC | p.15 |
| RESEARCH STRATEGIES | p.17 |
| DEVELOPMENT OF THE EASTERN DOOR AND THE AHTF PROJECT | p.21 |
| THE SOCIAL CONTEXT: CHALLENGES AND COLLECTIVE EFFICACY | p.24 |
| POPULATION AND EDUCATION | p. 26 |
| POLICE DATA AND IMPACT FOR ED CLIENTS | p. 32 |
| ALCOHOL AND DRUG ABUSE | p. 39 |
| COLLECTIVE EFFICACY | p. 43 |
| THE THREE DIMENSIONS OF A COMMUNITY BASED MODEL FOR DEALING WITH BIRTH DISABILITIES | |
| THE DIAGNOSTIC TEAM | p. 47 |
| KEY ISSUES | p. 49 |
| EVOLVING EXPLANATORY THRUSTS | p. 49 |
| PARENT-GUARDIAN VIEWS | p. 50 |
| FAMILY SUPPORT (FS) AND INTERVENTION | p. 53 |
| PRELUDE: PARENTS AND THE NOGEMAG PROJECT | p. 53 |
| PARENTS VIEWS ON ED AND FS IN 2010 | p. 57 |
| DESIGNER AND FS STAFF VIEWS | p. 66 |
| SUMMARY | p. 71 |
| PCAP: PREVENTION AND INTERVENTION | p. 73 |
| WHY PCAP WAS INTRODUCED: THE FIT | p. 73 |
| IMPLEMENTATION PHASE | p. 75 |
| CURRENT OPERATIONAL PHASE | p. 79 |
| PCAP STAFF PERSPECTIVES | p. 80 |
| PCAP CLIENT PERSPECTIVES | p. 83 |
| CLIENT EXPERIENCES | p. 86 |
| SUMMARY | p. 94 |
| INSTITUTIONALIZATION AND ENHANCEMENT: COMMUNITY COLLABORATION | p. 97 |
| INTRODUCTION | p. 97 |

DETAILED VIEWS OF OTHER SERVICES p. 107
CENTRAL THEMES p. 120
INTERVIEWS WITH KEY SERVICE PROVIDERS p. 120
SUMMARY p. 124

REACHING OUT TO THE LARGER ABORIGINAL COMMUNITY p. 125
PRE-2008 INITIATIVES p. 125
THE AHTF PROJECT p. 128
VIEWS OF THE PARTNERS p. 129
SUMMARY p. 134

EXTERNAL GOVERNMENTAL ASSESSMENTS p. 135
PERSPECTIVES p. 135

FUTURE DIRECTIONS AND A CENTRE OF EXCELLENCE p. 141

APPENDICES p. 148

INTERVIEW GUIDE A p. 148

INTERVIEW GUIDE B p. 151

INTERVIEW GUIDE C p. 154

INTERVIEW GUIDE D p. 158

## EXECUTIVE SUMMARY

This research entailed three objectives, namely (1) place the AHTF project in context by describing the development of the sponsoring Eastern Door program and its Elsipogtog context; (2) assess the institutionalization of the Eastern Door program in Elsipogtog, and the contribution to that development by the AHTF project; (3) explore the emergence and possible enhancement of the Eastern Door as a centre of excellence as a community-based model of prevention, diagnosis and intervention for non-genetic birth disabilities (especially FASD) and related secondary disabilities. These objectives were occasioned by, but not limited by, a required assessment of the AHTF project which emphasized objective # 2 and, to a much lesser extent, objective #3.

After elaborating on the objectives and implementation plans of the AHTF and discussing the methodology employed in this assessment, there is a brief description of the roots and evolution of the Eastern Door program followed by a detailed discussion of the Elsipogtog social context. The Eastern Door's roots lie in the efforts of Elsipogtog elementary school officials in the in the late 1990s / early 2000s to deal with extensive serious problems of erratic attendance, significant disruptive behaviour, and a poor standard of student accomplishment in comparison with provincial norms. Analyses led to the development of a culturally appropriate systems approach (e.g., the Nogemag model, the Medicine Wheel conceptualization) rooted in the evidence that FASD disability was pervasive among the young students. As successive external evaluations indicated, this considered response proved very effective. As the prevention / intervention model was being honed and communicated inside and outside the community, subsequent phases were envisioned to create a community-based holistic model of prevention, diagnosis and intervention, namely the emergence of the Eastern Door with its multi-disciplinary diagnostic team in 2006, and extensive partnering provincially and within Elsipogtog. Major challenges of collaboration and integration with local and other service providers and of long-term sustainability occasioned the AHTF project with the objectives noted above.

While Elsipogtog's INAC Wellbeing score in 2006 was higher than that of the other three largest First Nations (FNs) in Atlantic Canada, it was lower than most Canadian communities of its size and also lower than some Atlantic area FNs. In recent years there has been an economic spike as a result of the Supreme Court's ruling in the Marshall Eel fishing case, and evident signs of more entrepreneurship in the community. Still, the community remains economically depressed and a large proportion of the population is dependent on social assistance. In 2009 it was reported that the seasonally adjusted unemployment rate was 65%. The economic and concomitant socio-economic issues, such as income and quality of life variations, are not elaborated upon since the focus was on the pertinent "proximate" social context for the Eastern Door, namely challenges in relation to socio-demographics and post-secondary education, crime, social order and police statistics, and patterns of alcohol and drug abuse.

The holistic approach adopted in Elsipogtog is clearly evident in that all justice programming is embedded in the Health Centre and managed by its directors. Elsipogtog's vibrant restorative justice program is the most elaborate in New Brunswick, whether among FNs or mainstream communities. The demographic and educational data (e.g., gender imbalance at specific age groupings, females far more likely to obtain post-secondary education) suggest possible significant problems for interpersonal relationships, individuals and families; many young men appear to develop low self-esteem and have low status in the community. Not surprisingly, such implications become manifest in police statistics which indicate a very high level of interpersonal violence over the past decade and where the primary victims reportedly are young females. Alcohol and, perhaps especially, drug abuse clearly constitute major problems in Elsipogtog, and some Elsipogtog officials have properly characterized addiction as an epidemic. The patterns of drug abuse are highlighted in the text. Getting at the roots of the addiction epidemic, given the scale and formidable challenges of alcohol and drug abuse and the limited counseling resources available, is a major challenge for Elsipogtog and for the Eastern Door's objectives.

Community capacity and collective efficacy were also briefly described. The directly salient service and program capacity in Elsipogtog that the Eastern Door must collaborate with to achieve its objectives, appears, on first glance at least, quite

substantial, and, indeed, does represent something that most communities of its size would envy. However, there are some qualifications to note, one related to the adequacy of funding, and the other to the sophistication of personnel. According to a community report in 2009, 90% of community programs, from a funding standpoint, are either at risk or are short-term, and, according to some knowledgeable community service providers, a fair number of the services have some staff with minimal training and credentials.

The assessment then focused, in turn, on the three dimensions of the Eastern Door program, namely diagnosis activity (the Diagnostic Team), intervention (the Family Support Program), and prevention / intervention (Parent Child Assistance Program, PCAP).

**THE DIAGNOSTIC TEAM**: Description and analyses of the structure and functioning of the diagnostic team was only modestly a focus of this assessment but some research was required in order to appreciate the fit of the other Eastern Door programs and the requirements for collaboration and integration with services and programs inside and outside the community. Overall, the establishment and functioning of the diagnostic team has been a remarkable achievement and truly it is the centerpiece of the Eastern Door's service. Key issues now focus more on resources, especially the desirability of a full time coordinator without sacrificing the Family Support activity which is essential to the Eastern Door's unique status as the only community-based service model for dealing with non-genetic birth disorders and learning disabilities in Atlantic Canada. With the possibility of an FASD (and similar disabilities) provincial centre of excellence on the horizon, based in large measure on the Eastern Door model and partnering with it, the Eastern Door's diagnostic team will likely increase in significance. Add to this, the developments in the justice field where a Healing to Wellness court will presumably be seeking such diagnosis linked to the effective interventions it mandates, and the demands of other First Nations for access to culturally appropriate services in this area (especially the kind of diagnoses provided by the Eastern Door), one can predict that the diagnostic team will be called upon to play an increasingly crucial role for Elsipogtog and the other Aboriginal communities in the area.

**INTERVENTION AND FAMILY SUPPORT**: Working with parents/ guardians of school-age youth having some FASD conditions, was initiated on a project

basis prior to the existence of the Eastern Door. The analysis of the 2002 Nogemag project illustrated its value even at a less intensive and thorough level than the Family Support (FS) system of the Eastern Door. At that time, the parents/guardians of the Nogemag youth were quite positive about the short term project. They believed that their youths did need special programming, and that Nogemag, with its focus on FASD, was zeroing in on the underlying causal problems of the youth. They considered that they were well-informed and engaged by the Nogemag staff even while wanting more involvement in the future. Similarly, they considered that Nogemag had had a significantly positive impact on their youth (especially improving relations at home) but they generally felt that more progress was necessary.

With the Eastern Door those parental hopes were realized for similar youths who were diagnosed more precisely and for whom a more sophisticated interventionist plan was recommended. Even with its modest staffing and multiple and challenging tasks (including the coordination of the diagnostic team activities), the FS program has largely been accomplishing its objectives for the clients, parents / guardians and youths, and has facilitated their more effective utilization of extant Elsipogtog and other services and programs. The mechanisms for this success have been a sensitive, harm-reduction approach, an outreach style of engagement with clients, and an "aggressive" advocacy on behalf of the clients. A number of key themes were identified in the parental-guardian interviews in 2010, such as (a) that the youths in the FS program had exhibited serious behavioural problems ("hyper-active", "frustrated", "angry" and "did not get along well with other children") prior to being registered for school, but that school attendance brought the problem behaviour into crisis proportions (Interestingly, two thirds of the diagnosed youths were males, a fact consistent with the gender issues in elementary schooling); (b) that the parents, prior to involvement with Eastern Door, apparently for the most part, could not meaningfully "connect" with the local service providers / treatment professionals nor did they obtain, from their perspective, a clear, supportive, sustainable plan for change from those consultations that they did have about their youth; (c) that the impact of FS involvement has been very positive and pronounced for their youth and also for themselves.

The FS management and staff members constituted an effective team, positive in outlook and confident that the FS approach was succeeding. There was consensus that evidence would show that a number of clients had indeed been assisted not only in connecting better with other services but also in turning to a more healing life path. They were clearly on the same wave length as the clients with respect to what the parental expectations and hopes were and what were deemed to be shortcomings in the service provided. A number of significant challenges were identified by the respondents especially in light of a major budgetary cut in April 2010, including concerns about the future of the program, the commitment of top Elsipogtog management in a looming period of financial constraint to the priorities of the Eastern Door vis-à-vis core community services, and the sustainability of the integration and coordination among local service agencies that had been achieved over the past year. Their own suggestions for improving the FS service, (e.g., more staff, flex time), were consistent with those offered by the parents. Finally, the respondents agreed that the Eastern Door should be a centre of excellence for the prevention, diagnosis and intervention concerning FASD and other such disabilities.

The writer would agree with virtually all the above interpretations and suggestions for change but would also add the need for more attention to monitoring and measuring the changes over time in the attitudes and behaviours of the youths and parents since such data are crucial for regular internal and external evaluation. The motivational interviewing approach in dealing with clients should be enhanced and employed by both coordinator and outreach worker. Mediation and conflict resolution training, as for example in the Elsipogtog Apigsigtoagen approach, could pay dividends in advocacy work for clients.

**PCAP PREVENTION AND INTERVENTION**: In the case of the PCAP program, it seems clear from the research carried out that the program has been well-received by the other service providers in Elsipogtog and by its clients. It was an initiative that other service providers acknowledged as filling an important gap in the community-based prevention - diagnosis - intervention model that the Eastern Door has been developing since 2006. Everyone acknowledged that young pregnant women or new mothers, in vulnerable condition because of their addiction and usually unstable family

situation, need help and are a crucial link in the prevention and intervention for birth disabilities, other disabilities and learning problems. The staff is competent and confident with respect to the PCAP objectives and strategies and the clients clearly value the program. It is to the immense credit of the director of the Health Centre that she appreciated the value of the PCAP program and arranged for its funding in Elsipogtog, and to the management of the Eastern Door that PCAP has been well-implemented in Elsipogtog, far better, according to federal and provincial authorities, than in other New Brunswick FNs. The PCAP program has followed the successful Seattle Washington model in its emphasis on a harm reduction philosophy, long-term commitment to clients, strict eligibility criteria and protocols, and an insistent, active outreach strategy for referring and navigating clients through the various services and programs available in Elsipogtog and beyond.

There are some issues and challenges. The ratio of staff to client caseload is not out of line with standards elsewhere but administrative backup is problematic (i.e., no designated secretarial / office assistance) as are infra-structure type considerations such as cell phones, transportation allowance and so forth. There may be, because of these shortfalls, a negative implication for monitoring the impact of the program on the clients. That internal assessment is a central feature of the PCAP program as developed in the U.S.A. but appears weakly developed in Elsipogtog (e.g., monitoring the ASI measure over time, determining what variables to obtain longitudinal measures on). There has been some criticism from some other local service providers that PCAP staff members smother clients with attention and intervention (e.g., transporting them to meeting with other local service providers) and, in these ways, perhaps some difficulty in appreciating the PCAP outreach approach. However, it does appear that the conventional support and services system in Elsipogtog was not being utilized effectively by the young women. Another issue is the potential problem of staff turnover. As both the PCAP staff and the clients have indicated, building a relationship and establishing trust takes time and is pivotal to the clients accepting the challenge of taking control of their lives. There is little doubt about the significance of these and other challenges but then, if accommodated, the gains can be great and trans-generational too.

Another major concern of course is how effective the program is with the young women. On the one hand, there is evidence of continuing addiction problems and both multiple drug use and unstable home situations. On the other hand, there are many indications from the clients that there has been a significant positive impact for them, such as being able to keep or get back their babies, more confidence in relating to other local service providers, and, remember, the program has only been in existence a little over a year. It will be important to measure change and other objectives of the program such as the extent to which the clients make better use of the local services and programs available to them.

The PCAP approach underlines the value sometimes of a "parallel process" model rather than a "wraparound" model. In the latter, a team of professional and / or expert practitioners meets to deal with a client or problem, melding their insights into an effective package of interventions (e.g., the S.O.S. and Child Development Program referred to below). In PCAP, the staff members advocate and navigate for their clients with the different other service providers and agencies. One area then, worthy of consideration, is better networking with the other service providers by both the PCAP staff and the clients. Significant outreach has to be balanced by an appreciation of others' mandates and organizational philosophies as well as their own. Staff members have to be skilled at mediation and dispute resolution in order not to rouse opposition needlessly. The Apigsigtoagen approach pioneered in Elsipogtog may well provide an additional, effective orientation for staff members. Similarly, the motivational interviewing and difference game approaches used in PCAP might well include, if they do not now, how clients relate to the service providers; again, it would be important that PCAP staff members do not lose credibility with local service providers by being dragged into conflict by ill-advised strategies used by their clients. After all, PCAP cannot and does not provide the services and programs that the clients require. It needs the full collaboration of these other players given the great challenges being faced.

**COLLABORATION AND INTEGRATION**: A crucial aspect of the AHTF project and more generally of this research assessment has been the focus on institutionalization (i.e., collaboration and integration with other local services and programs). The analyses, provided below in the text, indicate a strong acceptance by

Elsipogtog service providers of the Eastern Door message that non-genetic birth disorders, especially FASD, are central to many of the school, justice and other problems in Elsipogtog. The Eastern Door's premises and definition of the situation have much public support and, one might say, now constitutes the "official" position in Elsipogtog. What other service providers almost unanimously contended was needed to deal with the problems of birth disabilities and drinking and drug abuse was what the Eastern Door has been doing in linking solid diagnosis with specific intervention / treatment plans and prevention strategies that involve both the community at large and the health professionals. Eastern Door's services and advocacy are increasingly well accepted, especially PCAP which relates to the priorities of virtually all the local services and agencies, while some other ED thrusts may be seen more as revolving around the school milieu. There are still rough edges in the networking and assessments as might be expected among services and agencies with different philosophies / approaches and mandates, as well as different ways of relating to clients. But there has also been a congruent and mutual evolving of services' mandates and styles on the part of Eastern Door and also on the part of some local agencies. There is some tension too among the services, given that many, including the Eastern Door, are on relatively short funding leashes and thus potential competitors for scarce resources. In any event, while more integration and collaboration is needed to optimize clients' use of Elsipogtog services, there seems little doubt that much has been accomplished in the way of integration and collaboration over the past three years.

**THE CENTRE REACHING OUT TO OTHER FIRST NATIONS**: Another central concern of the AHTF and this assessment has been the reaching out of the Eastern Door program to other First Nations in the area. From the get-go, the Elsipogtog initiative in responding to the prevalence of FASD birth disabilities, which have haunted many Aboriginal communities in Atlantic Canada, has had a policy of reaching out to others. As the director of the Eastern Door stated at a quasi-public meeting in 2009 "our policy is to share and other FNs have to develop models so they can profit from the sharing … we emphasize cooperation and other FNs do not have to pay for accessing resources such as the diagnostic service for FASD". That outreach viewpoint has been central, too, to the vision provided by the designer-initiator of the Eastern Door since the FASD issues were

crystallized by her in the design of the Nogemag project and the Medicine Wheel model years earlier. For a variety of reasons – staff turnover, lack of resources, no clear strategy for meaningful involvement of the other partnering FNs - the AHTF project did not advance much that ‘reaching out’ objective, and the partnering FN representatives were dissatisfied with the benefits provided for their community. Their appetites were wetted by the workshops provided and the increased awareness of the Eastern Door services but it was very unclear to them exactly how in supporting the Eastern Door’s ambitions they could realize such services for their own people. Clearly much more planning – and more resources – will have to be done to move more substantially to an Aboriginal centre of excellence, rooted in Elsipogtog, for preventable birth disabilities and learning disabilities, that is widely accepted by other New Brunswick First Nations.

**THE CENTRE: EXTERNAL GOVERNMENTAL VIEWS**: The chief way liaison was maintained between Elsipogtog’s Eastern Door and the external governmental and First Nation governance for the AHTF project was through the project’s steering committee. There were representatives of the federal and provincial governments and the Union of New Brunswick Indians (UNBI) plus the three partnering FNs. The external governmental collaborators, not including in this category the three FN partners, shared the view that the Eastern Door should deal with a range of birth and learning disabilities, not just FASD cases, though the latter would remain the core Eastern Door focus. In interviews they appeared also to share the view that an Aboriginal centre of excellence for a comprehensive holistic response to these disabilities was desirable and that Elsipogtog, and only Elsipogtog through its Eastern Door, could provide that model. It was commonly noted by these steering committee members that such a centre of excellence would require protocols and mechanisms for linking other First Nations to the Eastern Door expertise. Most external governmental collaborators indicated that indeed the sustainability of the Eastern Door, from an external funding perspective, required an enhancement in these ways of the Eastern Door as an Aboriginal centre of excellence. Overall, there was a strong consensus that the Eastern Door program was a well-conceived program that was well-implemented, and so the focus of these governmental and UNBI respondents was very much directed at the future namely, where is the Eastern

Door and the province heading with respect to the FASD and related issues and how can other FNs be more meaningful involved.

**FUTURE DIRECTIONS**: The final section of this assessment focused on possible future directions. Clearly the resource issue emerged as paramount. More resources are required to effect the establishment of appropriate data systems and subsequently the monitoring and regular internal evaluation of the programs and services; this shortfall has been the reality, as noted in the text, in the diagnostic activity and in the functioning of the prevention and intervention services (i.e., PCAP and Family Support). Long-term funding was deemed crucial to secure partnership and collaboration within and beyond Elsipogtog as otherwise, with virtually all collaborators on a short funding leash, competitive and centrifugal factors loom large. Unfortunately, even while the Eastern Door initiative was proving itself more and more path-breaking in its community-based model of prevention, diagnosis and intervention – and reaping appropriate kudos from national and provincial authorities – the funding was being cut, not increased. Compounding this 'disconnect', on the immediate horizon are two major developments that will apparently lean heavily upon the Eastern Door's capacity both as a model and as a functioning Aboriginal centre of excellence. These are (a) the provincial government's health strategy for FASD and kindred disabilities that has been heavily influenced by the Eastern Door approach and which will require a partnering Aboriginal centre of excellence, and (b) the evolving significance in the criminal justice system of the problem-solving court and the accompanying greater expectations for treatment and services in response to disability such as FASD and issues of addiction – these are highlighted especially of course in the imminent Healing to Wellness Court to be established at Elsipogtog.

In conclusion, this assessment has shown that an important, effective service has been established at Elsipogtog in response to a set of prevalent birth disabilities and serious social problems. The Eastern Door's evolution into a full-fledged community-based model of prevention, diagnosis and intervention has been significant and the AHTF project has contributed to this success. It is clear that a major step forward has been taken in integrating the ED's service with other services and programs in Elsipogtog though more needs to be done in that regard. Similarly, there has been progress in reaching out to

the other First Nations though clearly much more has to be done in terms of defining - and implementing - how other FNs can profit from and network with the Eastern Door's expertise and services. These challenges will likely become more demanding in the light of reduced funding for some ED functions such as Family Support, and, as noted above, the growing demands from new developments at the provincial level in terms of responding to birth disabilities, and from the increased attention to birth disabilities and related problems in the justice system, both in general and in the Healing to Wellness court to be established in Elsipogtog. From a policy perspective, the Eastern Door is, to use a Churchillian expression, "at the end of the beginning". It is poised to make a much greater substantive impact, on the issues to which it has been addressed, in the community, in other Aboriginal communities, and in New Brunswick more generally. It appears to be up to the challenges but clearly more resources will be required as will strategic action plans to respond to the challenges.

## THE TASKS OF THE ASSESSMENT: THE PROBLEMATIC

The AHTF project essentially began in the fall of 2007, roughly sixteen months after the Eastern Door's first client diagnosis was completed (June 2006). The central, and really the only, new ED position created by the project was the role of coordinator where the broad project objectives were the enhancement of the collaboration of the Eastern Door and local service providers and, of much less though not insignificant importance, the continuing dissemination of the Eastern Door vision and programming approaches to other Aboriginal communities, especially the three small First Nations designated as "partners" for the AHTF project, namely Fort Folly, Indian Island and Bouctouche. Initially, apparently in order to jump start the project, the central designer – initiator (D-I) of the Eastern Door in Elsipogtog, in addition to her considerable regular workload, also acted as the coordinator. In September 2008 a full-time coordinator was hired specifically for this designated "one time" project. After he resigned in May of 2009 there was a hiatus (i.e., an interruption of some aspects of the intended role functions) until a replacement was engaged for the closing period October 2009 to March 2010. The chief specific tasks of the coordinator were to meet and network on behalf of the ED with the other service providers, explore gaps and opportunities in the collaboration (e.g., prepare, distribute and gather questionnaires), organize and attend a large variety of meetings to report on progress (e.g., the steering committee) or to advance it (e.g., Save Our Students, Early Childhood Development), collaborate with the D-I in making presentations or holding workshops with various segments of service providers (Health professionals, Justice role players and the three First Nation partners), prepare job descriptions and assist in helping the ED's programs in data management. The evaluation was authorized in the early spring of 2009.

There was general consensus among the ED's leadership about the AHTF project's objectives, and they were designated by top management, in similar phrasing, as assisting in (a) "Integration / coordination inside and outside Elsipogtog and achieving a sustainable outcome"; (b) "Integration of the FASD approach at the community level then mentoring it to others. Community capacity and sustainability were central

concerns". The other key ED official – the D-I of the project and very close operationally to the work of the coordinators - articulated the ED Focus of AHTF as chiefly, though not only, as "integrating an Aboriginal community-based service delivery model for FASD diagnosis, prevention and intervention in Elsipogtog". Both full-time coordinators also saw their general objectives in similar terms. One identified his tasks as "networking and capacity building and identifying gaps in system integration" while the other ranked his responsibilities as first, "Connecting other agencies either locally or provincially with Eastern Door to inform and collaborate", secondly, "Help develop a systematic, efficient process which would funnel clients into Eastern Door, closing the gap in health status and helping the ED evolve". The terms of reference for the coordinator role were complex and, given the relatively short time on the job, a difficult challenge especially as most of it involved meetings with others at times and places convenient for them, not at the coordinator's preference, and exploring collaboration with a mandate but a limited authority base.

The AHTF project was appropriately seen as crucial for the evolution and institutionalization of the Eastern Door service. The diagnostic team was already up and running and sustained by both federal and provincial funding, the former from FNIHB and the latter in the form of secondments to the diagnostic team (i.e., the doctor, occupational therapist and so on) and some funding for the Family Support worker. The community's contribution was substantial in terms of secondments to the diagnostic team (e.g., the D-I, the Nurse, School specialists), other service providers' collaboration, and, later, through Alcohol and Drugs' funding for the Parent Child Assistance Program (PCAP). The AHTF project was to significantly advance the evolution of the ED. Much in the way of the institutionalizing the ED in Elsipogtog would hinge on collaboration with other service agencies and programs. The ED's prevention and intervention services (PCAP, Family Support), which differentiated it from a hospital-based model for dealing with birth disabilities and related problems (which would basically offer just the diagnostic activity) provided advocates, supporters, facilitators, but would not themselves provide the expert programs and services that their clients would require. Accordingly, the collaboration especially with local service providers would be essential and the AHTF project was designed to enhance that integration. Some tension and friction with the other

local services providers would seem inevitable if changes were to be made, not just discussed, since these services / agencies could be presumed to have their own theoretical frameworks, priorities, and operating procedures. Also, the liaison with provincial health services, and, through presentations and other activities, exploring and expanding ED's possible linkages to other FNs would be crucial to the sustainability of the ED in an era of limited resources and demands from other Aboriginal communities.

The evaluation, then, had two major foci, namely (a) examining how the AHTF contributed to the embeddedness of the ED's focus on non-genetic birth disabilities and related issues in the community (i.e., the institutionalization, sustainability, efficacy, identifying and responding to gaps); (b) examining its contribution to ED becoming a centre of excellence in its field and linking up with and providing mentoring and leadership to other FNs.

**RESEARCH STRATEGIES**

A wide range of research strategies were employed for this assessment; however, the assessment operated within certain constraints. One was that the focus was to be on the prevention and intervention dimensions of the Eastern Door programming, not the diagnosis dimension since the AHTF project essentially involved building up the community –based model of dealing with birth disabilities (in contradistinction to a hospital model). The diagnostic activity was already extant so the research in that area was limited to interviews with members of the diagnostic team concerning its evolution and the implications thereof for resources requirements and for prevention and intervention developments. Another constraint was that the evaluation did not begin until the spring of 2009, essentially then in the last year of the three year AHTF project. Consequently, there were no baseline measures available to assess the central AHTF objective of growth in collective efficacy – the changes in integration / collaboration approaches and practices among local services and agencies salient for responding effectively to birth disabilities. It was possible to explore this AHTF objective somewhat

through examination of the questionnaires distributed over a two year period to the staff of the local services / agencies by the AHTF staff. Also, repeat interviews with staff members of certain key services within the one year period did shed some light on possibly evolving trends. Similarly, there were no baseline measures specifically identified for evaluation purposes to compare with in 2009-2010 in order to determine the impact on their clients of the Eastern Door's PCAP and Family Support services. It might have been possible to do periodic measurement of the ASI (addiction severity index) used by PCAP in its acceptance of referrals but that program began receiving referrals only in late winter 2009. Some administrative data for the Family Support and PCAP programs were accessible but they were very limited in enabling the research to see how the clients may have changes in world views, attitudes and behaviours in the course of the three year project. The chief source of data for the clients was the one-on-one interviews conducted in the assessment. A third constraint was the turnover among the Eastern Door's staffing including the coordinator position and the PCAP and Family Support positions. For example, there was no full-time coordinator until September 2008, over a year after the AHTF project began, and neither of the two coordinators serially engaged occupied the position for more than eight months. The discontinuity had negative implications for data management and data collection (e.g., completing tasks such as having other service providers fill out questionnaires), meeting minutes, and, of course, networking with local service providers and the three partnering First Nation communities.

The following research strategies were carried out:

1. Literature and document review – here there was an updating of the literature reviewed for earlier studies of the Elsipogtog response to FASD and birth disabilities by the researcher, and, additionally, the literature on PCAP, the motivational interviewing technique in which PCAP and FS managers were trained, similar well-known community-based models such as the Lakeland project in Alberta, and an increasingly large literature on FASD and the criminal justice system.

2. Document review – here there were review and analyses of documents such as the quarterly PCAP reports, year-end AHTF reports to the funding bodies, program statistics, brochures, job descriptions, minutes of the steering / advisory committee, and background reports for Elsipogtog on relevant matters such as the Nogemag Healing Farm project, a report on Methadone service delivery and so forth.
3. Secondary data in the form of statistical data from sources such as INAC (population patterns, wellbeing scores, and post-secondary education statistics), RCMP police statistics, NB Health statistics (i.e., methadone use data) were gathered and analysed.
4. Analyses of the fifty plus questionnaires dealing with gaps in the awareness of FASD and the collaboration with Eastern Door services on the part of local service providers, distributed and gathered by AHTF coordinators.
5. One-on-one interviews (usually multiple interviews over time) with AHTF coordinators, the designer and initiator (D-I)of the Eastern Door, the director of the Eastern Door and other Health Centre top management.
6. One-on-one interviews (some tape-recorded) with all the management and staff of the PCAP and FS programs and some members of the Diagnostic team.
7. One-on-one interviews with the adult clients of the PCAP and FS programs – virtually all PCAP and 40% of the FS clients (a handful was tape-recorded).
8. One-on-one interviews with the directors and/or staff members of other community organizations including multiple interviews with the key salient service providers, namely Child and Family Services, Psychological Services / Mental Health, Elsipogtog school and the RCMP detachment.
9. One-on-one interviews with provincial, federal and external FN representatives – usually multiple instances and in Fredericton, Moncton and Halifax.
10. One-on-one interviews with representatives from two of the three partnering FNs.

11. Observational strategies included attendance at steering committee meetings, at an operational session of the Diagnostic team, and at other pertinent community meetings.

## DEVELOPMENT OF THE EASTERN DOOR AND THE AHTF PROJECT

The origins of the Eastern Door and the significance of the AHTF project lie in the creative efforts of the newly-hired ph'd (Education) and other school officials in the late 1990s / early 2000s to deal with extensive serious problems in the Elsipogtog elementary school, problems of erratic attendance, significant disruptive behaviour and a poor standard of accomplishment in comparison with provincial norms. The key agent of change wrote "Analyses led to a window on the problems. A system approach was implemented after identification of the problems, focused on assessment, intervention, evaluation and evidence, and parent and staff collaboration. The Needs Assessment led to the diagnosis of FASD which in turn led to the Nogemag model". Three separate external assessments of the Elsipogtog school trace the evolution of the situation there and indicate the effectiveness of the changes introduced. A 1996 evaluation represented a pre-intervention description of the unacceptable conditions. It cited the dysfunctional character of the school, the high level of behavioural and learning problems there and raised the issue of a possibly pervasive FAS condition (see Appendix F). Subsequent estimates based on relevant criteria for indications of FASD indicated that as many as 20% of the school children might have FASD conditions.

A second external assessment completed in 2002 noted that the changes introduced at the school, in terms of special education programming based on a heuristic conceptualization of the underlying causation and an accompanying strategy for intervention, had proven valuable in increasing the level of student attainment in several grades. The third external evaluation in 2006 analysed the school systems in the school district as well as in Elsipogtog and offered deep praise for the Elsipogtog school, namely 'The leadership and staff have accomplished some impressive changes since the last evaluation….they are to be commended highly for what they have been able to accomplish". The 2006 evaluation noted the considerable data collection and inventive, cultural conceptions (e.g., the Nogemag model, the Medicine Wheel) in the programming and in that report the Elsipogtog school had no area in which it was not functional and for the most part it received the highest ratings of "effective" or "very effective" in every category evaluated.

A second major step in the evolution to the current Eastern Door centre was in the Nogemag farm (healing lodge) 2002 initiative for expelled and difficult to work-with children. The Nogemag site (a re-modeled farm house along the river, well apart from the Elsipogtog School) allowed for intensive interventionist programming for designated youths “who have been suspended or expelled from school and who have been or are at risk of being in conflict with the law”. The intervention approach there was based on an evolving understanding of how to respond to children with FASD conditions and the incorporation of cultural relevant symbolization and practices into more standard mainstream, intervention techniques for FASD-impacted children and youth (e.g., one-on-one learning, repetitive simple exercises, physical activity such as gardening etc). It proved to be a successful initiative. It was well-implemented by committed leadership and achieved the basic objectives, well-appreciated by the clientele, and respected for the achievements by key, salient community stakeholders. Nogemag's achievements ranged from putting in place a valuable community asset (i.e., the Nogemag farm and shore side cabins) to reducing crime among the clientele and facilitating their re-entry the following year into the mainstream school system from which most had been expelled. – all but one of the handful of Nogemag “regulars” (i.e., participating on a regular daily basis) were subsequently, satisfactorily re-enrolled in the regular school system).The Nogemag experience was quickly seen to be particularly salient in Aboriginal communities other than Elsipogtog given the cultural adaptation of the intervention model and of course the common, devastating, colonialist legacy that has generated much substance abuse and consequently much risk of FASD birth disabilities and related learning problems.

During this earlier period, 2002 to 2005 in particular, the Nogemag model and its Medicine Wheel interventionist tools and framework were being honed and also disseminated to others (see the section below on Reaching Out to Other Aboriginal Communities). There was an increasing awareness of FASD in the criminal justice system and in medical / health circles. In Elsipogtog there was an increasing dialogue about the engagement beyond the school milieu which directly led to the development of the Diagnostic, Intervention and Prevention Centre, the Eastern Door. It had become clear that more sophisticated multi-disciplinary diagnoses were pivotal for family and community involvement in both prevention and intervention and thus it was necessary to

be associated with the Elsipogtog Health Centre – its mandate and resources - which provided a doorway into the community. The proposal for an Eastern Door diagnostic team was submitted in summer of 2005 to the federal FNIHB for funding. It was successful and the first client was diagnosed in that Health Centre setting in June 2006.

Extending from the Spring of 2005 to the Spring of 2007, the appended chronology (see Appendix F) describes the various trajectories of the Elsipogtog (especially the D-I's) thrusts on FASD and other non-genetic birth disabilities, namely the testing, refinement and formalization of the Medicine Wheel tools, the establishment and solidification of community support leading to the development of the Elsipogtog Eastern Door FASD program with its singular diagnostic and treatment capacity, the partnering with other key role players to effect the emergence of an FASD strategy and diagnostic capacity at the provincial level, ongoing meeting and collaboration to establish a diagnostic capacity at the Georges Dumont Hospital in Moncton, the constant dissemination of the Nogemag approach and Medicine Wheel tools to other aboriginal communities in Atlantic Canada and to mainstream communities as well, the extension of training and presentations beyond the primary educational focus to justice, social work and health professionals, the presentations at national and international conferences, and the multi-media outreach reflected in the video documentary, website, and academic papers.

Still, it was apparent that progress in the post-implementation stage of the Eastern Door would depend significantly on extensive collaboration (and outreach) with service providers locally and beyond. The challenge became to enhance the "institutionalization" of the Eastern Door in Elsipogtog, increase the collective efficacy in Elsipogtog for dealing with FASD and similar problems, and secure its greater sustainability. As discussed above in the section of "The Problematic", that was the raison d'etre for the federally AHTF project which began in October 2007.

Currently, summer 2010, the Eastern Door services include the full range of preventative, diagnostic and interventionist programming. The PCAP service focused on young mothers with serious vulnerabilities was added in January 2009. In addition to its own specific services, the Eastern Door took the lead in establishing interagency or "wraparound" programs such as Save Our Students and Early Childhood Development.

Other important collaborative initiatives are anticipated such as a Family Resource Centre. The Eastern Door also continues to be a significant player in collaboration with the Provincial Consultative Team on FASD and the community-based service delivery model it has advocated. The ED service and its D-I continue to be influential nationally (e.g., influencing SOGC guidelines) and throughout Aboriginal communities in Atlantic Canada (see below, Reaching Out…). The funding for the Eastern Door represents a unique assembly of resources, drawing upon federal funding, provincial secondments and direct funding, and community transfers and collaboration. It could be characterized as a highly successful initiative, imaginatively conceptualized and constructed, but also having a somewhat perilous financial infrastructure.

## SOCIAL CONTEXT FOR THE EASTERN DOOR

### ELSIPOGTOG CHALLENGES AND CAPACITIES

INAC has published Wellbeing scores for all communities in Canada with a population greater than 65. It is based on an index of four factors, namely level of post-secondary education, labour force participation and employment, housing quantity and quality, and income per capita. Elsipogtog's Wellbeing score, using data from 2006, was 66, higher than the other three largest FNs in Atlantic Canada (i.e., Tobique (63), Burnt Church (57) and Eskasoni (62)) but lower than most Canadian communities of its size (White and Maxim, INAC, 2007) and lower than some Atlantic area FNs (e.g., Membertou (74) and Millbrook (73)). In recent years there has been an economic spike as a result of the Supreme Court's ruling in the Marshall Eel fishing case and evident signs of more entrepreneurship in the community. Still, the community remains economically depressed and a large proportion of the population is dependent on social assistance. In 2009 it was reported that the seasonally adjusted unemployment rate was 65%. The economic and concomitant socio-economic issues, such as income and quality of life variations, are not elaborated upon here where the focus is on the pertinent proximate social context for the Eastern Door, and its various programs, as it struggles to achieve a

level of excellence in its services and programs in the face of challenges and significant collective efficacy.

The challenges are discussed below in relation to socio-demographics and post-secondary education, crime, social order and police statistics, and patterns of alcohol and drug abuse. The implications for Eastern Door's programs and services are considered. Then there is a brief note on community capacity. The directly salient service and program capacity in Elsipogtog that the Eastern Door must collaborate with to achieve its objectives, on first glance, at least, appears quite substantial, and indeed does represent something that most communities of its size would envy. However, there are some qualifications to note at the outset, one related to the adequacy of funding and the other to the sophistication of personnel. According to a community report in 2009, 90% of community programs are either at risk or are short-term, and, according to some knowledgeable community service providers, a fair number of the services have some staff with minimal training and credentials. The jewels of Elsipogtog community service capacity arguably would be the elementary school with its special programs for special need students which, as noted above, has achieved considerable progress over the past decade vis-à-vis the mainstream standards, the Health Centre with its multiple services such as Psychological Services / Mental Health (its reputation is reflected also in other FNs' referrals to its service), the Eastern Door (provincially and nationally recognized for its community model of prevention, diagnosis, and treatment / intervention for birth disabilities) and the Heath Centre more generally which is regarded as, by far, the best among all FNs in New Brunswick and probably better than most mainstream medical services complexes in communities of similar population size.

The holistic approach adopted in Elsipogtog is clearly evident in that all Justice programming is embedded in the Health Centre and managed by its directors. The linkage of justice services to Eastern Door programming will likely become even more significant as the community establishes its Healing to Wellness Court in the fall of 2010 where issues of FASD and other birth disabilities can be expected to loom large in Court deliberations and treatment assessments and recommendations. Currently, it would be fair to hold that Elsipogtog has the most elaborate restorative justice service among all New Brunswick FNs; indeed the province as a whole basically still employs the alternative

measures system. In addition to a huge increase in pre-charge referrals from the local RCMP detachment, the restorative justice RJ program has lately been getting referrals from the Crown and has held a few sentencing circles. It is unknown how often Eastern Door clients would be charged in court or get referred to restorative justice but it can be expected that the health –justice link will grow with the arrival of the Healing to Wellness court.

## POPULATION AND EDUCATION

As indicated in tables A and B below**,** the total registered population of Elsipogtog has grown steadily. The average annual rate of growth was over 2% per year between 1995 and 2006 and just slightly under 2% since then. As of April 2010, the registered population was 3006. The growing population – a sharp contrast to the surrounding communities in the region – has a high proportion of youth, estimated to be about 40% aged 17 or under, twice the provincial percentage, so Elsipogtog will likely continue to the lead its region in population growth for the next fifteen years as well, Since 2000 the proportion of the Elsipogtog registered population living off reserve has hovered at 23%-24%, evidence perhaps of the continuing high demand for housing on reserve.

The total numbers of males and females in the total registered population (on and off reserve) were quite similar, namely 1406 males and 1420 females in 2006 and 1495 males and 1511 females in 2010. Interestingly, males typically have outnumbered females in the age categories 25 and under, but females have outnumbered males in all age categories from 26 years of age on; for example, in 2007 where in the age categories 0-5, 6-17 and 18-25, the gender difference favoured males by 10, 27 and 46 respectively while in the older categories 26-45, 46-65 and 66 -100, the gender gap favoured females by 14, 33 and 35 respectively; in 2008, males outnumbered females in the age categories 0-5, 6-17 and 18-25 by 2, 31 and 51 respectively while in the older categories the females outnumbered the males by 10, 38 and 38 respectively. The social and policy implications of these population dynamics are unclear. The roughly 20% more females in the age grouping 45 plus does not appear unusual but to have such larger disproportions of males

in the 6-17 and 18-25 age categories – a differential of 73 in 2007, 84 in 2008 and 80 in 2009 and fully 30% more males than females in the age category 18-25, appears puzzling and begs for some in-depth analysis with respect to the social implications. It does appear that females may emigrate more; for example, in 1995, off-reserve, there were 222 females and only 166 males, and in 2000 it was 252 to 184 respectively. Reportedly, the pattern of gender difference in migration has continued, presumably fuelled by pursuit of higher education and marriage. Leaving Elsipogtog then for marriage or education would presumably aggravate the gender imbalance.

**Turning to post-secondary education**, data was accessed from INAC on the number of Elsipogtog residents funded in post-secondary academic institutions (there could be an occasional trade program participant funded under the band's discretion) for the fiscal years 2006-2007 to 2009-2010 (see Table C). According to INAC sources, there have been no new programs or significant policy changes in the funding for post-secondary education since 2006 but there has been a modest 1.5% budget increase for a band's PSE eligibility - "Agreements have formula adjustments (DFNFA defined) in the neighbourhood of 1 to 2 percent. That's all, no program change, no big budget change." The figures for the two First Nations in PEI are provided for comparison purposes. The number of post-secondary enrollments has stayed relatively constant in Elsipogtog over the four fiscal years (63, 58, 60 and 62) while both Lennox Island and Abegweit have experienced declines. Were one to compare the FNs using, at the low end, registered on-reserve populations and then, at the high end, all registered members living on or off reserve plus others' band members living on site, the comparisons might be more meaningful. The bracketed numbers in Table C represent the low and high ends as described. Clearly, whatever population base is used to calculate a rate of enrollments, Lennox Island has done better than Abegweit in securing INAC's PSE funding. It has also done better than Elsipogtog but only if the comparison is based solely on the number of band members living on reserve.

Table C also provides a breakdown of the post-secondary enrollment data by gender. It can be seen that there is a very significant disparity between males and females in terms of obtaining the designated funding support. In the case of Elsipogtog, for fiscal years 2006-07 and 2007-08 there were 94 females vs 27 males; for fiscal years 2008-09

and 2009-10, the figures were 90 vs 32 so overall females were about three times as likely to receive such funding and attend higher education. Whether post-secondary education was obtained outside the INAC funding could not be determined but reliable sources suggest that it would be uncommon and would not affect the differential described here. The pattern holds also for the two PEI First Nations, Lennox Island and Abegweit where, overall, in the last two years there were 39 females vs 15 males receiving the funding, roughly the same three to one differential as in Elsipogtog. The accessible INAC data could also be broken down by whether the student was pursuing a graduate degree, regular university degree, a non-university program or was not seeking a qualification. In the case of Elsipogtog, since 2006 there has been an annual average of four graduate-level and forty-eight undergraduate-level enrollments, seven non-university program enrollments and two instances where the individual was not seeking a qualification; information was lacking on the gender breakdown for these programs.

The demographic and educational data suggest possibly significant problems for interpersonal relationships, individuals and families in Elsipogtog. In many Aboriginal and mainstream communities in Canada, especially the Aboriginal communities, the pattern of young male adults often having low self or community esteem (‘zero status” is the concept researchers have used) as a result of poor school performance, limited skills and limited job opportunities, has been associated with high levels of violence where young women have been the usual victims, and unstable relationships where the male role as partner and father is marginalized. In interviews some Elsipogtog CFS professionals have commented on these issues, noting that “it’s the same thing here” [and] “when CFS deals with foster home guardians, it is almost always with the mom / woman, and virtually always assumed that the male is likely to drift on so is a less important resource. Male roles have for many evolved into a self-defeating system”. Other interviewees engaged in the school system have made similar comments and have pointed out that, even in elementary school, the children with serious behavioural problems are overwhelming male. It can also be noted that in the Eastern Door boys have been more likely to be diagnosed and to be clients of the Family Support program by a margin of two to one, according to the administrative records since 2007, and that ratio was also found in the earlier Nogemag program. A number of interviewees

also commented on the implications of male status issues for weak family formation; one nurse observed, “Most of the young mothers are not married though there are many “common-laws” of various duration. There is not a high rate of formal marriage or of formal separation and divorce”. The implications of these same patterns for violence and abuse can be seen in police statistics to which we now turn.

**Table A**

**Elsipogtog Population, 1995 to 2006**

| 1995 | 2000 | 2006 |
|---|---|---|
| 1700 On-reserve (Own Band) | 1924 On-reserve (Own Band) | 2131 On-reserve (Own Band) |
| 51 On-reserve (Other Bands) | 59 On-reserve (Other Bands) | 38 On-reserve (Other Bands) |
| 1751 Total On-reserve | 1974 Total On-reserve | 2169 Total On-reserve |
| 388 (18%) Off-reserve | 436 (18%) Off-reserve | 657 (24%) Off-reserve |
| 2139 Total | 2410 Total | 2826 Total |

*INAC's Indian registration system, July 2007

**Table B**

**Elsipogtog Population, 2007 to 2010**

| 2007 | 2009 | 2010 April |
|---|---|---|
| 2177 On-reserve (Own Band) | 2247 On-reserve (Own Band) | 2270 On-reserve (Own Band) |
| 35 On-reserve (Other Bands) | 41 On-reserve (Other Bands) | 40 On-reserve (Other Bands) |
| 2212 Total On-reserve | 2288 Total On-reserve | 2310 Total On-reserve |
| 669 (23%) Off-reserve | 692 (23%) Off-reserve | 696 (23%) Off-reserve |
| 2881 Total | 2980 Total | 3006 Total |

*INAC's Indian registration system, June 2010

**Table C**

Post-Secondary Enrollments: Student Counts, Lennox Island, Abegweit and Elsipogtog

| First Nation | 2006~ 2007 | 2007-2008 | 2008- 2009 | 2009~ 2010 |
|---|---|---|---|---|
| | M F T | M F T | M F T | M F T |
| Lennox Island (362 to 805)* | 9 16 25 | 8 12 20 | 6 17 23 | 7 13 20 |
| Abegweit (176 to 312)* | 2 8 10 | 1 8 9 | 2 5 7 | 0 4 4 |
| Elsipogtog (2131 to 2826)* | 13 50 63 | 14 44 58 | 15 45 60 | 17 45 62 |

*Population counts on reserve and total band membership are bracketed.

*Source: INAC – Atlantic. 2010

**Police Statistics Offending in Elsipogtog: Implications for Eastern Door Clients**

The five tables included here deal with actual (not reported) incidents of offending in New Brunswick's largest First Nation. Comparable patterns are found in the two largest First Nations in Nova Scotia, namely Eskasoni and Indian Brook (Clairmont and McMillan, 2006). An examination of tables 4 and 5 below which detail actual offences for the period 2003 to 2009 makes it very evident that the violence and public safety patterns cry out for more effective solutions. Interpersonal assaults, domestic violence, and property offences are indeed at very high levels, far greater than in surrounding mainstream communities with larger populations (see tables 1, 2 and 3), and unfortunately they show no sign of lessening. Sexual assaults and assaults causing bodily harm are especially high vis-à-vis more populous surrounding mainstream communities. Moreover, according to RCMP officers, while property crimes are primarily carried out by a small number either of adults or youths, violent offences are well distributed among Elsipogtog adults (personal communication, 2010). Also, according to the RCMP, fully 60% of all cases going to the Richibucto court come from Elsipogtog, and "no shows" and delays in court processing – something which particularly frustrates Aboriginal victims - are especially characteristic of the Elsipogtog cases (for several reasons, including the type of offences as cases of interpersonal violence are especially subject to delays in court processing).

Indications of the legacy of mainstream domination and social malaise permeate the police records and suggest a pervasive collective victimization. Police interventions under the mental health act (typically involving a person threatening self-harm) are very high, as is community expert assessments of the number of children and youth impacted at fetus by FASD (i.e., a rate of 20% according to experts associated with Elsipogtog's Eastern Door). The drug abuse situation among adults is epidemic in scale, methadone use alone being at least 50 times the per capita rate of Halifax Regional Municipality, the major urban centre for drug abuse and drug dealing in Atlantic Canada (Clairmont and Augustine, 2009). The police to population ratio is far higher than in most areas (i.e., 14 RCMP officers police the community of roughly 2500 persons) but policing, understandably, is basically reactive given the heavy caseload.

There appears little doubt that the community as a whole has to be more fully engaged and take ownership in getting at the roots of these problems. Given the level of interpersonal violence and alcohol and drug abuse, victimization is rampant and the historic legacy of domination has indeed victimized the whole community. At the same time, the aspect of the colonialist legacy that caused people to protect or shield their own versus the outside justice system, and to adopt the view that non-natives are the problem, is increasingly incongruent with the current realities based on greatly enhanced band council authority and administrative responsibility, and the significant economic and political developments especially over the past decade. The combination of these factors – a sense of community victimization which blurs offender / victim roles, political economic and socio-economic variation within FNs which sharpens the offender-victim role differences, and increasing expectations for community engagement - appears to spawn diverse implications for responding to Aboriginal victimization in the CJS. On the one hand, there is some momentum for launching restorative approaches and, on the other hand, there may be increasing similarity with mainstream society with respect to the needs and concerns of the crime victims.

In any event, there is little doubt that young women have been in large number victims of sexual abuse (one Eastern Door official commented that nearly all the young women she has dealt with have reportedly been sexually abused in their younger years). The recent Elsipogtog household survey (Clairmont, 2006) found that women, especially young adult women, were more likely than males to state that such abuse occurs, and to contend that it often goes officially unreported, and that there is also no effective informal or alternative response to the abuse (e.g., familial or politically). Perhaps, then, it is not surprisingly then that many young women drift into alcohol and, especially nowadays, drug abuse. The link between substance abuse and the extraordinarily large number of 911 calls to the police service recorded as "assistance under the Mental Health Act" have been described by a senior local police officer as follows: "The majority if not all clients are under the influence of a substance when they indicate they are going to harm themselves". It has also been confirmed by Elsipogtog RCMP that young women (17 to 30 years of age) are especially common among this "911" clientele and that a

number of the women are repeat callers, often intoxicated and upset over the break-up of relationships when the police assistance is requested (personal communication, 2010).

**TABLE 1**
**A COMPARISON OF RCMP STATISTICS FOR ELSIPOGTOG AND NEIGHBOURING COMMUNITIES**
**2003-2004**

| Year | Elsipogtog (pop. 2200) | | Richibucto (pop. 1400) | | St. Louis (pop. 1000) | |
|---|---|---|---|---|---|---|
| | 2003 | 2004 | 2003 | 2004 | 2003 | 2004 |
| Sexual Assault | 18 | 14 | 2 | 3 | 2 | 2 |
| Assault Level I | 265 | 159 | 46 | 22 | 13 | 12 |
| **Assault Level II** | 60 | 42 | 6 | 2 | 3 | 0 |
| Damage to Property | 162 | 173 | 31 | 45 | 32 | 31 |
| Suicides | 0 | 1 | 0 | 1 | 0 | 0 |
| Attempted Suicides | 5 | 27 | 2 | 0 | 0 | 1 |
| **Spousal Assault (Male offender)** | 10 | 22 | 0 | 1 | 1 | 0 |
| Spousal Assault (Female offender) | 2 | 0 | 0 | 1 | 0 | 0 |
| **Mental Health Act** | 152 | 112 | 19 | 29 | 9 | 9 |

**TABLE 2**
**ELSIPOGTOG AND NEIGHBOURING COMMUNITIES: A COMPARISON OF POLICE STATISTICS 2005**

| VIOLATION (2005) | Elsipogtog (pop 2400) | Bouctouche MUN (pop 2500) | Richibucto MUN (pop 1400) |
|---|---|---|---|
| Intoxicated Persons Detention Act - Offences Only | 3 | 0 | 1 |
| Intoxicated Persons Detention Act - Other Activities | 26 | 1 | 9 |
| Mental Health Act - Offences Only | 0 | 0 | 0 |
| **Mental Health Act - Other Activities** | 30 | 1 | 8 |
| Fail to comply w/ condition of undertaking or recog… | 1 | 0 | 1 |
| **Disturbing the peace** | 36 | 4 | 6 |
| Resists/obstructs peace officer | 3 | 0 | 0 |
| Fail to comply probation order | 3 | 1 | 2 |
| Harassing phone calls | 5 | 1 | 0 |
| Uttering Threats Against Property or an Animal | 3 | 0 | 0 |
| **Breach of Peace** | 34 | 4 | 3 |
| Public Mischief | 2 | 0 | 0 |
| Drug Offences – Trafficking | 0 | 0 | 1 |
| Total Sexual Offences | 5 | 0 | 1 |
| **Robbery/Extortion/Harassment/Threats** | 19 | 3 | 6 |
| Assault on Police Officer | 1 | 0 | 1 |
| **Aggravated Assault/Assault with Weapon or Causing Bodily Harm** | 18 | 0 | 1 |
| **Total Assaults (Excl. sexual assaults, Incl. Aggravated Assault, Assault with Weapon, Assault Police)** | 66 | 2 | 1 |
| Total theft under $5000.00 | 27 | 9 | 10 |
| **Break and Enter** | 32 | 3 | 5 |
| False Alarms | 31 | 0 | 9 |
| **Crime against property - Mischief** (exclu. Offences related to death) | 52 | 2 | 21 |

**TABLE 3**

**ELSIPOGTOG AND NEIGHBOURING COMMUNITIES: A COMPARISON OF POLICE STATISTICS 2006**

| VIOLATION (2006) | Elsipogtog (pop 2400) | Bouctouche MUN (pop 2500) | Richibucto MUN (pop 1400) |
|---|---|---|---|
| Intoxicated Persons Detention Act - Offences Only | 2 | 1 | 2 |
| **Intoxicated Persons Detention Act - Other Activities** | 45 | 1 | 13 |
| Mental Health Act - Offences Only | 1 | 1 | 1 |
| **Mental Health Act - Other Activities** | 75 | 6 | 7 |
| Fail to comply w/ condition of undertaking or recog… | 8 | 1 | 1 |
| **Disturbing the peace** | 56 | 3 | 24 |
| **Resists/obstructs peace officer** | 12 | 1 | 3 |
| Fail to comply probation order (3520) | 8 | 3 | 0 |
| Harassing phone calls | 12 | 2 | 4 |
| Uttering Threats Against Property or an Animal | 9 | 1 | 0 |
| Breach of Peace | 111 | 6 | 13 |
| Public Mischief | 6 | 0 | 2 |
| **Drug Offences – Trafficking** | 8 | 1 | 0 |
| Total Sexual Offences | 6 | 1 | 0 |
| **Robbery/Extortion/Harassment/Threats** | 52 | 8 | 15 |
| Assault on Police Officer | 6 | 1 | 2 |
| **Aggravated Assault/Assault with Weapon or Causing Bodily Harm** | 21 | 0 | 4 |
| **Total Assaults (Excl. sexual assaults, Incl. Aggravated Assault, Assault with Weapon, Assault Police)** | 147 | 11 | 21 |
| Total theft under $5000.00 | 52 | 40 | 15 |
| **Break and Enter** | 71 | 6 | 5 |
| False Alarms | 51 | 38 | 14 |
| **Crime against property - Mischief** (exclu. Offences related to death) | 102 | 14 | 32 |

**TABLE 4**

**ELSIPOGTOG POLICE STATISTICS 2005 THRU 2008**

| VIOLATION | Elsipogtog 2005 | Elsipogtog 2006 | Elsipogtog 2007 | Elsipogtog 2008 |
|---|---|---|---|---|
| Intoxicated Persons Detention Act - Offences Only | 3 | 2 | 2 | 2 |
| Intoxicated Persons Detention Act - Other Activities | 26 | 45 | 44 | 31 |
| Mental Health Act - Offences Only | 0 | 1 | 3 | 0 |
| **Mental Health Act - Other Activities** | 30 | 75 | 125 | 111 |
| Fail to comply w/ condition of undertaking or recog… | 1 | 8 | 22 | 21 |
| **Disturbing the peace** | 36 | 56 | 131 | 152 |
| Resists/obstructs peace officer | 3 | 12 | 7 | 17 |
| **Fail to comply probation order** | 3 | 8 | 17 | 30 |
| Harassing phone calls | 5 | 12 | 15 | 13 |
| Uttering Threats Against Property or an Animal | 3 | 9 | 4 | 6 |
| Breach of Peace | 34 | 111 | 158 | 55 |
| Public Mischief | 2 | 6 | 9 | 2 |
| **Drug Offences – Trafficking** | 0 | 8 | 13 | 18 |
| Total Sexual Offences | 5 | 6 | 33 | 22 |
| **Robbery/Extortion/Harassment/Threats** | 19 | 52 | 64 | 56 |
| Assault on Police Officer | 1 | 6 | 12 | 7 |
| **Aggravated Assault/Assault with Weapon or Causing Bodily Harm** | 18 | 21 | 55 | 65 |
| **Total Assaults (Excl. sexual assaults, Incl. Aggravated Assault, Assault with Weapon, Assault Police)** | 66 | 147 | 225 | 246 |
| Total theft under $5000.00 | 27 | 52 | 73 | 74 |
| **Break and Enter** | 32 | 71 | 68 | 81 |
| False Alarms | 31 | 51 | 89 | 103 |
| **Crime against property - Mischief** (exclu. Offences related to death) | 52 | 102 | 136 | 172 |

**TABLE 5**

**ELSIPOGTOG FIRST NATIONS RCMP POLICE ACTIVITY REPORT 2008 and 2009**

| OFFENCES REPORTED | 2008 | 2009 |
|---|---|---|
| ASSAULT | 189 | 189 |
| SEXUAL ASSAULT | 28 | 22 |
| ASSAULT CAUSING | 68 | 69 |
| ASSAULT P.O | 7 | 4 |
| UTTERING THREATS | 66 | 65 |
| BREAK & ENTER | 91 | 118 |
| THEFT | 110 | 113 |
| DAMAGE TO PROPERTY | 184 | 160 |
| FAIL TO COMPLY | 82 | 80 |
| IMPAIRED DRIVING | 78 | 60 |
| DRUG TRAF / POSS | 34 | 25 |
| INCARCERATED PERSONS | 286 | 306 |
| OTHER CRIMINAL CODE | 418 | 360 |
| MENTAL HEALTH ACT | 113 | 96 |
| 911 ACT OFFENCES | 381 | 704 |
| # OF CASES SENT TO CROWN | 549 | 497 |
| RESTORATIVE JUSTICE CIRCLES | 43 | 55 |

Elsipogtog RCMP First Nations Detachment, 2010

**Alcohol and Drug Abuse Issues**

Alcohol and drug abuse have not been especially noted in police reports. The charges for drug trafficking and possession appear on the rise, going from 0 in 2005 to 34 and 25 in 2008 and 2009 respectively, but a caveat is that in the earlier period the figure applied solely to trafficking. Impaired driving has been significant but somewhat on the decline, with 78 and 60 charges in 2008 and 2009 respectively; for several years there has been an average of 40 police interventions per year under the Intoxicated Person Detention Act. While alcohol abuse remains a significant issue in Elsipogtog and RCMP officers suggest that a very high proportion of the incidents they deal with and of the charges they make involve alcohol abuse, it is clear that most informed respondents have emphasized drug abuse as the more important social problem, as it appears to be among several other FNs in Atlantic Canada and of course in the consciousness of mainstream society as well.

In 2009, according to the New Brunswick Department of Health, there were 383 distinct clients registered to bands in New Brunswick who had methadone for addictions, covered by NIHB, that was dispensed at any Atlantic area pharmacy. Of those, 131 were registered to Elsipogtog persons. It appears that all these distinct clients may not have been in authorized programs for the entire year but perhaps for some periods during the year. In any event, based on the fact that virtually all Elsipogtog methadone-authorized users were between 20 and 45 years of age and that there were approximately 1150 to 1200 of these adult Elsipogtog members (including on and off reserve), the rate of usage for that age category is one of every nine, truly a very high rate. In Halifax Regional Municipal, generally considered the major centre for drug addiction in Atlantic Canada, the corresponding rate has been, roughly but maximally, one of every 400 among adults between 20 and 45 years of age. In other words the Elsipogtog rate appears to be at least 50 times as great. Some other FNs in Atlantic Canada, especially Oromocto in New Brunswick and Indian Brook in Nova Scotia have been reported to have rates similar to Elsipogtog. The extensive public funding of methadone maintenance programs throughout New Brunswick is an increasing problem for the Department of Health since drug purchases constitute the third largest budget item after doctors and hospitals and is rising fast (e.g., there is no generic pricing so the methadone budget is said to be "sky-

rocketing”). One Health official commented, “The methadone program at the community level is out of control financially”.

Of course, drug use in Elsipogtog is not confined to persons enrolled in methadone treatment or to adults between 20 and 45 years of age. Informed estimates, made by key Elsipogtog service providers, suggest that there would be at any given time an average of at least 50 and perhaps 75 others using “hard drugs”. Most local experts report, too, that overall drug abuse in Elsipogtog is a fairly balanced split by gender. The path to methadone, according to the key Elsipogtog service providers, is through oxycontin and lectopam (prescription drugs), as it reportedly is in Indian Brook and Oromocto. Drugs such as lectopam are accessed in capsule form but sometimes, according to local officials, users employ needles to inject the drug which provides for a faster effect and a more efficient use of the amount they have (i.e., a person can get the effect out of half the capsule and still have some for latter). In order to be authorized for methadone by the nurse in charge of the Elsipogtog program, usage is apparently thoroughly determined and only “hard drug addicts” are accepted into that treatment program.

The methadone program was established in Elsipogtog in 2007-2008. Prior to that time, people seeking methadone treatment to deal with their addiction to opiates such as heroin, oxycontin, and dilaudid (methadone is not used to treat dependence on alcohol or cocaine and indeed when combined with any of them the result can be very dangerous to one’s health) went into Moncton. There was an initial transfer of the Moncton cases to Elsipogtog where there would be determination of addiction and prescriptions granted to secure methadone in liquid form from a Richibucto pharmacy, roughly a ten minute drive away. The Elsipogtog nurse practitioner who manages the methadone program deals currently with roughly 50 clients. No youths are allowed into the program though the key officials report that some youths in the community definitely use heavy drugs. Apparently there is at least an equal number of Elsipogtog clients who go into Moncton for their methadone prescription and supply. There is no appreciable waiting list for the methadone program in Elsipogtog and, what waiting list there is, is presumably a function of the capacities of the Richibucto pharmacy and the Elsipogtog methadone program, not by administrative fiat. The waiting list for detox in Moncton also is not long

– just one or two weeks to get in. To get into the traditional substance abuse treatment program at Lone Eagle in Elsipogtog, one must have gone through a detox program (usually that means the one in Moncton).

Methadone treatment is generally defined as a harm reduction strategy, not desirable in itself but better than the alternative of opiate addiction. The evidence is complex. There is strong support for the position that a methadone maintenance program does reduce crime. A major Australian study (Lind, 2005) of over 8000 people who were registered in a public methadone treatment program during a two year period found (as determined by examining court docket data) that they were significantly less likely to commit crimes in those periods when they were in the program than when they were not. Elsipogtog RCMP officials generally contend that crime is down in part because of the methadone program. It seems reasonable that the pervasive methadone treatment would reduce property crime simply because the clients would have reduced need to obtain money for illicit drugs. The presumption, shared by police and some nurses, also is that people take methadone not to "get a high" but as a sedative, a calmer that makes them less tense, and, more controversially, puts them into a kind of stupor. Perhaps violent crime might be less likely under such circumstances. Unfortunately, the tabular data depicted above do not convincingly support that position, at least at first glance but the RCMP a few years back changed the formats for reporting crime. New Brunswick Department of Health officials reported that there is anecdotal evidence that the methadone program has led to less crime at the community level and more children being re-united with parents but they acknowledge that there are no hard data to support these contentions.

Beyond crime patterns, the impact of the methadone treatment approach is more diversely interpreted. In Elsipogtog, the most common view among local service providers is that the methadone program enables many people to get a grip on their lives and does facilitate family re-integration. Methadone clients interviewed in a recent evaluation of the Elsipogtog program rendered positive claims for improvements in family ties, feeling and acting better and even liking the staff and being monitored (Skead and Hubbard, 2010). But clearly these are not easily accomplished objectives. Consistent with the harm reduction perspective, the clients who are regularly tested for other drug

use (e.g., urine samples are sent to Moncton) are given substantial leeway before they are ejected from the program. Three failures in any two month period could lead to ejection. Smoking pot and the use of some specific prescription drugs are not considered as failures in the tests .As noted above, there is however, a significant level of hard drug usage by some methadone clients, reportedly, especially what is generally known as "eight ball" (primarily a mixture with cocaine or crack cocaine but possibly "meth"). The Elsipogtog methadone nurse practitioner does provide some counseling, using the motivational interviewing approach, but the caseload limits that to a short session once every two weeks with the clients. In the case of the methadone clients using the Moncton program there appears to be even less counseling; as one Elsipogtog official commented, "There is supposed to be counseling but they manage to avoid it (e.g., someone is waiting in the car so I have to leave)".The high level of occasional use of other hard drugs by the methadone clients – several key officials considered it to be in the range of 75% of the clients – underline the challenge. One methadone official considered that only about 15 of the current 50 client caseload could be classified as "stable positives" and that many of the others have multiple problems (some informed estimates are that half the clientele have mental disorders) and frequently seek stronger doses of methadone when tense. Other service providers dealing with many of the methadone clientele attest to the multiple drug use and the long-term effort that success will require.

Overall, alcohol and perhaps especially drug abuse clearly constitute a major problem in Elsipogtog, and some Elsipogtog officials have properly characterized it as an epidemic. The recent evaluation of the methadone program referred to above highlighted opportunities for improvement in the methadone operation especially highlighting more effective use of the outside medical specialists, better appointment times to avoid disorder in the waiting room, better data management and working towards on-site dispensing of methadone. Little was said with respect to the reduction of drug abuse problem or the disadvantages of on-site dispensing (e.g., the official in charge of prescriptions already has experienced significant threats from users). With respect to getting at the roots of the drug abuse epidemic, given the scale and formidable challenges of drug abuse and the limited counseling in the methadone program, and given that the Elsipogtog methadone program in July 2010 had 30 females and 19 males, one can

appreciate the possible significance of PCAP since virtually all the PCAP clients are also registered with the methadone program. The agencies' collaboration is crucial if progress is to be made on a long-term solution to the drug abuse and by implication to unhealthy mothers and children. Apparently, good relationships have developed between the two programs, despite the outreach advocacy role of PCAP staff which could occasionally put them at odds, testimony perhaps to their realization of the complex and long-term needs of their clients. Both programs also share a focus on the client and less directly on the family unit.

**Elsipogtog and Collective Efficacy**

The socio-demographic, educational, crime and substance abuse problems are one dimension of the social context for the Eastern Door and its programs. Another equally important dimension is the tremendous capacity for collective efficacy which also characterizes this small community of less than 3000 on-reserve residents. The following table, adapted from a recent Elsipogtog submission for court services, depicts the various social services and agencies which exist in the community, and provides a crucial asset mapping for the Eastern Door. As noted often in this assessment, apart from diagnosis, the chief Eastern Door activities which underline its unique community approach to FASD and other birth disabilities, are essentially outreach in thrust. PCAP and Family Support staff members refer and advocate, enabling their clients to deal with their problems / conditions by better embedding themselves in extant services and agencies. A key objective of the AHTF project has been to enhance the implementation of this objective through meetings with other service providers, informing them about the Eastern Door programs and the AHTF coordinators doing what they can to facilitate an integrated community response to FASD and related problems. These activities are discussed below in the section on collaboration among community service providers.

It can be noted here that the umbrella framework of services / agencies in Elsipogtog is divided into two sections. Section A identifies the service providers directly salient for Eastern Door prevention, diagnosis and intervention. The section A service providers constitute the community assets that the Eastern Door must collaborate with in

accomplishing its objectives. For example, there are several services in the Justice field beyond policing and restorative justice, such as persons trained in “traditional” dispute resolution, victim services, and an extensive coordination and planning capacity (e.g., working committees on violence, a broad-based justice advisory committee). Increasingly, the capacity and the will to deal with the very challenging issues are there and the focus is shifting to putting in place a justice system that the community fully participates in and that resonates well with its needs and values. Section B identifies the conventional programs and agencies that made up the infrastructure for community capacity such as economic and social development, fisheries, and forestry.

Section A lists some 22 different services, including several interagency bodies that have been established as a result of Eastern Door “wrap-around” strategies, namely S.O.S., focusing on at-risk school children with poor attendance records and often learning disabilities, and the Early Childhood Development (ECD) Team which aims at enhanced collaboration among the services in and outside Elsipogtog responding to ECD conditions, from prenatal exposure to alcohol to traumas and related factors (e.g., screening high risk pregnancies and monitoring contact points from prenatal to school entry). FASD and other birth disabilities as well as developmental / learning disabilities of whatever root cause are central foci. While the Eastern Door does not have an operational oversight committee composed of key community collaborators, through these “wraparound” teams and, to a lesser extent, the involvement of several service agencies on the diagnostic team, the collaboration has been formalized.

**Umbrella Framework of Services in Elsipogtog**

**A. Directly Salient Local Services / Programs**

1. **Health and Wellness Centre (1.5 FTE Doctors + 7 Nurses)**
2. **Children and Family Services (Staff of 8 including adm support)**
3. **Nurse Practitioner ( 1 FT and 1 support staff)**
4. **Save Our Students (Community Interagency Network, no staff)**
5. **Home and Community Care Program (8 Home Care Workers plus administrative staff)**
6. **Methadone Treatment Program (54 of the 135 Elsipogtog resident authorized to receive methadone are processed through this program which has 1 PT Doctor, 1 FT Nurse Practitioner and 1 support staff )**
7. **Eastern Door Centre (Prevention, Diagnosis and Intervention for FASD and other birth and learning disabilities. The multi-disciplinary diagnostic team includes 10 Elsipogtog and New Brunswick-provided professionals, an elder and a FT coordinator). There is also an executive director for the Eastern Door.**
8. **Family Support Program for Eastern Door Clients (2 FT Staff)**
9. **Parent-Child Assistance program (2 FT PCAP Staff)**
10. **Early Childhood Development Team (Community Interagency Network, no staff)**
11. **Alcohol and Drug Prevention Program (3 FT Staff)**
12. **Mental Health Program (2 Psychologists, 1 Resident in Psychology and 1 Clinical Social Worker + 2 support staff)**
13. **Lone Eagle Treatment Centre (2 FT Treatment Staff, 1 support staff. Traditional Healing Emphasized)**
14. **Restorative Justice Program (2 FT Case Workers, 1 PT Adm Support)**
15. **Victim Assistance Program (1 FT )**
16. **Crisis Centre Helpline, Outreach and Referral Services (4 Staff)***
17. **Grief and Loss Treatment Program***
18. **Traditional Healing and Healing Community Health Representative (1 Elder)**
19. **Elsipogtog Headstart Program (5 staff and one support staff)***
20. **Physiotherapist (1 FT Staff)**
21. **Indian Residential School Survivors' Support Services (1 staff)***
22. **Anti-Violence Interagency Committee (interagency, no staff)**
23. **Apigsigtoagen Traditional Dispute Resolution (12 trained , no permanent staff)**

**B. General Community Services / Programs**

24. **Elsipogtog Elementary School**
25. **Elsipogtog Daycare Centre**
26. **Adult Learning Centre**

**27. Elsipogtog Trades Training Program Alternative Schools for Youth**
**28. Elsipogtogeoei Community Newspaper**
**29. RCMP Detachment (14 Officers + Support Staff)**
**30. Aboriginal Duty Counsel (N.B. Legal Aid)**
**31. Fire Department and Ambulance Services**
**32. Community Leisure and Cultural Development Program**
**33. Health and Fitness Program**
**34. Economic Development (6 Staff)**
**35. Forestry and Fisheries Program**
**36. Social Development Program**

## THE THREE DIMENSIONS OF A COMMUNITY BASED MODEL FOR DEALING WITH BIRTH DISABILITIES

### THE DIAGNOSTIC TEAM

This assessment is focused on the AHTF project not on the diagnostic team but some context from that central dimension of the Eastern Door service is warranted. The Eastern Door, a formalization and elaboration of FASD-initiatives in Elsipogtog beginning in the late 1990s, became operative in October 2005 and its first client was diagnosed by the multi-professional team in June 2006. According to administrative records, some 34 children and youths have been diagnosed as of May 2010, males outnumbering females by a two to one margin. The diagnostic team (DT) meets once a month during the school year to discuss the diagnosis and suggested interventions for a single referral. Individually the team members usually have met with the client prior to the team meeting. The client is of course not present for the team meeting but later in the day the doctor, coordinator, school specialist, and occasionally the designated elder, will meet with the parent-guardian to discuss the diagnosis and intervention suggestions, to answer queries and hear the parent's response. Funding for the diagnostic team is cost-shared in that federal agencies (i.e., Public Health) fund the coordinator role while the province provides for certain personnel (e.g., the doctor, speech pathologist, occupational therapist) and the community, through transfers and secondments, provides both personnel and other resources. One knowledgeable Elsipogtog member of the diagnostic team has referred to the complex funding arrangement as "a unique assembly of resources".

The diagnostic team consists of twelve people, namely a doctor, team coordinator, nurse practitioner, mental health specialist in child psychology, speech pathologist, occupational therapist, elder, social worker with CFS, family support worker and three school specialists (two educational psychologists and a methods/resource specialist). Virtually all the referrals to the diagnostic team come through the elementary school officials and apparently the core recommended intervention program, though not the only intervention suggestion advanced by the diagnostic team, entails client engagement in special learning programs carried out at the school. At the diagnostic team meetings the

team participants can provide input whether in the form of their assessment of the client, comments or suggested interventions; a significant team exercise is assessing the extent to which the child client can be assessed as having FASD conditions. The coordinator reported that the recommendations advanced by the DT members are not rank-ordered but rather all become part of her agenda for implementation.

The chief criteria utilized to assess for FASD have been (a) disclosure of alcohol consumption by the mother during pregnancy (the first trimester) and (b) significant inappropriate behaviour which may be manifested in learning issues or in social interaction more generally. The DT members interviewed advanced the concept of a continuum of FASD disability and apparently the positive diagnoses thus far have been considered to be cases of “mild” FASD conditions. Using the approved Canadian guidelines for the scoring system there has not yet been a full score case of FASD diagnosed. Essentially the doctor examines the width of the eyes (i.e., small eyes), lips, height and weight (there is no brain imaging and no DNA tests) while Mental Health’s child psychologist looks at behaviour and social interaction learning (described as “new psychology”, “a holistic approach”). The nurse practitioner prepares the medical reports for all referrals. The occupational therapist presents her assessment based more on motor skills and any physical impairment impact on learning, and the coordinator provides input on the family history and social circumstances. One educational psychologist brings to the table school performance measures while the chief educational psychologist discusses school behaviour and chairs the segment where scores for FASD condition are tabulated. In keeping with Canadian Guidelines, both psychological and medical data and assessment are required and for those reasons no diagnosis is carried out with children prior to age six or seven – as one respondent commented, “there could be some medical assessment with children as young as two but such children would have to have special pronounced features which are rare, and in any event, Canadian Guidelines rule out psychological assessment at that age”.

Clearly, the coordinator role is crucial both in arranging for the diagnostic team meeting, including the meeting with the parent-guardian in the afternoon, and also in monitoring the intervention and actively advocating on behalf of clients (now both child and parent) with the service providers whose services they require. The latter activity

underlines that coordinator role also organizes and engages in the Family Support activities. These multiple functions, on the one hand, can facilitate a greater awareness of the clients' life situation and a shared understanding with them that can in turn be quite crucial in linking DT members with the clients in a full sense, as well as providing updates on the intervention. On the other hand, however, as the interviewed DT members noted, those multiple tasks, required because of limited funding, coupled with the lack of any secretarial backup, may translate into fewer updated reports and less effective formal monitoring assessments; indeed, the desirability of having a fulltime DT coordinator was frequently stated by all members of the DT.

**Key Issues related to the AHTF Project Objectives**

The DT members are mostly Caucasian and do not live on reserve but they are quite sensitive to these facts and encourage the attendance of the elder and the two other professional members who are band members. One DT member noted that she definitely likes to see an elder present at meetings when the diagnosis and intervention suggestions are discussed with the parents, adding "otherwise it may appear to the native parent that they are being lectured at by Whites". Much of the symbolism utilized, such as the Medicine Wheel concept, also attempts to transcend cultural barriers. It may be noted that none of the parents, when interviewed, raised the cultural issue in describing their experience with the diagnostic meeting.

**Evolution of the Diagnostic / Eastern Door Thrust**

While the core focus of the DT remains on the FASD and other non-generic birth disabilities, the members interviewed emphasized that the DT considers the impact of the mother's drug taking and smoking (e.g., mother's smoking has been shown to impact on the child's height) and learning disabilities in general. Most interviewees reported an increased openness of the DT to a broader range of theoretical frameworks and diverse intervention strategies, perhaps an inevitable result of the maturation of a community-based, holistic systems approach. Certainly, too, it was common for them to cite the importance of family background (e.g., stable relationships, drug-free households) and even dietary factors. While all DT members always acknowledged the reality and

importance of the FASD explanatory framework, some reported much less tension now that, unlike in the earlier phase of the DT experience, there is a more flexible open approach adopted. Some of the theoretical frameworks they advanced, such as attention deficit disorder, ADHD, and attachment disorder, are conditions they argued where alcohol and drug use during pregnancy could be factors along with poor nutrition and other parental /family factors. The main point, however, is that most DT members appeared to hold that the evolution in the DT conceptualization has been advantageous to the diagnoses and interventions recommended, without sacrificing the essential thrust of the Eastern Door's FASD theme.

**Caseload**

Can the diagnostic team handle a larger caseload? This could be an issue not only because of the high estimates of the proportion of Elsipogtog babies that may have FASD-related birth defects but also because, if the Eastern Door is to become a centre of excellence, one could well expect that other First Nations would want access to the ED diagnostic process; there was much interest expressed in this dimension of the Eastern Door service by the other First Nation people interviewed (see the section below, Reaching Out …). It is unclear whether there is a waiting list of possible Elsipogtog clients for the diagnostic service. One external member of the team commented, "I don't know if there is a waiting list but I know there is always a client available for our monthly diagnostic casework". In the event that the Eastern Door was to provide diagnoses for other First Nations in the area, the caseload issue would arise. It would appear that a larger caseload would require more resources. It can be noted that the diagnostic team did start off meeting more frequently and considering two clients a month, but that ended because, as one member noted, "it is demanding work and an additional workload for most team participants".

**Parents / Guardians Views on the Diagnosis of Their Child**

Although it cannot be said that the sample of parents and guardians whose children were diagnosed by the ED team was representative of all who have had that experience at Elsipogtog, it is nevertheless a sample of interest. The clients' view of the

diagnostic experience was quite positive. While only a few respondents stated that the diagnosis was understandable and in line with their own expectations, the common position was they did have an opportunity to ask questions and they usually received answers that they could understand. Especially significant in most accounts was that the lay DT coordinator was able to relate well to them, to help them understand what they were being told about the underlying conditions, the strategic action plan that the diagnostic team was recommending, and the practicalities of its implementation. Usually, it appears, the chief implication was that their child or youth would be able to access a specially designed learning program at the school, and that the Family Support coordinator, also the coordinator for the Diagnostic team, would work closely with them to implement the recommended plan of action.. Virtually all the parents / guardians reported that they knew something was wrong with their child and for them the crucial issue was not so much the underlying causal factors but more the putting into place of a program for effecting positive behavioural change at the school. For some it was significant to learn more about underlying factors and these parents / guardians expressed appreciation for the information they obtained and the websites and other sources recommended to them at the post-diagnosis meeting. Two of the eight parents reported themselves upset at the post-diagnostic meeting but only one indicated that this feeling extended beyond the explanation to the plan of action being suggested. Asked to rate their experience with the diagnosis meeting on a one to ten scale, the common score given was ‘eight’.

Overall, then, the establishment and functioning of the diagnostic team has been a remarkable achievement and truly it is the centerpiece of the Eastern Door’s service. Key issues now focus more on resources, especially the desirability of a full time coordinator without sacrificing the Family Support activity which is essential to the Eastern Door’s unique status as the only community-based service model for dealing with non-genetic birth disorders and learning disabilities in Atlantic Canada. With the possibility of a provincial centre of excellence on the horizon, based in large measure on the Eastern Door model and partnering with it, the Eastern Door’s diagnostic team will likely increase in significance. Add to this, the developments in the justice field where a Healing to Wellness court will presumably be seeking such diagnosis linked to the

effective interventions, and the demands of other First Nations for access to culturally appropriate services (especially the kind of diagnoses provided by the Eastern Door) in this area, one can predict that the diagnostic team will be called upon to play an increasingly crucial role for Elsipogtog and the other Aboriginal communities in the area.

## PERSPECTIVES ON EASTERN DOOR AND THE FAMILY SUPPORT PROGRAM

## PRELUDE: THE 2003 PERSPECTIVE OF PARENTS / GUARDIANS ON THE NOGEMAG PROJECT

The Nogemag Healing Lodge initiative launched in 2002 was a major step in the emergence of a creative, sophisticated community-based approach to non-genetic birth disorders in Elsipogtog. As described at length in the author's 2003 report, and "placed' in the section, "Background to the Eastern Door" in this assessment, it was a bold strategy of dealing with youths who had essentially been expelled from or refused to attend the regular Elsipogtog school program even with the innovative special learning programs that had been introduced there. The Nogemag model involved working with the youths - and as much as possible involving their parents in the process – who had been considered likely to have FASD conditions based on preliminary assessments of their background and some diagnostic work. The activity took place outside the school at the 'farm' or healing lodge on a daily basis during the school year, and was organized consistent with best practices for working with youths with FASD disabilities. The project was a significant success as all the regular attendees were back in school the next year and they also avoided any run-ins with the criminal justice system. It was a short-term project but its legacy was especially the Medicine Wheel approach and subsequently the Eastern Door. As part of the assessment of the Nogemag project in 2002-2003, eight parents/guardians of youths who had participated in Nogemag on a full-time, regular basis were interviewed. The interview guide focused on the pre-Nogemag situation with their youth, their sense of the underlying causes of their youth's problem behaviour, their knowledge of the Nogemag initiative and contact with its staff, the impact to date of the Nogemag experience for their youth, their satisfaction with Nogemag and their suggestions for changes in the Nogemag program.

In all cases where the informant was parent or guardian for a regular participant, it was reported that the youth had had serious behavioural problems over the past three years. Virtually always the problems reportedly occurred at school, were of long duration

and quite disruptive (e.g., much absenteeism, being expelled). Roughly half the youths were deemed to have caused significant trouble at home. Only a few were said to have had "trouble with the law" but those denying such trouble usually qualified their "no" with words such as "almost but no", "he is too young for that".

The parents/guardians varied quite a lot in their assessment of the causes of the youth's problem behaviour. Most affirmed, following the motif of the Nogemag program, that FASD was the main cause but several were hesitant to apply that label either because they had no diagnostic confirmation (e.g., "I don't know; he was not diagnosed") or because they identified some other factor as primary (e.g., "his mother's death", "a learning disability"). The parents/guardians usually had at least one source of professional assessment of their youth to draw upon, whether it be some medical diagnosis, social workers' tests, or assessments from the school psychologists. Indeed, most reported having information from both medical diagnosis and school psychologists (e.g., tests at school).

The frustration experienced by the parents/guardians in the pre-Nogemag period became evident when they were asked whether, before Nogemag, they had found useful, helpful ways to deal with their youth's problems at home or at school. About half held that some school programs were at least of some value (e.g., the one-on-one resource class) but others reported little effective school intervention and indicated that their youth reacted negatively to the school format. As for the home milieu, it was commonly stated that "we struggled", "it was hard", "when I look back on it, I don't know how we managed, day by day I guess".

All the parents/guardians indicated that they came to know about the Nogemag program through Dr. Cox, the school professional educational psychologist in charge of dealing with assessment programs and the chief advocate and mobilizing agent for the Nogemag initiative. From the point of view of learning about Nogemag, no one reported significant contact with, or information-gathering from, other school officials or other parents/guardians of youths with similar problems. Typically, the parents/guardians reported that they were open to such an interventionist strategy as Nogemag and had no especial concern, other than that their youth would eventually be able to function well in

the regular school setting, that is learn to read and write, "learn a lot" etc. None mentioned any concern about their youth being "labelled" upon going to Nogemag.

Virtually all these parents/guardians reported that they had had "a lot of contact with the Nogemag operation". There had been frequent contact by telephone and they had visited the Nogemag “farm house” at least a couple of times and, with one exception, had participated in at least one family circle at Nogemag. Most reported, too, that they had been visited at home or at work by Nogemag staff, had received reports from Nogemag staff concerning their youth's progress, and had been contacted by the FASD family worker. Presumably because of this regularized contact, the parents/guardians considered that they had a good knowledge of the Nogemag program and what they do there with the youths. Only one person did not take that position. All but one informant reported themselves satisfied with the contact and the information they had but most went on to say that "I would like to be more involved".

The parents/guardians all indicated that the impact of Nogemag has been quite significant for their youth, even while noting that more progress was both needed and hoped for. They often found it difficult to articulate the positive benefits of Nogemag but a few spontaneous comments were interesting; one parent said "Yes there have been good results, his behaviour; he (a twelve year old) used to stay out late, break into stores and I couldn't find him, but ever since Nogemag he started coming home"; another parent said of her thirteen year old grandson, "yes, good results, he passed, he learned a lot, it changed him", while still another parent said of her thirteen year old, "the biggest change I have ever seen in my son! He is more happy and content; he gets up every morning and can't wait to go there". No parent or guardian reported that any "poor results" for their youth occurred as a result of the Nogemag experience. All but one parent/guardian reported that the youth's attitudes and behaviours at home had changed for the better; the grandmother of a thirteen year old reported that "we don't fight any more"; one parent observed of her sixteen year old, "well, yes, but he is just one of a kind; he has realized that he should not be doing what he was doing"; another guardian, responsible for a twelve year old, reported, "yes, there has been a change but he is still too hyper". Few guardians, however, noted much significant changes in other respects (e.g., readiness for regular schooling, community activities, trouble with the law), several suggesting that "a

bit improvement I guess; maybe by next year he will catch on more". Several parents/guardians reported that they did receive suggestions from Nogemag staff about how to better cope with their youth at home but most said "no", and the former did not elaborate on the nature of the suggestions.

Looking to the future, the parents/guardians generally were positive about having their youth re-attend the Nogemag "farm" for the new school year (2003-2004), echoing one who said that "another year would be good for him". In terms of changes that they would like to see in the Nogemag farm project, all but one of the eight parents/guardians wanted their youth to spend more time at Nogemag (i.e., a longer day), and have different programming (typically more of the basics, reading, writing and mathematics). There was little doubt that these interviewees were still concerned about their youth ultimately learning skills that would enable them to succeed in school and in life generally. Beyond these changes, the respondents advanced few suggestions for change, being quite content with the different activities at Nogemag and with the Nogemag staff. The only other suggestion was made by a grandmother of one of the older Nogemag youths (a sixteen year old) who felt that older youths should be separated from the younger ones.

Overall, then, the parents/guardians of the regularly attending Nogemag youth were quite positive about the project. They believed that their youth did need special programming and that Nogemag, with its focus on FASD, was zeroing in on the underlying causal problems of the youth. They considered that they were well-informed and engaged by the Nogemag staff even while wanting more involvement in the future. Similarly, they considered that Nogemag had had a significantly positive impact on their youth (especially improving relations at home) but they generally felt that more progress was necessary. The parents/guardians suggested few changes be made in the Nogemag program and virtually all suggested changes had to do with ensuring that their youth would ultimately be able to succeed in the regular school system. Finally, all these parents/guardians cooperated fully with the interviewer, in large part because they were positive about Nogemag; indeed, one person conveyed more widespread sentiments, when, in response to a standard statement that the interview contents would be kept anonymous and confidential, she responded, "Why? That school is so good everyone should hear about it".

## THE 2010 PERSPECTIVE OF PARENTS / GUARDIANS INVOLVED IN THE EASTERN DOOR'S FAMILY SUPPORT SYSTEM

The Eastern Door program followed the Nogemag project by several years. It built upon the latter but was much more elaborate and sophisticated in all three dimensions, namely prevention, diagnosis and intervention. Community informational networks were established, information brochures created and distributed, and prevention strategies such as FASD day in Elsipogtog were launched. Major initiatives, most notably PCAP in 2009, were developed for preventative and interventionist objectives. The diagnoses of FASD and related disabilities impacting on learning, and, indeed, developmental and behavioural problems in general, have been the centrepiece of the Eastern Door. Careful examination through tests, interviews and various measurements, of a wide range of physical, psychological and behavioural factors by a large professional, multi-disciplinary team has provided the basis for sophisticated diagnoses and well-conceptualized and evidence-based intervention plans for the clients; indeed, in these regards, Elsipogtog's Eastern Door has established itself as a centre of excellence and acquired prominence for its work on FASD and kindred disabilities throughout Atlantic Canada and beyond (CITE SOURCES HERE SUCH AS PROVINCIAL AND NATIONAL RECOGNITION). It is nothing short of amazing how Elsipogtog, a small, economically struggling community, has been able to put together such an impressive initiative as the Easter Door, really the only one of its in-depth, comprehensive kind in Atlantic Canada.

If the diagnostic program has been the centrepiece of the Eastern Door, The Family Support (FS) program has been the central mechanism for making the Eastern Door work. This program contributes significantly to the Eastern Door's preventative activities (e.g., community communications including a monthly column in the community newspaper) and coordinates the activities of diagnostic team as well as the intervention plans developed for clients, advocating and networking among extant local services and beyond. At the time of this assessment, the FS staff consisted of two full-time employees, both of who had been engaged with the FS program for less than a year.

One person, the senior staff member, coordinates the Eastern Door diagnostic activities and sessions. She typically contacts the members of the Diagnostic Team prior to their monthly meeting where reports on the client of the month by team members - the doctor, school specialists, child psychologist, occupational therapist and others – are discussed; the recommendations are collated and the coordinator then works with the clients and services involved to see to their implementation. In addition, this FS staffer also directly provides family support for a handful of clients, while the other FS staffer focuses entirely on providing support to the remaining client families. The central thrusts of the family support entails support and advocacy for the family (children/youth and guardians alike) and assisting the family in following up on the recommendations of the diagnostic team.

At the time of assessment there were 24 clients (and their families) on current file with Family Support and 16 were deemed to be currently "involved" by the FS staff. Some of the clients dated back to the beginnings of the Eastern Door more than three years earlier while a few became clients during the winter of 2010. The ages of the youths ranged from 5 to 16 years old. Virtually all the client families had been recommended by the Elsipogtog school officials to the Eastern Door for diagnosis of the child / youth and subsequent support for the family unit, but there were a very few cases where the parent / guardian directly sought out the Eastern Door program (in at least one of these cases the young teen had not attended school for years). Whether recommended initially by school officials or not, according to the coordinator the rule is that a child / youth has to be in school to be accepted for diagnosis. The young clients were predominantly male; indeed 16 of the 24 youths on file were male, as were 23 of the 34 boys and girls who were ever involved with the diagnostic / family support components of the Eastern Door so there was a 2 to 1 ratio. The young clients, and often their parents or guardians, subsequent to the recommendations of the diagnostic team were referred to special Elsipogtog school services or programs, and, with significant Family Support advocacy, to a variety of local service agencies, and, sometimes to programs and services external to Elsipogtog, usually in Moncton but in a few cases to special treatment centres as far away as Alberta's well-known Nightwind Treatment Centre. It is clear from examining the referral patterns of on-file cases that most client families (youth and / or

parent / guardian) were referred to more than two local service programs, the most common being special school programs (10 cases), mental health and the child psychologist (8 cases), speech and language pathology (7 cases) and general health services such as audiologist, optometrist, dietician (16 cases)*.

Eight parents / guardians were interviewed (see the interview guide in appendix C), several tape-recorded, for this project. They were all among the "involved" grouping as defined by FS staff, and quite representative of that grouping by the age range and gender of their youths served (e.g., 5 of the youth clients were male). Since a handful of other parent /guardians were contacted but declined to participate, it cannot be said that the eight respondents constitute a representative sample of parents / guardians but it can be noted that the refusals were not identified as especially different in their known perspectives on the Eastern Door and the Family Support program. In discussing their views below, use of case specifics has been limited for reasons of promised anonymity and confidentiality.

**Key Themes in the Parent / Guardian Client Interviews**

There was a diversity of family structure among the eight cases and in no case was the client youth parented in the classic nuclear family mode (i.e., two parents and offspring); single parents, whether male or female, and grandparents were the rule with one possible exception. Some of the parents / guardians had experienced – indeed, about half were still trying to cope with - significant personal problems in their lives such as alcohol or drug addiction. In a few cases it emerged during the interview that the parent's resolution of personal problems was intricately linked to success in dealing with the child / youth problems in the sense that a positive parent-child relationship was seen as an anchor for the parent's stabilization; as one parent commented, a major issue in his reintegration in Elsipogtog was for him to gain access to his son.

All but one of the parents / guardians reported that their youth in the FS program had exhibited serious behavioural problems prior to being registered for school. It was commonly stated that the child had been "hyper-active", "frustrated", "angry" and "did not get along well with other children". At the same time, they all reported that school

attendance brought the problem behaviour into crisis proportions with their youth doing poorly there and constantly in conflict with other students as well as teachers, very frequently being ejected from class and frequently either expelled from the school or stubbornly unwilling to attend school. According to the parents / guardians, typically, the youths experienced multiple problems in infancy and early childhood, including the death or suicide of close family members (e.g., mothers, siblings) and / or close friends, different types of abuse, and ineffective parental response (i.e., neglect and periodic verbal and physical violence) to their disruptive behaviours. The parents / guardians indicated that they were frustrated, wanting to help, fearful of losing the child, and in a few, more extreme, instances almost shunned by neighbours and family members because of the actions of the unruly child (one grandmother guardian commented "people would not allow her [the youth] into their homes"). One parent, for example, observed that his young boy, not yet ten years old, had always been difficult, fighting with others and running away from school. It was added that the youth had been born into a drug-addicted parental household, abandoned by the mother and sent to about ten foster households over a two year period; in addition, reportedly, the youth had been sexually abused. A young mother described her child as having multiple problems (attributable in her view to his being sexually abused) which continued into the school milieu and caused considerable stress at home. Another mother stated that before school her child seemed "developmentally delayed, had a bad temper, and other kids and adults treated him differently"; when he got enrolled in school, "he seemed to be outside of class more than he was in". Three parents, however, contended that they were able to more or less cope with their children, "hyperactive and impulsive since birth" in the words of one client, until the children enrolled in school.

The adaptations of the parents / guardians to their youths' disruptive behaviours, previous to their involvement in the Eastern Door and Family Support, was limited in part because of their own and other familial issues and also because either they could not meaningfully "connect" with the local service providers / treatment professionals or because no clear supportive, sustainable plan for change was ever advanced at these consultations, at least from their perspective. One grandparent, who had provide the primary care for the diagnosed child all her life, reported that she had received ADD and

other assessments from outside professionals and school specialists which helped her understand the child but there was never any meaningful follow-up, in part because the child would not open up to these persons. The interviewees did sometimes report some valued assistance from these sources (e.g., respite, parenting courses offered through Child and Family Services, assistance from consultations for themselves or their youth with Mental Health, special school assessments) but, apparently, for the reasons mentioned, it was quite limited. Usually, friends and close family members (here there were a few exceptions) reportedly were also of limited assistance for a variety of reasons, often merely advising the parent / guardian "to be more strict" with the disruptive child (some professionals may offer similar advice but presumably would accompany the advice with a plan or intervention strategy for changing the parenting style). The parent / guardians typically were at "wits end" and both they and the youths bore the price in a variety of ways. One mother, however, reported that, while her child had many problems at school and at home, she sought no support outside her immediate family but drew on her own patience and creative routines to regulate the child's behaviour until Elsipogtog school officials referred the child to Eastern Door diagnosis. She went along with the referral but, to date (several months post diagnosis), has followed only the diagnostic team's recommendations that related to school services for her son, a learning programming that she conceded has been more appropriate than what the child previously had.

As noted above, with one exception, all the youth clients were referred to the Eastern Door diagnostic team through the Elsipogtog elementary school, and with that same one exception, all the young clients completed the diagnostic process. Most interviewees considered that the diagnostic process, the actual diagnoses advanced and the treatment / intervention plan suggested by the diagnostic team, were clearly explained to them and were reasonably understood by them. One mother, for example, noted that there had been a suggestion from a school specialist that her child may have had a neurological condition so "I was willing to try anything to know why she was that way and find someone or some program that could help"; she added that she was fine with the diagnostic process and found it very helpful. Two of the eight parents / guardians reported that they did not understand much of the diagnosis but even they stated that their

questions were discussed at the meeting they had with the coordinator, the doctor and a few other members of the diagnostic team - usually the coordinator, the doctor, some school professional, and an elder meet with the parent / guardian clients immediately subsequent to the diagnostic team's meeting on the case. It was not clear usually whether the parents-guardians accepted the underlying diagnosis whether FASD or whatever; one parent reported herself to be skeptical while another stated that he was not at all pleased by the diagnosis and a third claimed to find it confusing. Overall, on a scale from 1 to 10, almost all clients rated this process a 7 or an 8. There was, however, a strong consensus that the process of diagnosis and recommended actions had yielded an operational plan for the parent-guardian and the youth that facilitated positive meaningful change, that the FS coordinator helped them understand the diagnostic report, and that the FS program was providing support and advocacy to assist them in realizing that change.

The basic way that parents / guardians and their youths directly dealt with the FS staff was through home visits by the staff and telephone calls back and forth to arrange appointments with other services and deal with crises. There were a few visits to the FS office at the Elsipogtog Health Centre (also where the diagnostic team met for its deliberations) but the parent / guardian clients' preference was clearly for home visits. Another key common pattern was for the home visits reportedly to decline over time, from once a week or more to once a month and then when necessary to supplement telephone contact. This pattern is precisely what one would have expected if the FS program were working well as a "needs-based delivery of services", since its services were more that of advocacy and "navigation" among local and other specific service providers. As clients were effectively linked with these latter services, presumably the role of FS staff in providing support, communication and networking for the clients would require fewer face-to-face meetings.

Clearly, in the views of seven of the eight interviewed clients, the FS staff's support was crucial since the FS staff's non-judgmental approach and their accessibility, the "being there for me", as it were, were pivotal to the relationship of trust that reportedly developed. The FS staff "actively outreached" at the beginning of a relationship with a client and then responded to the continuing clients' crises on an on-going basis. That trust and confidence, in conjunction with FS staff's networking and

advocacy vis-à-vis other services and programs (e.g., medical and mental health, learning centre programming), in turn, reportedly led to a much more effective utilization of the latter than had been the pattern prior to the clients' engagement with the Eastern Door. One parent, for example, commented that the difference has been that, with the diagnosis and treatment / intervention plan, and the considerable FS assistance, it has been possible to target the needed services in a more helpful way, whether it be at the school, with Mental Health, Child and Family Services or others. Several other clients echoed those comments about now having a plan that builds on the diagnosis identifying the roots of the problem. One young mother, for example, highlighted her family's (she and her youth) much greater use of local services as well as special outside programs for herself (coping with ADHD and pFASD) and her offspring (summer camp). The sole exception to the pattern of greater use of Elsipogtog and outside services and programs was a mother who reported herself skeptical of the Eastern Door diagnosis (perhaps because the troubled son has a twin who apparently has had few developmental problems) and to date has had limited involvement with FS staff and not followed the diagnostic team's recommendations apart from school programming.

The interviewees usually cited significant improvement for their youth and often also for themselves as a result of their engagement with the Eastern Door and the FS program, the former giving them a direction and a plan for change and the latter guiding them through the implementation in a supportive fashion. A grandmother commented that, since her child entered the Eastern Door program two years earlier, she has seen a big improvement in how the youth relates to other local service providers and she herself is more confident about being able to handle and parent the youth. She added, "[She] has few friends but is doing better in school", testifying to both the progress and the continuing challenges for her youth. Another grandmother, parenting a particularly aggressive and disruptive youth, emphasized that the youth will always need considerable attention and support but "now she is getting the kind of help she needs", adding that her own life has improved and she feels better prepared now to deal with the youth. A young mother, involved with the Eastern Door and FS for over two years, reported that her child "is functioning close to expected grade level now and has become involved with activities such as volleyball and girls' groups". A single parent dad commented "the

intervention program at school is working and I am much calmer because of anger management classes". A young mother, involved with FS for less than two months at the time of the interview, told the interviewer that "since Eastern Door she has been involved with medical services, intervention services at the school and mental health again and it seems to be working better for them". Several parents / guardians shared the view of a young dad who commented that FS staff has been very helpful in arranging appointments for him with key Elsipogtog service providers and getting him there.

Asked to comment overall on what the major impact of their involvement with the Eastern Door's programming has been to date, about half the interviewees claimed it has been life changing for their youth and / or themselves One grandmother stated, "I would have lost her if the Eastern Door was not there to help" while another commented, "Without the Eastern Door [she] would probably be dead now and I don't know where I would be". A single parent dad held that "eastern Door has changed [my son's] outlook on life". The other interviewees also gave quite positive statements about the impact, such as "I am a much better parent now and there has been much improvement in the youth's behaviour" and "[My son] has been doing better at school and getting along better with others. There is less stress at home. I don't yell as much – as the interviewer commented, "she likes what she sees so far (two months into the program) and trusts that Eastern Door is doing the right things". A young mother pointed to her daughter significant progress over two years in school and in social relationships, adding that while there will always be challenges and struggles, she is now more confident she can cope – "before I would never pick up the phone to make appointments but I can now". Two parents reported quite limited but still positive FS impact; in one case, the parent has yet (several months in the FS program) to take much advantage of FS assistance while in the other case the youth's profoundly serious problems have been resistant for years to major change by any Elsipogtog agency including the Eastern Door, though the parent credited the FS staff with building up trust with the youth, advocating and navigating on his behalf, and perhaps "putting him on a better path".

Virtually all interviewed clients did offer some suggestions for improving the FS program, the essential one being that there be more activities (e.g., parenting, household economics and solidarity boosting activities among the families in the program) and

contact possibilities outside of the usual office hours (i.e., evenings and weekends). It was common, too, to suggest that more FS staff be hired. There was also a frequent spontaneous suggestion that more emphasis be placed on encouraging solidarity among the participating families; as one parent said in making this suggestion, "Families having trouble need to know they are not alone". It was clear in the interviews that, with perhaps two exceptions, the parents / guardians saw a continuing if sporadic and crisis-based need for FS support. All respondents indicated that they would strongly recommend the FS program for other parents / guardians facing similar issues and several indicated that they have already done so. The widely shared underpinnings of the positive recommendations were that because of the Eastern Door – the diagnosis and the FS program – the lives of the parent / guardian and the child / youth have changed for the better and the right strategies have been put in place to continue that progress. Moreover, as one parent observed, "The kind of help you get with the Eastern Door, you can't get anywhere else in this community".

Clearly, the FS program has largely been accomplishing its objectives for the clients, parents / guardians and youths, and has facilitated their more effective utilization of extant Elsipogtog and other programs. The mechanisms for this success have been a sensitive, harm-reduction approach, an outreach style of engagement with clients, and an "aggressive" advocacy on behalf of the clients. Apparently, a strong positive relationship was usually established with most clients after several months. One issue, not asked of the clients, would be whether that relationship could survive the turnover in FS staff. Given that the interviewed staffers had been in their FS roles for less than a year and were no longer there as this assessment was being written up, how much of the trust and positive relationship would survive the turnover? Also, it must be underlined that the above assessments are the views of the parents / guardians who might understandably be mixing fervent hopes with actual results.

## THE FAMILY SUPPORT PROGRAM FROM THE DESIGNER'S AND STAFF'S PERSPECTIVES

Interviews were also conducted, on multiple occasions, with three key persons responsible for either designing or delivering the FS program. Their perspectives were somewhat different in keeping with their roles in the FS program. The designer-initiator (D-I), a PhD in Education, had more of a 'big picture' perspective, reflecting her pivotal role and her long experience in identifying and responding to FASD and related or similar learning disabilities in Elsipogtog. In 2002, she had conceived and operated the Nogemag intervention discussed above and since that time, on the basis of her programmatic initiatives as well as her writings and presentations, had become a nationally recognized authority on FASD. The staff interviewees were focused more on their role vis-à-vis the clients and had been with the program and in the community for less than a year. The senior FS staff member complemented her graduate-level education with a commitment to social service and a capacity to deal firmly when necessary with professionals and service providers; she was also trained in motivational interviewing and reportedly used that approach in working with FS clients. Together the FS coordinator staff / management (D-I and director) were an effective team for realizing some of the objectives of the Eastern Door with respect to intervention in the face of formidable client problems and major organizational issues in optimizing service delivery coordination in Elsipogtog.

The D-I characterized the objectives of the FS program as "intervention and support to prevent secondary disabilities and to improve outcomes of the primary disability (FASD etc) based on assessment and diagnosis", while the two staff persons referred, in more concrete strategic terms, to building a relationship of trust with clients "without which none of the diagnostic team's recommendations will be implemented" and "creating relationships … to support client families accessing the Eastern Door program". All three interviewees envisioned the main FS tasks as support, advocacy and navigation for clients as they work through the diagnostic team's recommendations. All three considered that the central mechanism for success in the tasks was a very active outreach, "investing time into families and not giving up" said one FS staff, "being in contact [accessible] with clients all the time" said the other. The D-I characterized this

outreach strategy as follows: “not waiting for clients to come to the program but taking the program to them … outreach is a new way of working and is showing signs of success but is not yet a fully functioning model”.

While all three interviewees acknowledged that support, effective navigation among the services and programs available, and crisis management were diverse dimensions of the FS staff’s role, the staff members appeared to especially underline the demands of crisis management; this is not surprisingly given their identification of building relationships and establishing trust with clients, who have serious, sometimes “unmanageable” problems, as the central underpinning of the FS program. The D-I, more analytical, commented that “The roles depend on the families, where they are in the process and the situation. The advocacy [navigation plus] role is very important and changes as the parent / guardian builds esteem”; here the D-I was presumably highlighting that the FS program aims at connecting the clients much better with the local and outside services and programs they need and, if successful, the role for FS staff obviously evolves. All three respondents considered that some success has been achieved for most clients on the three FS roles, especially crisis management.

Asked what they considered to be the major successes so far with the FS program, the three respondents expressed in different words basically the same message, namely that the healing path has been established. One staff member noted, “Children and families having appropriate support that cannot be taken away”, while other staffer stated that trust has been established between families and the other agencies, and client capacity to better themselves and take the initiative has been achieved [in a number of cases]. The D-I addressed the big picture saying, “The Eastern Door is a ground breaking program and has become the model to be replicated and demonstrated …Diagnosis is now available to youth and families of Elsipogtog… The healing process has begun”.

The respondents were asked whether all role players involved with the Eastern Door, including top management of the Health Centre, shared the goals of the FS program as they articulated them. Here they differed in their assessments, although all three, while appreciating the general support provided them, suggested there was apparently some ambivalence among the top management concerning the priority to be given to Eastern Door issues in a financial crunch. As it happened, the interviews with FS

staff were essentially completed subsequent to the end of the 2009-2010 fiscal year and federal funding for the Eastern Door initiative was reduced in the 2010-2011 budget; this meant that one staff position was cut and the other also affected. Under the circumstances, and given their belief in the importance of their work and the heavy workload required by the FS strategy of outreach, accessibility and advocacy, it is understandable that the staff would raise questions concerning the priority to be accorded by top management to the Eastern Door and the FS program. Even with the prior budget, there was no secretarial support for the FS program, and administrative tasks, such as preparing manuals for the FS program and for the diagnostic team, were completed by the senior FS staff member under the supervision of the D-I. Of course, top management of the Health Centre always has to balance and prioritize the needs and benefits of a variety of programs in a context of myriad, short-term external funding arrangements that underscore the "project" status (i.e., limited sustainability and infra-structure funding) of so many First Nation Health and Social Services programs today.

Other challenges for the Eastern Door and the FS program in achieving their objectives were identified by the respondents as including the degree of "buy-in" by other Elsipogtog agencies (especially their appreciating the outreach and persistent advocacy of the FS program), and the need for more staff to devote the necessary time to the very troubled families, citing here the formidable challenge of working with youth and adult clients who have experienced much trauma, as well as the youths' primary and secondary disability effects, and some parents / guardians' substance abuse. One respondent stated, "Parents are always in crisis mode and often have no phones or transportation". While the staff members were decidedly pessimistic that the challenges of agency buy-in and adequate resources for the FS program were going to be adequately met – recall the situation of a major budget cut for the FS program in 2010-2011 – the D-I was more optimistic, suggesting that there has been more understanding and buy-in among the local agencies as a result of the AHTF project and more appreciation of the value of the Eastern Door and its FS program throughout the community.

The three interviewees shared a quite positive view that they were on the same wave length with the parents / guardians and youth clients. In their view the parents / guardians valued the relationships established with the FS staff and appreciated the work

and commitment implied in the outreach and ready response to their crises. The respondents held that, as for the youth, the central parental concerns were that the child was experiencing significant success in school and having their traumas dealt with. All three interviewees considered that the parental clients appreciated the "good, solid help that is empowering, not condescending" and, overall, that the hardest challenges were not the clients but rather obtaining the full collaboration of other agencies and the priority to be given the Eastern Door and the FS program by top Elsipogtog management.

The three respondents were also in agreement that the two most central local agencies for the FS program have been the Elsipogtog school system and Child and Family Services. Each cited a different third most central agency, the staff members stating Mental Health and Alcohol and Drugs respectively and the D-I citing the Health Centre itself. Predictably the school system, where the FASD thrust in Elsipogtog initially emerged, was considered by all interviewees to be 100% helpful. Collaboration with the other agencies cited was deemed by all persons to be "a work in progress", especially with Child and Family Services (basically for the same reasons as offered by PCAP staff above). The respondents also agreed in holding that, while more understanding of their FS work and changes in some agencies' approach are needed, there have been substantial improvements in the level of integration and coordination among Eastern Door and local service providers over the past year.

When discussing the most central provincial or regional agencies, the views of the interviewees differed significantly. The FS staff members' frame of reference was the agencies / services they dealt with as part of their advocacy and navigating for the FS clients; accordingly, for them the central agencies at this level were the Methadone Clinic and the Georges Dumont Hospital in Moncton, and the Mental Health service in nearby Richibucto; all were deemed quite helpful though requiring more understanding of the Eastern Door's and FS program's mandate and approach. For the D-I, the central outside agencies were the New Brunswick Department of Health which contributed professional personnel to the diagnostic team such as physicians and occupational therapist on a regular and valuable though limited basis, and the federal First Nations and Inuit Health Branch (FNIB), providing funding for Eastern Door activities, crucial funding but also

deemed to be too highly departmentalized and sometimes without consideration of any meaningful tripartite collaboration.

The respondents were asked in conclusion what improvements could be made to the FS program to enhance its effectiveness in facilitating the recommendations of the diagnostic team and assisting the parents / guardians and their youths. All suggested that there should be a dedicated FS program, with adequate staffing and housed in a more user-friendly facility outside the Health Centre (such as a family resource centre). They all also considered that the program would solidify relationships with and benefit clients more if there was flex-time, more outreach and basic allowances for transportation, cell phones and the like.

Overall, then, the perspectives of the Eastern Door's FS program's D-I and staff members shared many commonalities, and the differences in expressing the objectives of the FS program were largely related to the two different roles involved, one focusing more on the larger picture of the Eastern Door at Elsipogtog and the other focusing more on the interaction with clients and agencies in facilitating the recommendations of the diagnoses. The respondents were in consensus about the main tasks of the FS program and the central mechanism – an active outreach - adopted to achieve them. While all tasks were seen as being successfully pursued, crisis management was especially noted since it was considered both crucial to building relationships with clients and also requiring a significant investment of staff time and energy. There was consensus that evidence would show that a number of clients had indeed been assisted not only in connecting better with other services but also in turning to a more healing life path. A number of significant challenges were identified by the respondents especially in light of a major budgetary cut in April 2010; these included concerns about the future of the program, the commitment of top Elsipogtog management to the Eastern Door, and the sustainability of the integration and coordination among local service agencies that had been achieved over the past year. There was substantial agreement among the respondents concerning what the parents / guardians would see as the chief expectations and benefits of the FS program for their youth and themselves (e.g., success in school) and also about what the respondents advanced as their own main suggestions for improving the FS program (e.g., more staff, flex time). In both these regards, the views of the interviewees were indeed on

the same wave length as their clients. Finally, the respondents agreed that the Eastern Door should be a centre of excellence for the prevention, diagnosis and intervention concerning FASD and other such disabilities, and were quite willing to assist in providing information and training to other First Nations in order to advance that objective.

**Summary**

Working with parents/ guardians of school-age youth having some FASD conditions was initiated on a project basis prior to the existence of the Eastern Door. The analysis of the 2002 Nogemag project illustrated its value even at a less intensive and thorough level than the Family Support system. The parents/guardians of the Nogemag youth were quite positive about the one year project. They believed that their youth did need special programming, and that Nogemag, with its focus on FASD, was zeroing in on the underlying causal problems of the youth. They considered that they were well-informed and engaged by the Nogemag staff even while wanting more involvement in the future. Similarly, they considered that Nogemag had had a significantly positive impact on their youth (especially improving relations at home) but they generally felt that more progress was necessary.

With the Eastern Door those parental hopes were realized for similar youths diagnosed more precisely and for whom a more sophisticated interventionist plan was recommended. Even with its modest staffing and multiple and challenging tasks (including the coordination of the diagnostic team activities), the FS program has largely been accomplishing its objectives for the clients, parents / guardians and youths, and has facilitated their more effective utilization of extant Elsipogtog and other programs. The mechanisms for this success have been a sensitive, harm-reduction approach, an outreach style of engagement with clients, and an "aggressive" advocacy on behalf of the clients. A number of key themes were identified in the parental-guardian interviews, such as (a) that the youths in the FS program had exhibited serious behavioural problems ("hyper-active", "frustrated", "angry" and "did not get along well with other children") prior to being registered for school, but that school attendance brought the problem behaviour into crisis proportions (Interestingly, two thirds of the diagnosed youths were males, a

fact consistent with the gender issues in elementary schooling); (b) that the parents prior to involvement with Eastern Door apparently could not meaningfully "connect" with the local service providers / treatment professionals nor did they obtain, from their perspective, a clear, supportive, sustainable plan for change from those consultations that they did have about their youth; (c) that the impact of FS involvement has been very positive and pronounced for their youth and also for themselves.

The FS management and staff members constituted an effective team, positive in outlook and confident that the FS approach was succeeding. There was consensus that evidence would show that a number of clients had indeed been assisted not only in connecting better with other services but also in turning to a more healing life path. They were clearly on the same wave length as the clients with respect to what the parental expectations and hopes were and what were deemed to be shortcomings in the service provided. A number of significant challenges were identified by the respondents especially in light of a major budgetary cut in April 2010, including concerns about the future of the program, the commitment of top Elsipogtog management to the Eastern Door, and the sustainability of the integration and coordination among local service agencies that had been achieved over the past year. Their own suggestions for improving the FS service, (e.g., more staff, flex time), were consistent with those offered by the parents. Finally, the respondents agreed that the Eastern Door should be a centre of excellence for the prevention, diagnosis and intervention concerning FASD and other such disabilities.

The writer would agree with virtually all the above interpretations and suggestions for change but would also add the need for more attention to monitoring and measuring the changes over time in the attitudes and behaviours of the youths and parents since such data are crucial for regular internal and external evaluation. The motivational interviewing approach in dealing with clients should be enhanced and employed by both coordinator and outreach worker. Mediation and conflict resolution training as for example in the Elsipogtog Apigsigtoagen approach could pay dividends in advocacy work for clients.

## THE PARENT-CHILD ASSISTANCE PROGRAM

## THE PCAP PROGRAM AND WHY IT WAS INTRODUCED IN ELSIPOGTOG

"The Parent-Child Assistance Program (PCAP), originally known as the Seattle Birth to 3 Project, began in 1991 as a 5-year federally funded research demonstration project designed to test the efficacy of a model of intensive, long-term paraprofessional advocacy with high-risk mothers who abuse alcohol or drugs heavily during pregnancy and are estranged from community service providers. The primary goal of the program is a straightforward one -- to prevent alcohol and drug exposure among the future children of these mothers" (Grant, accessed 2009). The program has expanded throughout Washington State since then and has been recognized for its effectiveness by several authoritative national bodies and has been "replicated at over a dozen sites in the United States and Canada". PCAP paraprofessionals work with a caseload of approximately 15 families each, for 3 years beginning at enrollment during pregnancy or in the postpartum period. PCAP does not provide direct treatment services. Instead, it advocates, connect mothers and their families with existing community services, and coordinate services; "women are never asked to leave the program because of relapse or setbacks".

"The lives of mothers enrolled in PCAP are characterized by poverty, upbringing by substance-abusing parents, childhood abuse, abusive adult relationships, trouble with the law, and chaotic and unstable living conditions. As products of this background they are often distrustful of community service agencies. The PCAP program tries to overcome the alienation. Notably, there has been relatively low staff turnover in a field known for high rates of burnout. Three administrative components contribute to job satisfaction and retention: weekly group staffing, individual weekly supervision by a master's level supervisor, and a dynamic evaluation process allowing advocates to see that they are indeed helping clients make gains, as well as to observe areas for improvement". Evaluations of the program have provided excellent results for client change and sustainability and for staff retention (Grant, 2009).

There is little doubt that the PCAP fit to Elsipogtog was extraordinary. According to a Health Centre report, cited by Eastern Door officials nearly half of the pregnant women in the community in 2005-2006 were drinking and using illegal drugs. These

women had very unstable household situation, reported much sexual abuse and trauma (see below) and were falling between the stools of local services and agencies. The director of the Health Centre on an exploratory visit to Seattle Washington immediately grasped the potential value of PCAP and upon her return arranged for its funding through the Alcohol and Drugs program. Good networking remains between PCAP and Alcohol and Drugs, and staff in the latter program have taken PCAP orientation and training, but the PCAP program is linked closely to the Eastern Door; its staff and Family Support staff share office space and, though apparently there has been as yet (summer 2010) no overlap in clients (the two programs have different age foci), they share the Eastern Door's approach and collaborate in community communications.

PCAP in Elsipogtog generally has followed the Seattle model with emphasis on individual outreach, and a harm reduction approach coupled with long-term (at least three years) commitment to clients. Specific eligibility and protocol guidelines are also similar, as is the utilization of motivational interviewing and the 'difference game" (culturally adapted for Elsipogtog) – all of which fit well with the resources available to the program and its mandate. The formal objectives of PCAP in Elsipogtog as stated in the PCAP Quarterly Report for April-June 2009 have been:

1. to develop and implement locally driven plans for preventing births exposed to drugs and alcohol
2. to increase awareness of the effects of drugs and alcohol on the fetus, the mother and the family among pregnant women and new mothers. It is also for mothers with a child diagnosed with Fetal Alcohol Spectrum Disorder (FASD) or Partial Fetal Alcohol syndrome (pFAS) who are abusing drugs and/or alcohol
3. to improve the efforts to collaborate with other service providers and help create and strengthen collaborative approaches and links within community service providers and other stakeholders.

**Implementation Phase of PCAP**

The PCAP program in Elsipogtog was launched in early 2009 and began receiving clients in February of that year. It was defined by PCAP staff as "a three year voluntary program for women pregnant or with babies less than six months old and who are addicted and on methadone". The PCAP program, following the Washington State format, has made a strong commitment to adhere to that protocol, refusing possible clients either ordered by other local agencies to participate or who did not otherwise fit the eligibility criteria. PCAP staff members have pointed to the PCAP experience elsewhere indicating that the program works best when it rigorously follows the eligibility protocols. As will be noted below in the discussion of client interviews, while participation is voluntary there are "prodding sticks" at the community level, most notably the ever-present threat from the child protection-oriented Child and Family Services to take the baby from "unfit" parents where the child is "at-risk".

Table One presents some interesting data on the implementation phase, that is the first nine months of PCAP's existence in Elsipogtog. The table shows the steady evolution of the program in terms of staffing (from 0 to 2 full-time), clients (from 0 to 9 with three pending and being assessed) and time allotted to the various activities. In the time budget description provided below a distinction is drawn among three types of activities (the schematic was generated by the writer). Category A refers to activities carried out directly on specific clients' behalf and includes transporting clients to meetings, face to face meetings, phone calls, direct advocacy and case management. Category B refers to activities establishing the program in the community and linking up with other service providers; it includes communications, community meetings and collaborative practices). Category C's activities directly focused on implementing the program and maintaining its effective implementation; it includes work with staff, information management, developing a manual for standards and guidelines for the approval of the executive director Elsipogtog Health Centre and so on. In the first quarter of 2009, not unexpectedly, the time allotted to Category C, staff orientation and training, research activity and other program development tasks, took the lion's share of PCAP's time budget (i.e., 67%). By the end of the implementation phase – the third quarter – that

% had dropped to 47% while hours spent directly on clients' behalf (Category A) had increased from 17% in the first quarter to 30% in the second quarter and 40% in the third quarter; in particular, the huge increases over time in "face to face" meetings (e.g., from 88 hours in the second quarter to 214 in the third) and the increase in advocacy hours (i.e., essentially office phoning to local service providers on behalf of the clients) indicate that the PCAP program was at full throttle. It is to be expected that without any secretarial assistance to speak of, Category C, the regular program management and, lesser, the professional development activities, would always account for a significant share of the PCAP time budget but, by the end of the third quarter, it no longer accounted for the majority of the business hours. Category B activities, communications (e.g., contributing to the community newspaper etc), community meetings and, especially, informal and formal collaborative practice with other service providers were a steady budget item, hovering around 15% of the PCAP time over all three quarters of the implementation phase.

Several other interesting points can be drawn from the first three PCAP quarterly reports. Housing adequacy turned out to be a significant problem for PCAP clients and, by the end of the third quarter, only 3 of the 9 active clients were deemed by PCAP staff to have an adequate housing situation (not verging on homelessness nor living in precarious housing conditions). Referrals to PCAP primarily came from the Nurse Practitioner who also manages the methadone program in Elsipogtog but a few came from Child and Family Services, the Maternal Nurse or were self-referrals. There were three refusals by potential clients to become involved with PCAP, none in the third quarter which could suggest that there was positive word-of-mouth communication about the PCAP among vulnerable women. The PCAP clients were engaged in a number of local support programs including individual counseling at Mental Health Services and at Alcohol and Drugs. There were apparently few direct referrals made to local service providers (in several instances the clients refused to follow-up on a PCAP referral) so the implication is that the PCAP advocacy had largely to do with enhancement of clients' existing contacts. It is clear from the PCAP reports that, from the onset, smoking and drug use were identified as key issues for the clients. Alcohol abuse surprisingly was

indicated to be not a problem for two-thirds of the PCAP clients and indeed only one or two clients reportedly used alcohol during pregnancy.

**TABLE ONE**

**THE PCAP IMPLEMENTATION PHASE: THE FIRST NINE MONTHS, 2009**

| What was Done | 1st Q 2009 | 2nd Q 2009 | 3rd Q 2009 |
|---|---|---|---|
| # active clients (referrals) | 2 | 6(+3 referrals) | 9 (+3) |
| # referrals who declined | 1 | 2 | NA |
| Category A: Directly working on the clients' behalf (Includes transportation, face to face meetings, phone calls, direct advocacy and case management) | | | |
| #hrs face to face mtgs | 18 | 88 | 214 |
| #hrs transporting | 13 | 25 | 20 |
| #hrs advocacy (office) | 20 | 60 | 81 |
| #hrs phoning clients | 10 | 36 | 7 |
| #hrs case mgm't clients | 25 | 68* | 82* |
| #total hrs spent Cat A | 87 | 270 | 328 |
| #avge wkly Client hrs | 8 | 10 | 24 |
| #max wkly hrs any client | 6 | 5 | 6 |
| Category B: Directly working on establishing the program in the community and integrating it with other local services. (Includes communications, community meetings and collaborative practices) | | | |
| #hrs communication | 9 | 46 | 12 |
| #hr comm'ty mtgs | 12 | 46 | 42 |
| #collaboration | 60 | 65 | 50 |
| # total hrs spent Cat-B | 81 | 157 | 104 |
| Category C: Directly working on professional development, training and program management and development | | | |
| #total hrs spent Cat-C | 330 | 458 | 392 |
| #Grand total hrs | 498 | 885 | 824 |
| #hrs over req'd hrs | 10 | 109 | 42 |
| % hrs direct Client behalf | 17% | 30% | 40% |
| % hrs Category B | 16% | 17% | 13% |
| # Group sessions | NA | 9 | 5 |
| # Referrals made | 1 | 0 | 2 |
| # Referrals rec'd | 3 | 6 | 5 |

Source: PCAP Quarterly Reports, 2009

*There is some slight incongruence with reported statistics in these two instances.

## Current Operational Phase of PCAP

Consistent with the PCAP approach elsewhere, the Elsipogtog program accepts all clients fitting the eligibility criteria, adopting a long-term, harm-reduction commitment to addiction-vulnerable women often with traumatic legacies, practical problems such as inadequate housing and unrealistic aspirations given their limited education and job skills. As the senior PCAP staff member commented, "For many women we are the last resort, having burnt their bridges (with their families and local agencies) but we always take them". PCAP staff members utilize an active outreach strategy which entails much "chasing after the new clients" within the limits of a roughly 9 to 5, weekday work schedule, until the relationship stabilizes. In addition to the program features noted above (i.e., individual and group meetings, difference game etc), PCAP assists clients in re-connecting with local services and programs ("they [the agencies] will usually take them when we request") and their families (though reportedly this is problematic since frequently the fathers and mothers have similar issues), in filling out required forms, exploring new life paths (e.g., adult upgrading and the GED), and providing transportation to meetings with agencies.

By early summer, 2010, there were 13 clients registered with the program. Seven of the clients were aged between 19 and 25, two between 26 and 30 years and four were 31 years of age or older. The oldest client was a 37 year old woman who was recorded as "self-referred" to PCAP. Among the first four clients, three in fact were classified as "self-referred"; thereafter, all clients were recorded as referred by either the medical nurse (formally 'Nurse Practitioner') who managed the Elsipogtog methadone program (9 cases, 1 a joint referral with Child and Family Services) or the Maternal Health Nurse (2 cases). Broadly speaking then, the PCAP clients were, at core, young "new" mothers or expectant mothers with a history of drug abuse who were referred by the methadone nurse. It is not clear how many also had to deal with alcohol abuse or had abused alcohol during the early stages of their pregnancy; according to the Maternal Nurse, only a few of the clients indicated they had the latter problem or were otherwise known to have consumed alcohol during the pregnancy.

The administrative data for PCAP indicate that by May 2010 there was a median average of 25 one-on-one sessions with PCAP staff (i.e., the coordinator and the outreach worker) for the first five registered clients (a range from 10 to 33 sessions), 15 for the next five registered clients (a range of 5 to 26) and for the last three registrants the average number of sessions was 5 with a range from 3 to 11 sessions. The patterns are consistent with a practice of PCAP clients meeting with staff roughly on a bi-weekly basis but clearly there has been substantial variation quantitatively in the staff-client get-togethers / relationships. The recorded number of meetings probably understates the actual contact between clients and PCAP staff as PCAP employed a vigorous outreach strategy which meant more contacts (telephone and otherwise) than actual formal meetings (personal communications, 2010). The number of telephone contacts was not available to the evaluators but these could conceivably take up significant time, even though roughly 40% of the clients had "telephone disconnected" status by May 2010. In addition to one-on-one sessions, there were group support sessions instituted later in time by PCAP staff. These sessions – labeled the Thursday night sessions to differentiate them from a more general purpose Wednesday evening information / discussion session - could include both PCAP clients and interested other women. More than half the PCAP clients (8 of 13) had not participated in any group session at all, and, of those who did, the minimum number of one-on-one sessions also attended was 15, so clearly there was at least a modest pattern for different levels of exposure to the program. At the same time, PCAP officials reported that all clients but one were "involved in the program", though it was noted that for some clients the involvement took time to develop, and for others – about 25% - the involvement remained limited or sporadic.

**The PCAP Staff Perspective**

There are two PCAP staff members who also handle all the required secretarial and administrative tasks (e.g., administering the ASI). The senior member, who has a graduate degree in social work, coordinates the program and has a direct caseload of four or five clients while the outreach worker deals with the remainder. In their separate interviews these two respondents exhibited much similarity in their views on the program to date. They articulated the overall goals, stated as outcomes, as "helping women reach

their goals and motivating young women who think they don't have a chance". One interviewee added, "drug and alcohol – free women, good mothers". The two respondents reported that the PCAP goals were well appreciated by all central role players in the Eastern Door program but that the outreach and advocacy strategies of PCAP have occasionally met resistance from other local service agencies. The coordinator elaborated on the strategies as follows:

> "PCAP is an outreach program where the workers go to the client instead of waiting for the client to come in, building trust and a relationship to be able to help them set goals using the difference game. The strategies have been adequate but more time is needed and more cultural components are also needed".

The outreach worker highlighted the specific, field-level tasks in her characterization of strategies, namely "provide transportation, improve communication, talk to other agencies on clients' behalf, help clients make appointments".

Both PCAP workers emphasized that while there are multiple dimensions to their work with clients, such as advocacy and navigation with various agencies and programs, the fundamental requisite is building a relationship of trust with the clients. As one stated, "navigation is quite important since many of these women have never been taught to do things for themselves but before they allow us to navigate, trust must be built". Ultimately, success was defined as "drug and alcohol-free women starting to take responsibility in their lives and working with agencies". The major challenges for the programs were identified by one respondent as, in the first instance, "women who do not want to help themselves" and, by the other respondent, as system-level factors that limit the program's intervention, namely "lack of cultural components, service providers not understanding, the very high need limiting the service that can be provided". The respondents readily advanced possible corresponding ways to address the challenges to the program, namely by involving elders, giving presentations to other agencies and by hiring more staff.

The two PCAP staff members agreed that what PCAP clients would consider the most important benefit they received from the program would be the support they gained when dealing with other service providers, a perspective underlining that PCAP basically provides "connective" not "substantive" programming. While this point was not

elaborated upon, client interviews below indicate that perhaps the central reason for women volunteering for PCAP has been their concern to retain custody of their babies and, to do that, they presumably would require being able to meet the standards and concerns of local agencies, especially of course Child and Family Services (CFS). The respondents did elaborate on what they considered the two greatest challenges for PCAP staff in seeing that the clients profited from the program; here both PCAP staff members identified the misunderstandings with other service providers (i.e., appreciating the PCAP outreach approach) as one such challenge and, as the other, either community dynamics or limited time availability to build up trust with the clients.

The respondents both identified Child and Family Services as the most central agency they must work with in their support and advocacy of clients (many clients, they added, clearly perceive CFS as a threat). They noted that their own relationship with CFS had been improving over the past year but that there was still much room for improvement. Other agencies cited as important for the PCAP work included Alcohol and Drugs, Maternal Nursing, and the Crisis Centre, all of whom had taken PCAP orientation sessions. The respondents both stated that there had been significant improvement in the integration and coordination of PCAP and other local service providers over the past year and stressed that further orientation and upgrading should be carried out (i.e., periodic presentations about the PCAP model to other service providers). The respondents indicated that at the regional or provincial level, the key services or agencies were the hospitals ("they have the information you need"), the transition houses ("we have very good relations with them"), and the courts ("[courts officials] are starting to realize what PCAP does but more discussion is needed").

The PCAP respondents had no problem responding with suggestions when asked how to improve the PCAP performance to enhance its effectiveness within the Eastern Door context. Beyond the suggestions for cultural embeddedness, and periodic presentations about PCAP (particularly its approach and evidence about its success here and elsewhere) to other agencies, they emphasized, as did the Family Support program's staff members, the requirement for more resources (from staff to cell phones and a budget for transportation costs) given their outreach approach and the many crises experienced by their clients.

Overall, then, the PCAP staff members shared much consensus about PCAP objectives (e.g., more confident clients are accessing effectively the local services), operating philosophy (e.g., harm reduction), central strategies (e.g., outreach) and main functions (support, navigation and advocacy). They identified common challenges (e.g., building up trust with clients, getting their message out to the local agencies), and ways to deal with them (e.g., accessibility and being non-judgmental, periodic presentations to agencies). Generally, while acknowledging the need for more improvement and for significant change in some work issues (staffing, flex time, technology, and work expenses), they held that there had been positive gains made in their integration and coordination with other agencies over the past year. The differences in the views expressed by the PCAP respondents had largely to do with their different roles within the program, coordinator and outreach worker, respectively.

**The PCAP Client Perspectives**

Twelve of the thirteen PCAP clients were interviewed, one-on-one, either in their homes or at the Elsipogtog Health Centre. The interviews were, of course, voluntary and all participants received but a very modest gift certificate for their participation. Few client interviews were tape-recorded, in keeping with clients' wishes. The interview followed a guide aimed at exploring the clients' experiences in a casual, open-ended fashion with respect to seven key themes (see appendix A), namely

a. involvement in PCAP
b. assessment of PCAP's navigating and coordinating role for the client
c. assessment of PCAP's impact on the client's social support system
d. assessment of PCAP's impact in advising the client
e. the central impact of the PCAP experience for the client
f. specific ways whereby the PCAP benefited the client (navigating re other local agencies such as Child and Family Services, Mental health etc)
g. assessment of the design and implementation of PCAP from the client's perspective
h. suggestions for improvements in PCAP

i. whether the client would recommend the program to others involved in similar situations as themselves

There clearly was significant variety in the clients' perspectives but all clients valued their participation in PCAP and all indicated that they would recommend PCAP to other mothers or expectant mothers experiencing the problems they had; indeed, most clients reported that they had already recommended PCAP to others. All but one client indicated that they had - and typically continue to have - a drug addiction problem for which they were taking methadone. Only two of the clients referred to an alcohol addiction or problem. There was diversity among clients' views with respect to specific program features, such as whether they preferred to meet PCAP staff at the Health Centre or have the outreach worker come to their home, whether they wanted to participate in the Thursday evening group sessions or not, and their level of need and requests for PCAP assistance. The major articulated focus of most clients was their parenting and, especially, either getting a child back from Child and Family Services (CFS)' protection (where the children were placed in others' homes) or keeping their babies from being taken under CFS jurisdiction. Throughout most interviews, the intervention of CFS past, present and future loomed large.

Usually the clients' key valuation of PCAP centered upon the PCAP staff's advocacy for and sensitivity to their concerns. It was most common for clients to report that they trusted the PCAP staff - a process that sometimes took several months to take effect since for some clients "confidentiality" seemed to be a very crucial consideration in their accessing available Elsipogtog programs. All participants appeared confident of the staff's willingness to assist them across a wide range of personal problems, accessing services ranging from home care to parenting and "couples counseling". With one or two modest exceptions, the clients reported that they were now better able to manage their affairs and attributed much of that change to PCAP activities such as outreach visits, "the difference game" and sometimes the Thursday evening group sessions; one client commented, "you get helpful ideas for dealing with any problems you have had" while another participant reported, "the difference game helps you find out what you need,

what your problems are and what to do" and in the group sessions "cool things happened to all of us and people open up and talk about their problems".

Several central points emerged from the client interviews. One was that PCAP has clearly made a deep impact on the use of local services and programs by many young women / mothers in serious need. Prior to their PCAP involvement, the clients typically had "none" or "minimal" and unhelpful contact (according to them) with pivotal local agencies such as Alcohol and Drugs, Crisis Centre, Mental Health and Children and Family Services. After becoming involved with PCAP most clients claimed they were more involved with local agencies as PCAP staff provided better contacts and "navigation" for them. Several women explicitly mentioned that PCAP advocacy and support plus advice had significantly impacted not only upon accessibility but also made them more aware of how to work effectively with the local service providers. Related to this theme was the corollary for most clients that they now were better able to cope and were turning their lives around, working on the G.E.D., getting appropriate counseling, and having either or both of housing improvement and home care. Another central theme was that the positive motivation to successfully deal with their life challenges of substance abuse and related parental issues became more powerful. As noted, for many PCAP clients a major motivation was to get back or retain their children. With PCAP, virtually all clients found new positive support and some were able to rekindle positive social relationships with family members, thereby adding significant incentive to deal with their issues (i.e., not letting down PCAP staff or mom etc).

A further central theme was that there were apparently three dimensions to success through PCAP involvement. One was cognitive, clients coming to see alternatives and strategies for achieving them through contact with PCAP staff, "the difference game" and the group discussions. Another dimension was PCAP social support which provided empathetic backup for changes in life style (i.e., support correlated with trust and "being there"). The third dimension was PCAP navigational facilitation for clients' accessing the services and programs required to effect change (e.g., education, housing needs, couples counseling).

It was noted above that virtually all clients interviewed reported that they judged the program as valuable and would recommend it to other young mothers in similar

circumstances. The fact that most said they had already made such recommendations would suggest that PCAP should have a strong positive word-of-mouth reputation in Elsipogtog. The clients also drew attention to some possible changes that could improve the program (see below).

**Client Experiences**

There were several broad types of client-PCAP involvement, chiefly (a) the client reporting a very positive, full involvement; (b) the client reporting a positive though limited engagement in PCAP; (c) the client reporting ambivalence about the impact of PCAP on their life situation and a limited engagement in the program.

(a) The most common PCAP participant model was that where the client participated much and considered that PCAP had benefited them much. One such client noted that she had been referred to PCAP through "the Crisis Centre" where she gone depressed and suicidal, overwhelmed with addiction issues, justice issues and pregnancy. She participated fully in PCAP, receiving home visits from the outreach worker and attending many group sessions. She had utilized some local service programs (Alcohol and Drugs, traditional healing through Lone Eagle) with some positive results prior to becoming involved with PCAP but accessed more with better results since then, including Mental Health counsel, and medical services. She reported that PCAP has been assisting with her housing problems and in her accessing educational upgrading (i.e., G.E.D.). In her view, PCAP has provided enhanced social support and 'networked" for her. It has made, she believes, "a huge difference" in her life, and the staff's support, the group meetings, and the "difference game" discussions have helped her to better manage her life. She considered that she still need much support and would like to see more activities centered around the group sessions (e.g., sewing, craft making). She summed up her experience as follows:

> "PCAP has given me extra help dealing with my issues and kids. They help me to manage better in everyday living. I'm tired of bothering my family. They [PCAP] help me with transportation to get to my appointments and helped me get my apartment and are helping me to get a house off reserve. They help me to

budget and control myself. The group helps me to get along with other people. We don't look at each other the same in the group as we do outside. I have more patience for people. They also help me to stay sober and feel good within myself. They have taken me from being down to being up again … I feel like it (PCAP) has saved my life. I am much better today because of it".

Three other clients also reported much involvement with and much benefit from their PCAP experience to date. A common theme again was having lost children because of their previous life style and being faced with that prospect anew (i.e., addicted to prescription drugs, in the methadone program, and referred to PCAP by the Nurse Practitioner). The three clients cited here had all been in PCAP for about a year, receiving regular home visits and attending group sessions (two regularly and one infrequently). They differed in their pre-PCAP use of local service agencies but two had utilized Mental Health and Alcohol and Drugs, though with different reported results. Subsequent to joining PCAP, all three clients claimed to have become more active users of local services (e.g., home care services, parenting program) and reported better relations with the service providers they had previously been involved with, something all attributed to the support and advocacy of PCAP. One client commenting on the parenting class, mused "I wish I knew then what I know now" referring to her children who were taken away by Child and Family Services protection.

These three clients highlighted the support and advocacy functions of PCAP. All three reported having had few if any "support relationships", family or otherwise, in their lives immediately prior to PCAP. They claimed that since joining PCAP they have been able to establish some positive relationships with family members (e.g., a sister, a mom), deal more effectively with service agencies such as Child and Family Services (one client reported that she was now much closer to getting her baby back), and establish a trusting relationship with PCAP staff. The clients held that PCAP had given them a voice, made them more confident about planning their lives and been a lynchpin for their change as "they are there when I need them". PCAP staff's advocacy and navigator role was seen as very helpful in making them aware of what could be accessed and "getting services is easier with PCAP assistance and guidance". The clients were quite positive about other aspects of the PCAP program as well, namely the individual meetings with staff, the

“difference game” (“it’s a good start in identifying weaknesses or what to work on if you are uncertain”) and the group sessions (as one said, “it’s women expressing themselves and their issues, relating to and learning from one another”). All three clients indicated that because of their PCAP involvement they have grown as persons and parents; one expressed the common view that “I have grown into the program and trust them; I feel they can help me with anything. I am better now”.

Another client expressed well both the positive impact of PCAP involvement and the challenges of healing. She joined PCAP she stated “due to drug use during pregnancy”, having already had a child taken by Child and Family Services. She has participated much for over a year, having weekly home visits though not attending any group sessions. While noting that she had previously had numerous contacts with local service providers pertinent to her heavy drug use, she emphasized that PCAP was the first program she has ever stayed with, adding “there is no sense of pressure; they don’t force you but they just try to do what they can to help”. She reported that since becoming involved with PCAP she has tried more to turn her life around, accessing Adult Education and seeking “couples counseling” with her boyfriend through Mental Health. In her view, PCAP’s help regarding parenting has given her confidence that she is better prepared to raise her baby. The client observed that initially she disliked being referred to PCAP, felt forced to join and was reluctant to open her door to the outreach worker, and that she still does not understand aspects of the program such as “the difference game”. Nevertheless, she said that now she has a great sense of trust in PCAP staff and of not wanting to let them down as she tries harder to be clean [of drugs].

The same essential characterization of success and continuing challenge would apply to another client who was referred to the program by the Nurse Practitioner in charge of the methadone program. The client was in the latter program and had recently given birth. She has had an average level of involvement in PCAP, receiving home visits from PCAP staff several times a month and attending some of the group sessions. Despite serious drug problems and several relapses, she stated that she had used only the Crisis Centre prior to joining PCAP but since then she has been involved with Mental Health (i.e., couples counseling) and on-line training to secure her G.E.D. The client emphasized that PCAP support has been essential since she has had no support system

with local service providers or family members. PCAP apparently has generated positive relationships for her as well as facilitating her access to local services. She considered that the individual meetings with PCAP staff, especially the home visits, were quite helpful, that the "difference game helped me to figure out what I needed to do in my life", and that the group sessions were also beneficial though she reported that she has dropped out for the nonce because she did not feel comfortable with some new members. The central theme articulated by the client was that "I trust them [PCAP staff] 100%, like they have helped me come out of my shell, make decisions and deal with other agencies". The client has many extant challenges including parenting, limited social support and continuing drug addiction - recently she was removed from the methadone program and relapsed (the sequence of these two happenings was unclear) – but PCAP has provided continuing support and advocacy. Like the client described above, she indicated that she wants to "stay clean" because she does not want "to let them [PCAP staff] down".

Another client fits well in this broad category. She too has had a serious drug problem (now is on the methadone program) and joined PCAP in large part, she said, because she lost her children to Child and Family Services protection and wanted to get them back. For the past year she has been receiving PCAP home visits every couple of weeks "depending on how I am doing" and has attended a few group sessions. Since becoming involved with PCAP she reports being able to deal better with local service agencies; here she commented, "[PCAP] helped me to be patient with [other service providers]. Before, when I wanted something done, they didn't get it done right away and it would frustrate me. Instead, now they help me, saying, "okay we will try to get you an appointment", instead of me getting frustrated. They call me instead… Little stuff like that helps". In addition, the client noted that she has been able, with PCAP help, to access other services outside Elsipogtog such as detox, nutrition planning, a parenting course and psychological counseling. The result has been that she has her children back and reportedly is no longer depressed. PCAP has apparently been her main source of social support since she does not have a close relationship with her family; indeed she reported much conflict with family members over her children. She elaborated as follows: "They [PCAP] helped me get into detox. They come for home visits often – depends on how I am doing. If I'm doing alright, they will come every 2 weeks or a month. If I'm doing

really bad, they will come everyday if they have to". The client's changed strategy of life and her formidable challenges are captured in her closing comments

> "They [my sisters] will never be supporters… I have to accept them as they are, and do it on my own. Right now, I'm having my house fixed up. I bought a computer, TV for room… I'm gonna get a couch, and save up for a car… That's my ultimate goal, to be able to take care of my children. It's my nightmare. All the time I have this nightmare, about being stuck somewhere, not being able to get home…not having enough to… something like that. I want to be able to have enough so I don't have those nightmares, not worry about it… Right now, every month, I buy children stuff, baby stuff, so I don't have to go out… I buy it once a month so I don't have to worry about it all month".

(b) A few clients reported a quite positive though limited engagement in PCAP to date. In one case, the young woman, who became involved with PCAP just several months earlier, had had but a few one-on-one sessions or home visits and had yet to attend a group session. She was on the methadone program and had an unstable home situation but had not been involved with any other local services for any problems. In the short time with PCAP she has accessed Mental Health counseling and has had PCAP assistance in making appointments with other medical services. She has also found the "difference game" useful in identifying goals and what to work on. Overall, while still unhappy with her current housing arrangements, she now believes she has a better sense of direction and more confidence about dealing with her alcohol and drug abuse. She viewed PCAP as "a game changer", commenting

> "They help you get back on your feet; they help you get back to school or get training, make appointments or make suggestions on what I should do. They even help with getting me to appointments and babysitting."

Another client also could be described as having a positive but limited involvement. She had a drug addiction problem (is in the methadone program) and was

pregnant so was referred to PCAP by the Nurse Practitioner. In her case the PCAP involvement could be characterized as a strategic involvement in that she appeared quite content to limit her engagement to biweekly home visits by the outreach worker. Neither before nor since joining PCAP has she accessed support for her problems through local service agencies; indeed, while she said she depended very much on PCAP for support, for advice and for practical assistance including booking appointments and transportation, she also emphasized that she has close family ties and has expressly declined PCAP offers to help her access certain other local programs. Overall, the client held that her family life has really improved, that she is addressing her substance abuse issues (here she cited the value of the "difference game" as well as the support of the outreach worker) and would be open to further PCAP suggestions in accessing a parenting program. This client on the surface at least would appear to have fewer needs than most other PCAP participants interviewed. She has new, well-kept housing, appears confident and has an apparently stable relationship with her partner; the interviewer commented, "This was quite different [quite superior] from the other homes I have been in and the other PCAP women I have spoken with at the Health Centre".

(c) Three other PCAP clients could be characterized as having had limited involvement with PCAP to date (their participation ranged from four to seven months) and being but modestly impacted by the program. All three were young women (the oldest was 26), new mothers with a history of drug issues (all were in the methadone program and had been referred to PCAP by the Nurse Practitioner). All three had minimal contact with PCAP, basically limited to a small number of meetings with PCAP staff; indeed, one of the clients reported that she wanted PCAP to cut back on the home visits by the outreach worker and found PCAP staff "too strict". None of these clients reported utilizing PCAP much to get access to other local services nor, reportedly, did they secure significant assistance from such services prior to their PCAP involvement. Two clients allowed that in the past they did use the Crisis Centre (for depression and suicidal tendencies) and Alcohol and Drugs, and that PCAP had assisted them on some housing issues. Another participant identified her issues as largely "transportation and

babysitting" though she subsequently mentioned PCAP assistance in accessing a service which she declined to elaborate on.

Even though there was limited use, all three clients stated that they did appreciate the PCAP role in providing them with social support (especially through the outreach worker) and being an advocate/navigator with respect to their accessing social services and programs. One mentioned that she had no support system outside PCAP and that she appreciated that, if she calls, PCAP would make a good effort to help access services. Another client echoed that importance of PCAP social support, noting that only recently has she had a positive relationship with her mother and that she does not get along at all with her neighbours ("they always call the social worker on me for no reason"). The third client in this category reported that the PCAP outreach worker is important for her social support but added that her mother and sister have also become more supportive in her life since she joined PCAP.

All three clients exhibited some ambivalence in their assessments of the impact of PCAP on various dimensions of their lives. One client indicated that the impact thus far has largely been in causing her to think about life and what she is doing (she cited the "difference game" here for her setting goals and "realizing what is important and not so important"). Apart from that cognitive benefit, and knowing that PCAP staff are there should she need them, the client did not report any significant impact of PCAP involvement on her personal life, her parenting or her drug issues (she did not think she had a substance abuse problem) or her use of local services and programs. She was content with the service as she has engaged it, thinks more about what she is doing and where she wants to live, and likes being a mom.

The remaining two clients were more critical though still ambivalent. One indicated that she was fine in the area of parenting, accessing services and setting direction in her life, but needed more PCAP assistance with housing and material issues generally. Also, she reported that PCAP assistance with her substance abuse issues was limited because it operates on business hours and "that is not a 9 to 5 business hours kind of thing; what about support after hours? What about then"? She also questioned the alleged lack of follow-up to assess the implementation of goals / targets generated by the "difference game". Generally, she was positive about the PCAP program but contended

that PCAP lacks the necessary number of staff positions to follow through on some of their promises of help. The third client acknowledged some PCAP assistance with respect to housing repairs and related material needs but she considered that they should do much more in those areas. She was also critical of the PCAP home visits, contending that the outreach worker should do chores while she visits. She held that PCAP, like other local service providers, has not offered any helpful ideas or advice. As for her substance abuse problems, she allowed that she likes using soft drugs and "I don't think I could ever quit so why bother to try". Overall, the client sent mixed messages in the interview, complaining about PCAP but also saying that it has been helpful, supportive and has contributed to her getting along better with others. On the one hand she distanced herself from the program (e.g. does not appreciate PCAP making referrals for her to other services / programs) but, on the other hand, she wanted PCAP help on several issues. She concluded the interview by remarking that PCAP has been an important response to a widespread community problem and should be strengthened with more staff. She also stated that she would recommend the program to others in similar straits and had done so to a friend that very morning.

Overall, then, the PCAP clients valued the initiative and their nuanced assessments were congruent with the level of their engagement and the scale of their problems in Elsipogtog. Common suggestions among all categories of clients were the need for more PCAP staff and for their availability after hours and on weekends. Category (a) clients, the most active participants, frequently suggested that more awareness was needed in the community about the PCAP program and claimed that many young women are too scared to get involved because of a lack of information about the program - "any moms who are struggling and need help in their life and with their kids need to know about it". A number of clients emphasized that PCAP support was essential to their getting their children back from CFS protection and that, without PCAP, other young women would not be able to stand up to the challenges that entails (e.g., family challenges, rights vis-à-vis CFS). Several such clients also called for a wider range of cohesion-building activities for the group sessions and observed that staff shortfalls sometimes led to cancellation of the group sessions. They also suggested more babysitting type resources so they could participate even more and "so you can focus

more on the issues than [on] your children". Also, while all clients recommended the PCAP program, category (c) clients, the least engaged, rendered the more conditional recommendations; one such client said she would recommend the program to others to "get extra help if they need it", while another commented, "Yes, I would recommend it and I should have a reason why but I can't say it".

**Summary**

It seems clear from the above examination that the PCAP program has been well-received by the other service providers in Elsipogtog and by its clients. It seems to be an initiative that other service providers acknowledge is filling an important gap in the community-based prevention - diagnosis - intervention model that the Eastern Door has been developing since 2006. Everyone acknowledges that young pregnant or new mothers, in vulnerable condition because of their addiction and usually unstable family situation, need help and are a crucial link in the prevention and intervention for birth disabilities, other disabilities and learning problems. The staff is competent and confident with respect to the PCAP objectives and strategies and the clients clearly value the program. It is to the immense credit of the director of the Health Centre that she appreciated the value of the PCAP program and arranged for its funding in Elsipogtog, and to the management of the Eastern Door that PCAP has been well-implemented in Elsipogtog, far better according to federal and provincial authorities than in other New Brunswick FNs. The PCAP program has followed the successful Seattle Washington model in its emphasis on a harm reduction philosophy, long-term commitment to clients, strict eligibility criteria and protocols, and an insistent, active outreach strategy for referring and navigating clients through the various services and programs available in Elsipogtog and beyond.

There are some issues and challenges. The ratio of staff to client caseload is not out of line with standards elsewhere but administrative backup is problematic (i.e., no designated secretarial assistance) as are infra-structure type considerations such as cell phones, transportation allowance and so forth. There may be, because of these shortfalls, a negative implication for monitoring the impact of the program on the clients. That monitoring and internal assessment is a central feature of the PCAP program as

developed in the U.S.A. but appears weakly developed in Elsipogtog (e.g., monitoring the ASI measure over time, determining what variables to obtain longitudinal measures on). There has been some criticism from some other local service providers that PCAP staff members smother clients with attention and intervention (e.g., transporting them to meeting with other local service providers) and, in these ways, perhaps some difficulty in appreciating the PCAP outreach approach. However, it does appear that the conventional support and services system in Elsipogtog was not being utilized effectively by the young women. Another issue is the potential problem of staff turnover. As both the PCAP staff and the clients have indicated, building a relationship and establishing trust takes time and is pivotal to the clients accepting the challenge of taking control of their lives. There is little doubt about the significance of these factors and other challenges but then the potential gains can be great and trans-generational too.

Another major concern of course is how effective the program is with the young women. On the one hand, there is evidence of continuing addiction problems and both multiple drug use and unstable home situations. On the other hand, there are many indications from the clients that there has been a significant positive impact for them, such as being able to keep or get back their babies, more confidence in relating to other local service providers, and, remember, the program has only been in existence a little over a year. It will be important to measure change and other objectives of the program such as the extent to which the clients make better use of the local services and programs available to them.

The PCAP approach underlines the value sometimes of a “parallel process” model rather than a “wraparound” model. In the latter, a team of professional and / or expert practitioners meets to deal with a client or problem, melding their insights into an effective package of interventions (e.g., the S.O.S. and Child Development Program referred to elsewhere in this assessment). In PCAP, the staff members advocate and navigate for their clients with the different, other service providers and agencies. One area then, worthy of consideration, is better networking with the other service providers by both the PCAP staff and the clients. Significant outreach has to be balanced by an appreciation of others’ mandates and organizational philosophies as well as their own. Staff members have to be skilled at mediation and dispute resolution in order not to rouse

opposition needlessly. The Apigsigtoagen approach pioneered in Elsipogtog may well provide an additional, effective orientation for staff members. Similarly, the motivational interviewing and difference game approaches used in PCAP might well include, if they do not now, how clients relate to the service providers; again, it would be important that PCAP staff members do not lose credibility with local service providers by being dragged into conflict by ill-advised strategies used by their clients. After all, PCAP cannot and does not provide the services and programs that the clients require. It needs the full collaboration of these other players given the great challenges being faced.

## INTEGRATION AND COLLABORATION AMONG LOCAL SERVICES AND AGENCIES

### Introduction

Integration and collaboration with other local service providers was a central objective of the AHTF Eastern Door project. Indeed, the first full-time coordinator defined his main tasks as enhancement of these linkages and building community capacity. The Eastern Door's success as a community-based model for dealing with birth disabilities and related developmental and learning problems essentially hinged on these networks since, outside the school context, the Eastern Door services were largely referral and advocacy (i.e., outreach) for clients vis-à-vis other professional service providers in Elsipogtog and beyond. The AHTF coordinators spend considerable time meeting with various service providers (management and staff members), informing them about the Eastern Door, distributing pamphlets and dropping off questionnaires for them to complete and return. The latter represented an exploration as to where the local service providers stood in their awareness of FASD and birth-related problems, their views about the prevalence of these problems in Elsipogtog, and their knowledge of the Eastern Door services, how these services worked (their mandate and protocols) and how others could refer cases to the Eastern Door. The coordinators also attended meetings of the "wraparound" interagency structures that were established to target possible intervention in the school context (i.e., the SOS program) and outside it (i.e., the Early Childhood Development program for pre-schoolers). Overall, they found that their reception improved over time and that the different explanatory (causal) models) and priorities did not preclude collaboration. Perhaps the biggest issue reported was the diversity in views concerning the unusual insistent outreach of the PCAP and Family Support program staff.

In this assessment the focus has been on the views and engagement of service providers, not the community-wide views about the Eastern Door. A community survey of all EHWC services was conducted in 2009, something that the EHWC occasionally does. The survey data on the Eastern Door was not broken down by users / non-users though it was clear that there were three times as many non-users responding. Also, the survey did not break down the Eastern Door results by specific service (e.g., PCAP,

Family Support). Still, there were some interesting patterns found. There were concerns indicated in the community sample about the need to maintain confidentiality for the clients, a concern that the survey director indicated was common for EHWC services that dealt with "personally challenging areas". There was also a high level of satisfaction ("among the highest of all EHWC programs") recorded in the community sample by those who used the Eastern Door services. A third pattern was the relatively large proportion of respondent who identified the barriers of transportation and child care as impediments to their using the Eastern Door services. Fourthly, more so than in the case of other EHWC services, respondents identified as an organizational barrier to their use, the times the services are offered (i.e., 9 to 5, weekdays only) as a concern. As will be noted elsewhere, these issues were also prominent in the interviews with PCAP and Family Support clients. On the whole, the community survey yielded quite positive assessments of the Eastern Door and given the "good word-of-mouth" assessments reported by the Eastern Door staffs and their clients, one could reasonably expect even better community assessments in the future.

The following analyses deal with information obtained from questionnaires returned to the AHTF coordinator by staff members of the Elsipogtog local service agencies, band council representatives, and administrative officials. The questionnaires were generated at various times over a year and a half, from the summer of 2008 to the fall of 2009. The quality of response was quite uneven, as is common in such a "drop-off and pick-up" format. The samples of the different services' staffs are best seen as samples of interest which provide an interesting snapshot of the views of agency's members of all ranks. Table One provides a tabular overview of all the responses slightly modified from that developed by the AHTF coordinator in April 2010. It is provided here for interest only. The questionnaires used by the AHTF coordinators varied somewhat and were completed sometimes in 2008 and more often in 2009, and these circumstances limit their value when presented as an aggregate. Accordingly, more detailed analyses by type of local service and taking into account different services' questionnaires and the dates of completion were required. Such analyses follow the table immediately below. Perhaps the key point about the aggregated data was that everyone agreed that drinking alcohol of any amount during pregnancy was dangerous and a large number (77%) of the

respondents considered that women who do so, should be forced into treatment in order to protect the fetus / baby. Other salient statistics include (a) 80% of the respondents held that FASD was a problem in Elsipogtog and (b) 70% reported that they had in the past at least one client who they suspected of having FASD.

## ***Table One****

## ***Professionals Attitudes and Knowledge Regarding FASD***

These are the tabular depictions of survey data that was collected in Elsipogtog during the several "environmental scan" conducted throughout the AHTF project. The survey was given to members of various Elsipogtog agencies including Education, Child and Family Services, Home and Community Care, Mental Health, Crisis Centre, Chief and Council, Justice, RCMP, Nursing and the Eastern Door Centre. The far-right column gives the number and percentage for yes and no answers.

1. When did you first hear of FASD - related birth disorders?

| | | |
|---|---|---|
| a | within last 2 yrs | 6=11% |
| b | 3-4 yrs ago | 0=0% |
| c | **more than 4 yrs ago** | **47=87%** |
| d | never heard of it | 1=2% |

2. From what source?

| | | |
|---|---|---|
| a | mass media | 9=17% |
| b | **training, seminar, workshop** | **29=55%** |
| c | **Elsipogtog contacts** | **31=59%** |
| d | other | 13=25% |
| e | never heard of FAS | 1=2% |

3. Have you ever?

| | | | |
|---|---|---|---|
| a | been informed any clients had FASD | y- 28=55% | n- 23=45% |
| b | **suspected that any client might have FASD** | **y- 35=69%** | **n- 16=31%** |
| c | sent a client for FASD diagnosis | y- 2=4% | n- 48=96% |
| d | modified your practice because you suspected a client might | y- 16=34% | n- 31=66% |

| | have FASD | | |
|---|---|---|---|
| e | sought assistance of trained support person to assist you or your agency on how to respond to a client who might have FASD | y- 22=45% | n- 27=55% |

4. What measures could you take if you suspected a client had FASD or a related problem?

| a | **refer** | **16=43%** |
|---|---|---|
| b | consult with doctor or nurse | 4=11% |
| c | get training | 3=8% |
| d | consult with Eastern Door | 6=16% |
| e | consult with educational psychologist | 1=2% |
| f | make appropriate intervention | 3=8% |
| g | don’t know | 1=2% |
| h | nothing | 2=5% |

5. Could you---

| | | **yes** | **no** | **unsure** |
|---|---|---|---|---|
| a | delay intervention until there was an FASD diagnosis | 9=20% | 19=41% | 18=39% |
| b | directly request an FASD diagnosis for the client | 22=48% | 11=24% | 13=28% |
| c | **talk with a colleague very knowledgeable about FASD** | **40=85%** | **1=2%** | **6=13%** |
| d | change the service provided to the client | 18=42% | 10=25% | 15=35% |
| e | discuss the matter with a supervisor | 40=85% | 2=4% | 5=11% |
| f | ask the client directly if he/she had FASD | 12=26% | 18=39% | 16=23% |
| g | try to find out whether there is FASD diagnosis | 31=66% | 5=11% | 11=23% |

6. Could there be any physical indicators to suggest a person may have FASD?

| **Yes** | **40=76%** |
| --- | --- |
| No | 3=6% |
| unsure | 10=19% |

7. Could there be any behavioral indicators to suggest a person may have FASD?

| **Yes** | **43=83%** |
| --- | --- |
| No | 1=2% |
| unsure | 8=15% |

8. What is the leading non-genetic birth disability in Canada?

| Down syndrome | 7=15% |
| --- | --- |
| Cystic fibrosis | 2=4% |
| Spina bifida | 1=2% |
| **FASD** | **37=79%** |

9. What is the incidence of FASD in Canada?

| 0.05% | 1=2% |
| --- | --- |
| 0.5% | 4=10% |
| 1% | 15=39% |
| **2%** | **19=49%** |

10. What is the proven prevalence of FASD in some First Nation communities in Canada and US?

| 0.05% | 1=2% |
| --- | --- |
| 0.5% | 3=7% |
| 1% | 3=7% |
| 2-10% | 12=29% |
| **11-20%** | **22=54%** |

11. What % of women in Elsipogtog disclose their drug/alcohol use either before they know they are pregnant or after?

| | |
|---|---|
| <1% | 2=4% |
| 1-5% | 5=11% |
| 6-10% | 7=15% |
| 11-33% | 9=19% |
| 34-50% | 11=23% |
| **>50%** | **13=28%** |

12. What is the actual prevalence rate of FASD in Elsipogtog?

| | |
|---|---|
| 0.05% | 4=10% |
| 0.5% | 4=10% |
| 1% | 2=5% |
| 2-10% | 16=39% |
| **11-20%** | **15=37%** |

13. In the last few years has alcohol use during pregnancy

| | |
|---|---|
| **Increased** | **20=45%** |
| decreased | 15=34% |
| stayed the same | 9=21% |

14. Do you think it is safe for women to use alcohol when they are pregnant?

| | |
|---|---|
| Yes | 1=2% |
| **no** | **49=98%** |
| unsure | 0 |

15. How many alcoholic drinks would be safe to consume during pregnancy and at one time?

| | |
|---|---|
| **None** | **50=100%** |
| 1-2 | 0 |
| 3-4 | 0 |
| 5 | 0 |

| 6 | 0 |
|---|---|

16. Do you believe that

| | agree | disagree | uncertain |
|---|---|---|---|
| **FASD is a problem in the community** | **42=80%** | **10=20%** | **0** |
| **Women who continue to drink during pregnancy should be forced into treatment** | **40=77%** | **3=6%** | **9=17%** |
| FASD does not exist | 3=6% | 47=90% | 2=4% |
| FASD is an excuse for bad behavior | 4=8% | 46=89% | 2=4% |
| FASD should not be discussed as it will give the Community a bad name | 1=2% | 50=98% | 0 |
| FASD will just label people | 1=2% | 48=92% | 3=6% |
| **FASD can be a risk factor for youth crime** | **43=86%** | **2=4%** | **5=10%** |
| FASD can be a risk factor for suicide | 39=77% | 5=10% | 7=13% |

17. How would you rate your agency in terms of preparedness for dealing with clients who have an FASD related condition?

| Don't know | 11=24% |
|---|---|
| Very unprepared | 3=7% |
| Unprepared | 9=20% |
| **Prepared** | **14=30%** |
| **Very prepared** | **9=20%** |

18. What would you like to see your agency improve regarding FASD issues?

| | Unsure | not at all | some | much |
|---|---|---|---|---|
| More information | **-** | 1 | 16 | 32=65% |
| Agency guidelines on FASD | 1 | 2 | 20 | 25=52% |
| Practice guidelines on FASD | 2 | 2 | 20 | 24=50% |
| **Workshops by FASD experts** | **1** | **2** | **12** | **32=68%** |
| More personal training on FASD | - | 3 | 17 | 28=60% |
| Information about how to screen | 2 | 4 | 20 | 21=44% |
| Referral process in agency | 3 | 1 | 18 | 25=53% |
| Screening process in agency | 3 | 5 | 18 | 21=44% |

19. Are you familiar with the services of Eastern Door?

| **Yes** | **32=68%** |
|---|---|
| no | 12=26% |
| unsure | 3=6% |

20. Are you familiar with how to refer a client to the Eastern Door?

| **Yes** | **21=45%** |
|---|---|
| no | 17=36% |

| unsure | 9=19% |
|---|---|

21. Do you think that it is safe for women to drink when they are pregnant?

| Yes | 1=2% |
|---|---|
| **no** | **45=98%** |
| unsure | 0 |

22. Which one of the following best describe FASD in your opinion:

| a | **a chronic medical condition like diabetes that should be dealt with in the same way in terms of screening, diagnosis and treatment** | **38=73%** |
|---|---|---|
| b | a curable physical illness | 1=2% |
| c | a label that has actually little to do with a person's condition | 2=4% |
| d | do not know | 11=21% |

23. Would any of the following be a reason why a woman may not disclose alcohol use:

| a | ashamed---denial | 38=72% |
|---|---|---|
| b | **afraid of what other people might think** | **38=72%** |
| c | don't think alcohol harms baby or affects behavior | 30=57% |
| d | addicted to alcohol and drugs | 36=68% |

24. Do you think any of the following might be a factor in why women drink when they are pregnant:

| a | they don't think it harms the baby | 23=43% |
|---|---|---|
| b | they drink before they know they are pregnant | 34=64% |
| c | **they have drinking and drugging problems and they can't stop** | **41=77%** |
| d | they have serious mental problems due to trauma and drink to self medicate | 33=62% |

25. What could be done in the community to help reduce drinking and drugging during pregnancy?

| | | |
|---|---|---|
| a | More education in the school about effects of alcohol and drugs | 36=68% |
| b | more information given to young women by nurses and doctors | 41=77% |
| c | more screening of women by nurses and doctors for problem drinking | 41=77% |
| d | more referral to by nurses and doctors to drug and alcohol treatment | 37=70% |
| e | more training of professionals | 37=70% |
| f | birth control information for women who have alcohol and drug problems | 40=76% |
| g | long term drug and alcohol treatment for pregnant women where they can take their other children with them | 38=72% |
| h | **more counseling for women's problems that may be the root of the drinking for sexual abuse or PTSD** | **44=83%** |
| i | **Family support programs to help young families with alcohol and drug problems** | **47=87%** |

*Adapted from the report by Kirk O'Neil, AHTF Co-ordinator, 2010

## Detailed Analyses by Type of Local Service

### Health Professionals in Kindred Social Services

Six **Child and Family Services (CFS)** respondents filled out the questionnaire, Professional Attitudes and Knowledge Regarding FASD, three in April 2009 and three in November of the same year; given the anonymity of the questionnaire it is impossible to know how much overlap there was in the respondents. In the earlier period the CFS personnel varied in their assessment of the adequacy of their previous knowledge of "FASD and related developmental disorders" (the questionnaire item). All three sought more specific knowledge such as "what does the diagnosis mean … how does it help the child"; "what services are there in the community to help the parent learn how to parent or the child in school"; "how does it relate to child protection". Asked about four components of Eastern Door work, namely PCAP, Family Support, Diagnosis, and School Child Support, the CFS respondents reported little contact with or awareness of any of them; instead they raised questions about how each was being implemented (e.g., "does the parent understand the full impact of the diagnosis and what help is available to them and their children"); as one CFS staff member stated, "It is not cool to give a diagnosis and then not have the resources to give to the family afterwards". The general concern of the respondents, consistent with their emphasis on child protection was "resources and training in how to parent FASD".

In the second period, all CFS respondents indicated an awareness of FASD-related birth disorders, derived from their professional training and workshops. All indicated that they had had clients they suspected might have FASD and two of the three reported they had modified their practice on that basis or traded suggestions with other CFS staff members to that effect. All also indicated that they could take a variety of actions in response to a suspected FASD client, including requesting an FASD diagnosis if one had not been carried out. All three CFS respondents also identified facial (e.g., small eyes, thin lips) features and behaviours (e.g., low intelligence, short attention span) which they considered would be characteristics of FASD clients. The respondents all considered FASD to be the leading non-genetic birth disability in Canada and to be a

major problem in Elsipogtog. They all considered that alcohol was not safe to drink for pregnant women but none held that women's drinking during pregnancy had declined in recent years. Here they agreed that, in the majority of cases women do not disclose their alcohol drinking during pregnancy even when it may be clear that their child has serious problems, for a variety of reasons, including shame, strong addiction and the like. Two of the three respondents considered that their service was prepared to deal with clients who have an FASD condition. Still, they all generally held that the service or agency could "much" improve its service concerning FASD issues in virtually every way (e.g., more information, professional training on FASD etc).

All reported that they were familiar with the Eastern Door programs and how to refer clients to them. There was consensus as well that educational programs on FASD across all community services, counseling and programs for pregnant women, and enhanced family support systems were required to deal with the problem. Overall, then, the questionnaire data at two time periods indicated positive change in awareness of Eastern Door service and a consensus about the FASD message and premises. What the CFS respondents held to be needed to deal with the problems of birth disabilities and drinking and drug abuse was what the Eastern Door was doing in linking solid diagnosis with specific intervention / treatment plans and prevention strategies that involve both the community at large and the health professionals.

To protect anonymity, the questionnaire responses of **Mental Health** (3) and **Nurses** (2) are lumped together for analyses. With one exception, all of these questionnaires were completed in the second half of 2008, prior to the PCAP initiative at the Eastern Door. The nurses and the Mental Health professionals all reported a long-standing awareness of the FASD-related birth disorders, derived from professional training and local Elsipogtog contacts. They had been informed of clients with FASD and suspected others of having it. About half had altered their practice in relating to a client based on that evidence (e.g., a nurse said "I changed how to approach the client"). With one exception, these five respondents also reported that they could take a complete range of responses to a client with or suspected of being FASD, including requesting a diagnosis and changing the type of service provided to the client. But they were quite split on whether it would be appropriate to ask the client directly if he or she had FASD.

The respondents identified essentially the same facial features and behaviours as evidence of FASD as did the CFS sample and, like them, held that FASD was the leading non-genetic birth disability in Canada and a major problem in Elsipogtog where prevalence of FASD was considered to be between 2% and 10%. The Mental Health participants exhibited less consensus about the physical and behavioural correlates of FASD but suggested its prevalence in Elsipogtog could be as high as 20% (presumably of the births though the questionnaire item is somewhat ambiguous on the standard used). Both nurses and one of the Mental Health respondents held that drinking during pregnancy had increased "in the last few years" in Elsipogtog. Of course all respondent denied that it was safe for women to drink when they were pregnant even if but one drink. The nurses differed from the Mental Health respondents holding that their service or agency was unprepared to deal with clients who have an FASD condition; all the latter considered that their service was prepared or very well prepared to do so. Congruent with that difference, the Nurses reported themselves unsure about the services of the Eastern Door and how to refer clients there for diagnosis or intervention whereas all the Mental Health members expressed familiarity and awareness on both counts. The nurses and Mental Health respondents shared the consensus of the CFS representatives in contending that educational programs across all community services, counseling and programs for pregnant women, and family support systems were required to deal with the problem. Overall, the results were quite similar to those of the CFS sample but there were some differences between the nurses and the Mental Health respondents with respect to their knowledge of Eastern Door services and their own state of preparedness to deal with FASD issues (the Mental Health respondents were more confident).

**The School, Crisis Centre, Home Care and Justice Agencies**

Six respondents, interviewed in the summer of 2008, were employed as service providers with the **Crisis Centre** which deals with a wide range of calls for help, especially from people (or others on their behalf) threatening self harm . All stated that they have been aware of FASD-related birth disorders for some time (i.e., they selected the highest possible category namely, "more than four years"). Unlike the Health Professionals, their information reportedly was based on local Elsipogtog contacts, not

professional training (only two had university degrees). Most had only suspected a person might have FASD and had never been informed that a client did indeed have it nor did they ever make a referral or alter their practice because of any suspicion. They were also unsure about what measures they could adopt if they had such knowledge of a client's situation; the core responses here were "discuss it with my supervisor" and "refer the matter to the proper agency qualified for it". While most respondents did advance some suggested physical (e.g., facial signs such eyes and lips) and behavioural (e.g., short attention span) correlates of FASD, there were many "unsure" responses about the optional indicators suggested in the questionnaire. Half the participants held that FASD was the leading non-genetic birth disability in Canada and the others suggested other conditions such as Cystic Fibrosis. They were typically unsure about the prevalence of FASD in Elsipogtog and gave widely varying responses. However, all the Crisis Centre participants agreed that it is not safe for women to drink when they are pregnant, whatever the amount.

They mostly agreed that FASD was a problem in Elsipogtog but there were a few who were uncertain. All but one of the Crisis Centre participants approved that women who continue to drink during pregnancy should be forced into treatment to protect the baby. There was consensus too that FASD can be a risk factor for youth crime and for suicide. Generally, the Crisis Centre participants indicated that "we deal with anyone the same and the [underlying] conditions are not factors until an assessment is made by appropriate referrals". The majority held that their agency was not prepared to deal with clients who have an FASD condition and that "there hasn't been any training workshops as far as I know". Only two of the respondents indicated that they were familiar with the services of the Eastern Door and none was aware of how to refer a client to any of the Eastern Door's programs. There also was no consensus on whether women's drinking during pregnancy had changed in Elsipogtog in recent years nor as to why women drink when they are pregnant Most respondents did believe that, in a majority of cases, women would be reluctant to disclose that they had consumed alcohol during pregnancy even in the face of their child having serious problems in school; they would be ashamed and fearful of public censure. The respondents agreed that much more information about FASD needed to become widespread in the community and especially be communicated

to clients by the service providers. Some suggested more talking circles on the topic and others called for FASD training programs for themselves.

Overall, then, the Crisis Centre staff was less professionally trained and less likely to be familiar with Eastern Door programs or to believe their organization was prepared to deal with FASD cases. The lack of familiarity with Eastern Door programs would be very likely to have changed for Crisis Centre staff members when the PCAP program was initiated in January 2009 since indirect evidence strongly suggests that young, addicted and troubled mothers – the core PCAP target group - disproportionately call upon the services of this agency.

Five **Elsipogtog school staff** returned questionnaires in May – October 2009. These persons, ranging in rank from top administrator to teaching assistant, reported a long-time awareness of the link between alcohol use during pregnancy and FASD damage to the fetus / baby. They considered that drinking, drug taking and smoking were indeed being done by pregnant women in Elsipogtog and identified the usual factors for this usage as cited above by other respondents (e.g., they are addicted, don't believe it will harm the baby and so forth). Underlying factors causing young women to abuse alcohol and drugs, such as previous sexual abuse and family instability, were deemed to be very important in Elsipogtog. The school respondents also indicated there were some services available to help those affected by FASD but, somewhat surprisingly given the roots and focus of it, only one mentioned the Eastern Door as such. They all emphasized the highest need for more training, education and special school programs for those children with FASD conditions, and more family support. Some obstacles were also identified to the greater use of local services such as "confidentiality is not used in some cases which is why they [the parents] don't seek help" and "diagnosis is not the cure but that seems to be where it ends for these children [with FASD conditions]". The school questionnaires were quite incomplete and permitted no further analyses.

There were six usable questionnaires returned from personnel in the **Home Care Community Program (HCCP)**. None of these respondents had post-secondary education but most had been employed at HCCP for more than five years where they typically assisted the householder in cleaning and other home care activities. In three cases the questionnaires were completed in July 2008 and, in the other three instances, in

November 2009. The 2008 sub-grouping reported a long-term awareness of the link between consumption of alcohol and FASD damage to the fetus / baby, derived essential from local Elsipogtog contacts (i.e., not workshops or professional training). There were all quite unsure of what if anything they could and should do if their client's household was impacted by FASD. Indeed, they were generally unsure about anything relating to FASD, such as its prevalence in Elsipogtog, its physical and behavioural correlates, whether drinking during pregnancy is increasing or decreasing, whether it constituted a major problem in Elsipogtog, and what services were provided by the Eastern Door. These respondents did think that FASD is the leading non-genetic birth disability in Canada and that no amount of drinking during pregnancy would be safe. While they varied in their estimates of how many women who drank during pregnancy would not disclose that fact subsequently when the child was having trouble in school, they agreed that those not disclosing likely were ashamed and feared public scorn. As to why women would drink during pregnancy, it was generally held that they would have an addiction problem and "can't stop". One respondent added, "They still want to have fun and do not want to be tied down". They believed too that women who continue to drink during pregnancy should be forced into treatment to protect the baby. The three respondents held that more information and awareness about FASD is necessary as well as counseling for young women and family support programs.

The three HCCP staff members completing the questionnaire in November 2009 – subsequent to PCAP and a more active outreach from the Family Support team – were generally better informed about the Eastern Door and FASD. They indicated that their awareness of the alcohol-FASD linkage was derived from workshops and professional training. All were familiar with the services offered by the Eastern Door though, understandably uncertain about its protocols for referral. Like their 2008 counterparts they were quite uncertain about what measures they could or should take if they were informed or suspected that FASD had impacted a client's household; here their basic response for acting on suspicion of FASD was "contact a local nurse". The three 2009 sub-group respondents had quite diverse opinions about the prevalence of FASD in Elsipogtog but two of the three held that drinking during pregnancy was on the increase and all believed that FASD was a major problem for the community; indeed, they shared

the view of their 2008 counterparts that women who continue to drink during pregnancy should be forced into treatment in order to protect the baby. They also shared the views of the 2008 sub-grouping as to why women would not disclose such drinking and, more generally, the need for more communications about the impact of drinking and drug taking during pregnancy, more counseling for young pregnant women and more family support. Overall, then, the HCCP questionnaires completed in late 2009 indicated greater awareness of the Eastern Door services and of FASD than did those completed in 2008.

There were a large number of questionnaire returned from persons engaged in the justice sector, whether RCMP or in Elsipogtog justice programs such as the restorative justice agency. Six **RCMP** members completed the questionnaire, all but one in the summer of 2008. All but one of the officers was male and non-Aboriginal. The RCMP members were divided in their awareness of FASD, with half reporting that they had become aware of it only in the past two years. All participating officers noted that they had been informed that someone had FASD and four of the six stated that they had suspected other community members they dealt with of having it. Half the officers in fact indicated that they had altered their standard practice in dealing with a person reportedly having FASD (unfortunately no information was provided on the nature of the modification). The respondents also reported that in dealing with a presumed FASD disabled person, their basic response would be to consult with their supervisor. The officers were unsure of the physical correlates of the FASD conditions were (two did suggest small eyes, thin lips and small heads) but more readily identified behavioural correlates such as anger management and short attention span. The officers generally held that FASD was the leading non-genetic birth disability in Canada but they provided quite different estimates of the extent of the problem in Elsipogtog (from 2% to 20%). They all held that it was not safe for women to drink alcohol during pregnancy. Most but not all the RCMP members considered that FASD was a problem in Elsipogtog but with one unsure, they all agreed that it generated risks for the children and youths affected and that women who drink during pregnancy should be forced into treatment in order to protect the baby.

Most RCMP participants indicated that they were unsure if their organization was prepared for dealing with a significant FASD problem. Some pointed to a lack of

understanding and processes / protocols whereas others contended that police professionalism required equal treatment for all persons – “in our service we must treat them the same as anyone else”; “almost all the people we deal with have substance abuse problems”. Half the members called for more information and guidelines while others did not think the organization had any special needs with respect to dealing with FASD conditions. Only half the RCMP respondents were aware of the Eastern Door services at the time and even fewer knew how to refer people to those services. The officers considered that most women who consumed alcohol during pregnancy would be reluctant to acknowledge it even if their child was a problem in school or in the community, basically because they would ashamed and also because they may not think that it harmed the fetus / baby; as one stated, ”because they haven’t dealt with issues from past traumas”. All but one of the RCMP members held that a wide variety of things should be done to reduce drinking and drug taking during pregnancy including more community communications, more information provided to young women by the Health professionals, counseling to get at the roots of the women’s problems, and family support. Several officers contributed additional comments; one officer wrote

> “Need to try and take a drastic step in limiting supply or making the reserve a dry reserve. Substance abuse is the number one problem and it has been toyed with for too long. People are being killed. It should be taken to the extreme measure of eliminating the things that cannot be controlled”.

Five staff members associated with **Justice programming** in Elsipogtog – all five were females and band members – completed their questionnaires in November or December 2009. Four of the five reported a long-standing awareness of FASD-related birth disorders based on information from local contacts and secondarily professional training / workshops. Most reported having been informed that a client may have an FASD condition or themselves suspected it; several followed up on that information or suspicion by altering their standard practice for dealing with a client and / or by seeking the assistance of a trained support person in their dealings with the client. While no Justice participant reported that she could directly request an FASD diagnosis, several did

indicate that, where there was any inkling of FASD, they might consult with others about possible actions. Most respondents were uncertain about the physical or behavioural correlates of FASD. They was agreement among them that FASD was the leading non-genetic birth disability in Canada but much diversity in their estimate of its prevalent in Elsipogtog. All the Justice participants considered that it was not safe to consume any amount of alcohol during pregnant and most considered that that message was sinking in among young women as women's drinking during pregnancy had decreased in Elsipogtog in recent years.

The Justice participants were divided about whether or not FASD was a problem in Elsipogtog but most agreed that it could be a risk factor for youth crime and suicide and three of the five held that women drinking in pregnancy should be forced into treatment to protect the baby. The respondents mostly considered that their service was unprepared to deal with clients who have an FASD condition. One woman stated "We have never trained yet" while another commented "They definitely have clients who have an FASD condition and with more information and training they can better serve their clients". All respondents considered that more information about FASD and workshops on the topic could help improve their service's appreciation of FASD issues. All but one of the Justice participants indicated that they were familiar with Eastern Door services and how to refer to its various programs. They shared consensus that women who have consumed alcohol during pregnancy would usually be reluctant to disclosure the information when their child was having problems in school or elsewhere, essentially because they would feel ashamed or because they were still addicted. There agreed too that women drink when they are pregnant for a variety of reasons, including addiction, serious mental problems, ad not thinking that such consumption harms the fetus-baby. All the respondents shared the view that much more needed to be done in the community to reduce drinking and drug abuse during pregnancy – especially information about their effects, greater involvement of health professionals, counseling for the young women and family support programs. One respondent wrote: "All agencies do work collaboratively but they need more education and understanding about it [FASD-related disabilities] and on how to refer [cases]". Overall, then, the Justice respondents expressed diverse views but a majority of police and non-police considered that their organization was not week-

prepared to deal with "clients" who had FASD conditions and, unlike some other services' respondents, there was more uncertainty about the propriety of treating them differently.

**Band Council Members and Band Administrators**

Nine band council members and nine band administrators also completed the questionnaire. The former did so in November 2009 subsequent to a major presentation provided them by Eastern Door staff. The latter, the band administrators, mostly completed their questionnaires in 2008. The participants in the two grouping different quite sharply in their awareness of the Eastern Door programs and in their enthusiasm for them, but that may largely be accounted for by the political leaders completing their questionnaires both a year later (i.e., a full year of communication and networking by PCAP and Family Support staffs) and after the extensive presentation by Eastern Door personnel.

All but one of the **nine council members** who completed questionnaires stated that they had long appreciated the FASD issue, generally drawing upon professional training (workshops) and local Elsipogtog contacts. About half the respondents had suspected a person might have FASD or been so informed and subsequently sought out the views of a more knowledgeable person. They varied much in what course of action they believed they could take if they had confidence about a "client's" FASD condition but only two held that there was nothing they could do. The political leaders were split almost evenly over whether there were physical correlates of an FASD condition, the two most popular features noted were small eyes and thin lips. They were in greater agreement on the likely behavioural correlates, especially highlighting short attention span and problems with anger management. There was virtually complete consensus that FASD was the leading non-genetic birth disability in Canada and that it was never safe for a woman to drink alcohol during their pregnancy. The majority of these participants believed that between 10% and 20% of the Elsipogtog babies were affected by the FASD condition. A majority also held that women's drinking during pregnancy had declined in recent years in Elsipogtog but seven of the nine held that it is still a significant community problem (the other two were wrote "not sure") and that FASD constitutes a

risk factor for youth crime and suicide. Two-thirds of this sub-group agreed that if a pregnant woman continues to drink during pregnancy she should be forced into treatment for the protection of the fetus – baby.

The political leaders stood out from most other sub-groups participating in the survey in their strong praise for the Eastern Door programs. Eight of the nine reported that there were familiar with the services of the Eastern Door and a majority claimed also to be familiar with the referral policies and protocols. They generally considered that Elsipogtog was indeed prepared to deal with FASD issues, using adjectives such as fantastic, excellent, great; one respondent, for example, wrote "Very good, very proud of the [Eastern Door] people that are involved; they are doing a good job". The respondents offered some explanations for women not disclosing their earlier drinking during pregnancy when confronted with a child's subsequent seriously inappropriate behaviour in school, that were similar to those of respondents in other sub-groups (e.g., ashamed, addicted still) but they noted too the women's fear of their child and themselves being labeled; as one wrote, "[they fear] they will have a life-long label and so automatically will the children". The majority also held that women drink during their pregnancy for a variety of reasons, ranging from lack of knowledge to serious mental problems but the number one reason was deemed to be "they're addicted and can't stop". They called for continued community effort, more communications by health professionals, help to pregnant young women, counseling and family support. Several respondents concluded their questionnaire task with a statement such as this one, "very grateful to have this program. Thank you. Job well done".

The nine respondents involved in the **band administration** completed their questionnaires in 2008 prior to much Eastern Door activity such as write-ups in the community newspaper and the launching of PCAP. Like their political counterparts, the band administrators stated that they had been aware of FASD issues for some time, essentially based on information provided by local contacts; none cited professional training or workshops as the basis for their knowledge. The majority also reported that they had neither been informed about some resident they dealt with having FASD nor did they ever suspect it in a person. If the matter of a person having FASD came up in the course of their work duties, most band administration participants indicated that they

were either unsure as to what to do or consult a knowledgeable person. There was significant uncertainty too about any physical or behavioural correlates of an FASD condition but several respondents did mention facial features such as small eyes and thin lips, and behaviours such as readiness to anger and a short attention span. Only a third of these respondents considered that FASD was the leading non-genetic birth disability in Canada and a majority of those willing to provide an estimate of FASD rate in Elsipogtog selected the lowest category (0.5%) among the options offered to them.

Still, with one exception, all these respondents considered that FASD was a problem in Elsipogtog, that it was a risk factor in youth crime and suicide and that women who drink during pregnancy should be forced into treatment. They were unsure whether their organization or service was prepared to deal with FASD issues and believed that more information and orientation workshops would be helpful. Only one of the nine band administration respondents reported that he or she was familiar with the services offered by the Eastern Door or with the referral procedures to its programs. The respondents most often stated that only some of the mothers who had consumed alcohol during pregnancy would be unwilling to disclose that information at the expense of their child obtaining the pertinent diagnosis and treatment. In answering a question about why women drink when they are pregnant, the respondents acknowledged the usual factors such as mental problems, lack of awareness of the connection between drinking and FASD effects and so on, but several added that depression and fear of rejection were important; one respondent wrote "to fit in with the crowd", while another stated "they get depressed and afraid that they will be alone". In conclusion, in addition to more information, especially from health professionals, they called for more community support for young women, more counseling and family support. Overall, the elected politicians had much praise for the Eastern Door and because of it held that Elsipogtog was prepared to deal with the very pressing FASD issues it faced. Band administrators, on the other hand, completed their questionnaires a year earlier in 2008 and without the benefit of workshops or presentations and their views were quite different, holding that there was a low prevalence of FASD in Elsipogtog and being largely unaware of the Eastern Door services that it provides.

**Eastern Door**

There were five questionnaires completed by Eastern Door staff members in the fall of 2009. Not surprisingly, they exhibited much consensus concerning the high prevalence of drinking, drug taking and traumas among young women, the high rates of FASD in Elsipogtog, the physical and behavioural correlates of the FASD condition, and the extent to which FASD is a major problem. They concurred of course that no amount of alcohol consumption in early pregnancy is safe. The respondents held that it was quite common for females to be reluctant to disclose their alcohol use during pregnancy and thus not have their child referred for FASD diagnosis even when the child has significant trouble in school and elsewhere, basically because they are ashamed and addicted. One staffer commented, “There is a tremendous amount of guilt and grief among the moms associated with this problem. There is also a lack of information in the general public which results in the judging of the young moms”. The ED respondents considered that women drink when they are pregnant basically because “they don’t know they are pregnant”; “they have an addiction problem and cannot stop”, and “they suffer from mental health issues”. One respondent commented, “It’s a cultural norm. They are unaware of the harm, unaware of the pregnancy, and addiction is not reversible when you are already pregnant”. The ED staffers were split on whether women who continue to drink during pregnancy should be forced into treatment to protect the baby.

The respondents all considered that the Eastern Door was achieving its objectives and contributing much to attenuating the problems identified; one proudly wrote, “the Eastern Door is a model for services and agencies in Elsipogtog and for all other agencies dealing with FASD outside the community”. Still, they held that more community education about the implications of drinking, smoking, drug taking substance abuse during early pregnancy, more training of professionals providing services, counseling to vulnerable young women, and family support programs were needed. One ED respondent finished her questionnaire with the note:

> “Cultural sensitivity in educating young people is essential. Information about FASD should not be punitive. Eastern Door must be a catalyst for assisting

families whose children suffer from all developmental disorders. Loosen the focus on FASD and win the battle against the resistance to secure services".

**Central Themes from the Surveys**

Overall, then, there was a major enhancement of awareness and support for the Eastern Door definition of the FASD problem in Elsipogtog reflected in the comparison of 2008 and 2009 completed questionnaires, within and across service subgroups. The commonalities were noted above in the brief discussion of the aggregated data but the analyses by type of service provider also showed there were significant differences. Elected political leaders were especially positive about the Eastern Door activities and confident that the community has a capacity in place to deal with the damaging and prevalent FASD conditions. The Eastern Door staff members were proud of its accomplishments and confident it was achieving its objectives. The Justice respondents were more uncertain about their organizations' preparedness to respond to clients with FASD conditions. HCCP, Crisis Centre and band employees had less exposure to workshops and presentations and not surprisingly indicated that they were uncertain about Eastern Door and FASD in Elsipogtog. In all groupings there was indicated a need for more information on non-genetic birth disabilities and the kind of regular collaborative contact that the AHTF was aimed at. Almost all respondents also called for more of the very things that Eastern Door has been committed to achieve, namely more information, informed health professionals, counseling for the young women, and family support.

**Interviews with Key Persons in Pivotal Local Services or Agencies**

Over the last year of the AHTF project, one-on-one interviews, usually on several occasions, were conducted by this researcher with the local service providers most pivotal for Eastern Door (ED) programs (as identified by the ED staff), namely Child and Family Services (CFS), Mental Health / Psychological Services, Nurse Practitioner (whose central responsibility is for the methadone program), Maternal Nurse, the School's Educational Psychology and Special Programming, Justice Services, including the RCMP, and the Headstart Program. In addition, of course, there were frequent

meetings with Eastern Door's coordinators to discuss the on-going collaboration between Eastern Door services and other community service providers. To honour commitments to confidentiality and anonymity that accompanied the interviews, the focus here will be on significant themes that emerged over time from these interviews, not description of the views advanced by respondents associated with specific agencies.

One theme was that other leaders in Elsipogtog health and social services generally accepted the premises of the Eastern Doors and programs, namely that drinking alcohol during pregnancy could cause serious damage and long-run effects for the fetus / baby and that an aggressive policy of prevention, diagnosis and intervention was required in Elsipogtog. Most key officials indicated that they had been well aware of the linkages between alcohol consumption during pregnancy and prenatal fetus damage but acknowledged that the Eastern Door brought it to the fore in the community and laid out an impressive program of prevention, diagnosis and intervention.

A second theme was that the Eastern Door – at least until it launched the PCAP program and other initiatives such as Early Child Development – was seen by other service providers to have been essentially a school-based service. It had developed in the context of dealing with school problems and its centerpiece, the diagnostic team, essentially served students or drop-outs from the local elementary school. A few respondents also observed, in this connection, that the Save Our Students (S.O.S) interagency committee, focused on chronic attendance problems and considered by all to be a very valuable community resource, could be seen as a pivotal offshoot of the Eastern Door movement in Elsipogtog.

A third, related theme was that the leaders in key local service agencies considered that the Eastern Door had achieved significant positives for Elsipogtog in the few years since it was established (i.e., 2007). Here they usually pointed to a significant decline in drinking during pregnancy, and often pointed, as well, to the ED as contributing to the considerable recent improvements in the school environment and in the significant achievements of the students vis-à-vis the mainstream standards and patterns, to the significant federal funding and provincial services that Eastern Door has secured for Elsipogtog in dealing with major problems such as troubled youth and vulnerable young mothers – as one respondent observed, “the more services, the better” –

and to the networks and effective collaboration that have been generated (especially with PCAP).

A fourth theme was a pervasive sense among the other services and agencies that the Eastern Door leaders were sometimes overly zealous in advancing the case for very high levels of FASD among Elsipogtog babies and children and championing their own definition-of-the-situation or interpretation of children's problematic behaviour and learning disabilities. Several respondents, while acknowledging the significance of FASD in Elsipogtog, expressed concern over "too much pressure to identify alcohol as the cause of everything", "labeling people", and offered alternative explanations for the problem behaviour which they found relevant to their professional practice; a common view here was expressed by one respondent who stated, " usually in a serious case there are all kinds of problems and the quality of the parenting might be the most important consideration whatever the FASD diagnosis is". One respondent expressed confidence in her behavioural approach (a nuance of reward and 'punishment'), stating she may seek help from the school counselor with tough-to-handle children but she can usually draw from her experience "the right button to push to keep the kids in line". Other respondents considered that attention deficit and attachment disorder – considered by them to be more the result of family dynamics though not ruling out neurological causes – were appropriate diagnostic frameworks for Elsipogtog. This diversity in viewpoints did sometimes –and, according to some respondents, continues to – create tensions among the practitioners but it does not appear to have been outside the pale of normal processes of social change; a new perspective sometimes is stridently advocated until it becomes part of the therapeutic landscape and the conventional perspectives accommodate to it, all parties frequently evolving in their positions (see below). Differences of course may also flow from significant differences in central objectives and targets as, for example, CFS's prime responsibility being child protection whereas Eastern Door's PCAP and Family Support services emphasize the mother –child unit.

A fifth theme that emerged over time was the perception of increasing accommodation and collaboration between the Eastern Door services and other local service providers, an accommodation fuelled by developments on all sides. AHTF coordinators properly attributed some of this greater collaboration to the increased

contacts initiated by PCAP and Family Support outreach and navigational activity on behalf of clients, and to their own informational visits with the local services providers. Networks were established as the Eastern Door significantly enhanced its prevention and intervention activities. One respondent commented that, as the Eastern Door has focused more on dealing with actual problems, its approach had evolved along holistic lines and different explanatory frameworks were welcomed. The PCAP program, with its focus on vulnerable young women, recent or expectant moms, in particular was cited by other service providers as filling a real community need (indeed a priority concern for most services) and transcending any simple FASD categorization. Several service providers such as Headstart, Nurse Practitioner, Maternal Nurse and CFS reported significant collaboration with PCAP, not only exchanging information but cross-referrals; e.g., Headstart (through its Homebase program which deals with infants less than 2 years old) has given some priority (i.e., setting aside "seats") to working with PCAP mothers. Other evidence of the collaboration included, for example, CFS regular participation in the sessions of ED diagnostic team, and the development of interagency initiatives such as the S.O.S.program.

Several respondents commented favorably on ED expanding its mandate to include a variety of behavioural problems and learning disabilities, not linked too closely to alcohol consumption during pregnancy but still possibly representing a non-genetic birth disability. This greater "flexibility", it was argued, could mean that the ED could continue to be a great asset for Elsipogtog even if, as most respondents appeared to think, there has been a significant decline in drinking during the pregnancy's first trimester. Several health professionals in fact cited interview data gathered since 2004 to support their view that very few pregnant or new mothers apparently consumed alcohol during pregnancy. On the other hand, some agency leaders noted that they have expanded their own agency's mandate creating greater opportunity and need for collaboration with Eastern Door; for example, CFS is enhancing its prevention thrust and urging the establishment of a family resource centre. Respondents in the Justice area continue to indicate little impact of the Eastern Door programs in their field but even here there has been increased exposure to FASD issues through workshops and conferences. The RCMP continues to report that alcohol abuse, as well as drug abuse, remains a very large

problem in Elsipogtog. An issue for policing and FASD at present was identified as "officers do not know how many youths have been diagnosed as having FASD, the diagnosed severity of the condition, the treatment, or any prescribed police role". There were some implementation obstacles to collaboration identified. A few respondents commented that staff turnover at the Eastern Door has limited their networking with the Eastern Door, and some Eastern Door staff, on the other hand, considered that their 'outreach approach', involving actively reaching out to clients and advocating / navigating (and even transporting them to meetings) on their behalf through the local services, was sometimes misunderstood and not appreciated.

A sixth theme was a modest level of anxiety among local service providers with respect to the sustainability of the Eastern Door services. Here some of the other agency leaders expressed concern that, subsequent to what they considered to be a too short demonstration period, outside funding for Eastern Door might tail off and that they might be competing for the limited resources otherwise available only by the local band government. A few respondents held that were that to be the case – a cessation of external funding – funds for the Eastern Door would not be available at the community level since "ED has not established itself as a necessary item that other services would defer to".

**Summary**

The above analyses indicate a strong acceptance by Elsipogtog service providers of the Eastern Door message that non-genetic birth disorders, especially FASD, are central to many of the school, justice and other problems in Elsipogtog. The Eastern Door's premises and definition of the situation have much public support and one might say now constitutes the "official" position in Elsipogtog. What other service providers almost unanimously contended was needed to deal with the problems of birth disabilities and drinking and drug abuse was what the Eastern Door has been doing in linking solid diagnosis with specific intervention / treatment plans and prevention strategies that involve both the community at large and the health professionals. Eastern Door's services and advocacy is increasingly well accepted, especially PCAP which relates to the priorities of virtually all the local services and agencies, while some other ED thrusts

may be seen more as revolving around the school milieu. There are still rough edges in the networking and assessments as might be expected among services and agencies with different philosophies / approaches and mandates as well as different ways of relating to clients. But there has also been a congruent evolving of services' mandates and styles on the part of Eastern Door and also on the part of some local agencies. There is some tension too among the services, given that many, including the Eastern Door, are on relatively short funding leashes and thus potential competitors for scarce resources. In any event, while more integration and collaboration is needed to optimize clients' use of Elsipogtog services, there seems little doubt that much has been accomplished in the way of integration and collaboration over the past three years.

## REACHING OUT TO THE ABORIGINAL POPULATION

### Pre-2008 Reaching Out Initiatives

Subsequent to the successful Nogemag project in 2002-2003 and the formalization of the Medicine Wheel model which developed from it over the next few years, the designer-initiator (Dr. Cox) began giving workshops and telephone / e-mail information and advice on the Medicine Wheel Tools to virtually all of the directors of Education and many principals and resource teachers" in the New Brunswick First Nations**.** In New Brunswick the coordinator for FASD awareness among seven First Nation bands was very thankful for the networking established with the Elsipogtog FASD program. He wrote in 2006 that "at least 50% of the people in my communities are affected by FASD and I believe that this is a very conservative figure". He noted that Health Canada officials informed him of the work in Elsipogtog and he then contacted Dr. Cox in 2005. Subsequently, he attended a workshop presented by Dr. Cox and contacted her on many other occasions "for client consultation and other general information pertaining to FASD, Dr. Cox has never hesitated to help me with my FASD projects and has never asked for any compensation for her time or expertise". Among the

activities for which he sought and received Elsipogtog assistance were designing posters and pamphlets and giving courses, and asset mapping related to FASD prevention. He was particularly keen on the Medicine Wheel tools and considered that “that approach should be adopted by all aboriginal FASD workers”. In his summary statement he acknowledged that “Dr. Cox’s work has greatly benefited my people and I am grateful to her and the Elsipogtog Health staff for their guidance and help”.

The emerging Elsipogtog expertise and approach to FASD, including the Medicine Wheel tools were also made available to Aboriginal communities outside New Brunswick, including PEI and Labrador. In Prince Edward Island, the driving force behind FASD awareness has been the Aboriginal Women Association (AWA). Its leaders in 206-2007 readily acknowledged the contribution of the Nogemag Model and the pioneering work of the Elsipogtog school-based FASD work. The AWA leaders considered it important that FASD issues were correctly seen as a general social problem and not something limited to Aboriginal people. They recognized that there were far more significant and sophisticated developments concerning FASD in Elsipogtog than anywhere in PEI , PEI’s FNs or mainstream communities, and appreciated the workshop provided by Dr. Cox. One respondent, coordinating the Aboriginal FASD activity there in PEI, wrote “FASD is a major social problem in our area and the Island as a whole”. . She noted that the AWA initiative began with basic community development work such as talking circles, focus groups and the like, especially on the subject of alcohol abuse and how to intervene effectively. At that time, there was an awareness of the Elsipogtog program “because of the great work done at the school and the Nogemag program” that out-of-school youths with FASD were involved in. Subsequent to attending a meeting for medical professionals in Elsipogtog on its diagnostic-intervention model for FASD she noted, “After seeing the presentation and hearing about the intervention, I knew this program needed to be discussed in PEI. During the presentation, a young adult and a mother spoke and the diagnostic-intervention model focusing on the support and empowerment of the young adult and mother was explained. That is what we wanted in PEI”. Citing the culturally salient Medicine Wheel connector to Aboriginal people in conjunction with the multidisciplinary diagnostic professionalism and the empowerment of the family and individuals, another PEI respondent wrote

> "I would like to see it become a model site for FASD intervention in Canada, especially the rural areas. People could come and learn about the diagnostic-intervention process and especially the supportive, empowering work with individuals and families. Invite the Aboriginal women's groups from the Eastern provinces to learn from the Eastern Door program".

The Eastern Door approach was extended as well to Inuit school-based system in Labrador. Building upon earlier visits and information exchange, a two-day workshop was held in Elsipogtog in 2007 for Labradoreans key to educational programs and FASD-related issues there. The workshop evaluations and subsequent written comments by some attendees and school officials underline the strong impact that exposure to the Eastern Door approach had effected (Clairmont, 2007). One respondent conveyed a very common sentiment with her remark, "You are doing such good things within this school and community. It was very inspiring. This workshop gave us so much information to share and bring back to our community". Another participant summed up the general view quite well in her remarks, "This has been an amazing opportunity on many levels, emotionally, educationally, socially and spiritually. Being able to share the processes undertaken in Elsipogtog has been a tremendous experience". A senior government education official in Labrador wrote, "Elsipogtog's Eastern Door initiative will be a model for us …they are willing to share information and we are using the information from it and applying it to us as well".

In addition to consistently reaching out to other Aboriginal communities since the 2002 Nogemag initiative, Elsipogtog's D-I, with the support of others engaged in the FASD work in Elsipogtog, were involved throughout the period 2004 to 2010 in making presentations and holding workshops dealing with FASD and the Medicine Wheel model with a wide variety of health care specialists and justice officials locally, provincially and nationally. In particular, the D-I collaborated with provincial health care professionals and government officials in securing a diagnostic capacity in Moncton and a special provincial team to explore possible service delivery models with respect to FASD conditions (see Appendix F).

**The AHTF Project**

Clearly, one objective of the AHTF project was to disseminate information about FASD and related disabilities and about the Eastern Doors services. Also relevant here presumably would be the needs and service gaps in the partnering FNs. The three partnering FNs were Indian Island with a registered population of 87 persons on reserve and 60 off-reserve, Bouctouche (69 on reserve and 21 off-reserve) and Fort Folly (33 on reserve and 64 off-reserve). It is not clear on what meaningful basis these three FNs were selected as project partners but two are close by Elsipogtog (one virtually contiguous) while the other, the smallest, is an hour and a half drive away. The partnering FNs were basically invited to join the steering committee and received information and orientation through several visits by the coordinator and two workshops. Attendance at the steering committee meetings was poor and the outreach quite modest.

The AHTF coordinators never served in that role for more than eight months and they expressed much frustration in attempting to make the partnership linkage meaningful. One noted that he had visited the three FNs to arrange workshop and determine what the contacts wanted and needed with respect to FASD information. As for services from Elsipogtog, that issue was not highlighted. Both coordinators considered that "I don't think we have consensus on what the three partners are to get from the project". The other coordinator echoed this shortcoming of "we had no game plan" and reported that the partnering representatives properly complained about a lack of contact or knowing what is going on. The coordinators identified several reasons for the shortcoming including lack of resources, turnover and, perhaps most importantly, made the observation that "there is no infrastructure [for dealing with birth disabilities] at these small reserves so what services would the Eastern Door offer to them if anything other than information"? Generally, the coordinators considered that all three FNs were very interested in the program and would have liked to either have Eastern Door service them or, perhaps unrealistically, develop similar programs in their communities. Culturally sensitive manuals were prepared for distribution and an asset mapping workshop was conducted to help the three FNs identify resources that could be accessed to begin similar programs and to identify gaps in service that needed to be addressed. However, it was not clear what value these were for the small communities. It was held by the coordinators

that at the minimum much could be achieved on the prevention front but short of a larger or mobile Eastern Door diagnostic unit and significant enhancement in services for local intervention, it was unclear what could be achieved on the other dimensions of the issue. Clearly, much more planning, strategizing, and resourcing were needed.

**Views of the Partners: Workshops and Interviews**

Material was available to the evaluator with respect to two workshops held by Eastern Door staff in the communities of the partnering FNs, one at Fort Folly in 2009 where all attendees were from that community and the other in 2010 where representatives from all three participating FNs were present. It does not appear that other workshops were held, at least no others since the Fall of 2008.

About a dozen people representing the three FNs of Bouctouche, Fort Folly and Indian Island attended a three hour workshop in Bouctouche in January 2010. With one exception, all the attendees identified themselves as "service professional", typically health professionals or social workers. The themes of the workshop included FASD and the Eastern Door, and the workshop was guided by the D-I of the Eastern Door program. The evaluations completed on the spot by the attendees were quite positive, falling on average in the middle of the spectrum from satisfactory to excellent with respect to discussion of the problem, discussion of solutions and opportunity to provide input. The respondents exhibited some diversity in their expectations but the bottom line was the expectation of obtaining more information on FASD and the Eastern Door program and, in that regard, they considered that their expectations had been met. The respondents indicated that they were also looking for possible resources to network with; several persons reported how they would very much like to see "these programs implemented in our community".

Ten participants at Bouctouche workshop also completed a short questionnaire entitled "Understanding the Gaps in Services in Your Community". Three respondents from the Indian Island FN, virtually contiguous with Elsipogtog, all reported that they were aware of the link between the mother drinking alcohol or taking drugs during pregnancy and the harmful implications to the fetus / baby. At the same time, all also held

that, currently, in their community, pregnant mothers are indeed still drinking, smoking, taking drugs and experiencing trauma. While the key reasons for this dangerous and apparently widespread pattern of behaviour were deemed to be “they drink/take drugs/smoke before they know they are pregnant”, and “they have addiction problems and can’t stop entirely”, the participants also blamed the physicians for inadequate communication to the pregnant women about the dangers of drinking, drugs and smoking. The participants identified a diversity of traumas that cause young women to abuse substances, giving roughly equal weight to previous sexual abuse, family violence, grief, and severe family instability when they were children. The Indian Island respondents reported that there were very limited resources available in their small community for helping mothers having problems with alcohol and drugs during pregnancy.

The four Bouctouche participants respondents essentially fully shared the views of their Indian Island counterparts, indicating a long awareness of the substance abuse – pregnancy linkage, the continued prevalence in their community of drinking, drug use and smoking during pregnancy, and the same two dominant explanations for why that behaviour persists (especially here the factor “they have addiction problems and can’t stop entirely”); they differed primarily in that there was much less blame accorded to inadequate communication /advice from physicians. The Bouctouche participants shared fully as well the view that most young women who are substance abusers have experienced previous sexual abuse, family violence, unstable familial background and grief. As a grouping, they were more uncertain whether as to whether women abusing alcohol and drugs during pregnancy can get the help they need locally but, unlike the Indian island participants, they readily identified the community nurse and the Alcohol and Drugs worker as providing services to the mothers having problems with alcohol or drugs during pregnancy.

The three Fort Folly participants departed somewhat from the Indian Island / Bouctouche consensus. Smoking during pregnancy was the only behaviour they all agreed was prevalent among women during pregnancy in their small community of less than 50 on-reserve band members (INAC, 2005) – none cited trauma and only one either drinking or taking drugs. Also, their views on why women in their community might

drink and take drugs during pregnancy were quite varied but there was agreement with the Bouctouche participants who held that little blame should be directed at the physicians' communication or advice. Perhaps because they did not identify substance abuse as a prevalent issue in their community, they did not especially share the Indian Island / Bouctouche consensus view that factors such as previous sexual abuse, family violence and grief were causing young women in their community to use alcohol and drugs but they did agree that family instability had been a factor. The Fort Folly participants acknowledged that there was but limited help available in the community for women using alcohol and drugs during pregnancy but they all did cite the availability of the community nurse. Interestingly, the nine Fort Folly participants (one fifth of all Fort Folly residents) at the earlier April 2009 workshop in their community expressed very similar views (e.g., awareness of the alcohol-harm to the fetus linkage, drinking and drug use during pregnancy was not a problem, limited blame directed at physicians, family instability could lead to substance abuse among young women etc).

Turning to **Intervention and Diagnosis,** all three Indian Island participants endorsed strongly – considered very important – all the possible programs and services for dealing with the problem of substance abuse in pregnancy suggested in the Eastern Door questionnaire, namely school awareness programs, better, more in-depth information provided by doctors and health professionals, outreach family support services and counseling for underlying trauma. The respondents also were in complete consensus that, in order to help youth who may have been affected by prenatal exposure to alcohol and drugs and may have conditions like FASD, programs and services are needed, such as diagnostic services, school support and special programs, training for service professionals, and housing / employment programs. The participants acknowledged that they have never referred, for diagnostic services, a person suspected of problems such as FASD. The chief reason given for the lack of referrals was that no diagnostic services were available in the community.

The Bouctouche and the Fort Folly respondents shared fully the consensus of the Indian Island participants in identifying the valuable programs and services required to help the young women to avoid alcohol and drugs during pregnancy (e.g., school awareness programs, more information from physicians and health professionals) and in

endorsing all the suggested programs and services for dealing with children and youth who may have been affected by prenatal exposure to alcohol and drugs. Neither Bouctouche or Fort Folly respondents elaborated on specific services locally available for persons affected by alcohol or drug (e.g. FASD), apart from the Headstart program. Two Bouctouche participants and one from Fort Folly reported that they had in the past actually referred a case of suspected FASD disability, apparently in two instances, to a Moncton service for diagnostic assessment. The nine participants in the 2009 workshop in Fort Folly had earlier expressed very similar views (e.g., the importance of education provided in schools and from health professionals about the dangers of substance abuse during pregnancy, the great salience of family support where the youth has been affected by prenatal exposure to alcohol and drugs, two referrals to diagnostic services for suspected cases of such effects as FASD, and not referring because either they did not identify a problem case or did not how to make a referral.

Overall, then, the respondents indicated that they were aware of the linkage between alcohol, drugs, and smoking consumed / engaged in during pregnancy and possible harmful implications for the fetus and for the infants and children. With the exception of Fort Folly participants they considered that all these substance abuses were still prevalent among pregnant women in their communities. And, again with the exception of the Fort Folly respondents, they agreed on the underlying causes of women turning to alcohol or drug usage (e.g., previous sexual abuse). All respondents shared the consensus that there were but limited resources (e.g., the community nurse, Headstart officials) to help young pregnant women who have alcohol or drug problems. They also all shared similar views on what would be needed to deal with these issues and also with the issues of youths affected by prenatal exposure to alcohol and drugs. Three of the ten women reported that they had in the past referred for diagnosis a person they suspected might have been so affected and might have FASD. There was consensus agreement that the workshops were valuable and among most participants a desire to access programs such as those offered by the Eastern Door (especially diagnostic services).

The respondents interviewed by the evaluator allowed that their attendance was minimal at the Eastern Door AHTF project’s steering committee meetings and apparently there were only two incidents of partners’ attendance from the Fall of 2008 until the

project wrapped up at the end of March 2010. One respondent had a better attendance record than the others but she allowed that it fell off after 2008. Various practical reasons for such an attendance pattern were advanced (e.g., inconvenient time, distance) but it would appear that the central reason was that there was no apparent advantage for their community in their attendance. As one stated, "It was always about Elsipogtog and never anything about Bouctouche, Indian Island and Fort Folly". There was a clear perception of marginality; as one representative commented, whether at workshop or other meetings, "all we got was some information and some contact numbers … there were no services of any kind provided or offered so why were we there; it was as if we were outside looking in". That said, the respondents did hold that the Eastern Door presentations, especially the one at Bouctouche, were excellent, even "very exciting" according to one person.

It was acknowledged that their FNs were very small and of course limited in what could be done whether through PCAP, Diagnosis or Family Support. For example, one respondent noted that there were problems in her community with learning disabilities and non-diagnosed adults who may have something like FASD but there was no capacity to deal with these issues and none was offered to them. Another respondent echoed these comments and added that there is a pattern anyways of people in her community preferring to go to Moncton for such diagnosis and treatment (although she did indicate that some people had accessed the services of Elsipogtog Mental Health / psychological services). There was little doubt, however, but that the respondents were quite impressed with the Eastern Door program. One added that while she did not think FASD was the diagnosis for all the learning disabilities and so forth, she considered that the Eastern Door leaders "did not ignore other explanations and I applaud them for that". The general view expressed by the representatives was that a culturally sensitive, community-based model centre of excellence for birth and learning disabilities was very desirable and needed for the FNs in New Brunswick. Obviously, in this view, not every individual community could reproduce the Eastern Door but the concept of a mobile diagnostic team in conjunction with shared information and workshops on prevention and some working at the complex resource issues involved in intervention / treatment were seen as possibilities. At the same time the view appeared to be that if the Eastern Door is to be an Aboriginal centre of excellence in this field and if it expects support from other FNs in

the province, then Elsipogtog will have to do more to earn that, such as take referrals for diagnosis and so forth.

**Summary**

Overall, then, from the get-go, the Elsipogtog initiative in responding to the prevalence of FASD birth disabilities, which have haunted many Aboriginal communities in Atlantic Canada, has had a policy of reaching out to others. As the director of the Eastern Door stated at a quasi-public meeting in 2009 "our policy is to share and other FNs have to develop models so they can profit from the sharing … we emphasize cooperation and other FNs do not have to pay for accessing resources such as the diagnostic service for FASD". That outreach viewpoint has been central, too, to the vision provided by the designer-initiator of the Eastern Door concept since the FASD issues were crystallized by her in the design of the Nogemag project and the Medicine Wheel model years earlier. For a variety of reasons – staff turnover, lack of resources, no clear strategy for meaningful involvement of the other partnering FNs - the AHTF project did not advance much that 'reaching out' objective, and the partnering FN representatives were dissatisfied with the benefits provided for their community. Their appetites were wetted by the workshops provided and the increased awareness of the Eastern Door services but it was very unclear to them exactly how in supporting the Eastern Door's ambitions they could realize such services for their own people. Clearly much more planning – and more resources – will have to be done to move more substantially to an Aboriginal centre of excellence for birth disabilities and learning disabilities in Elsipogtog that is widely accepted by other New Brunswick First Nations.

## EXTERNAL GOVERNMENTAL PERSPECTIVE

### Introduction

The chief way liaison was maintained between Elsipogtog's Eastern Door and external governmental and First Nation governance for the AHTF project was through the project's steering committee. There were representatives of the federal and provincial governments (Health departments) and the Union of New Brunswick Indians plus the three partnering FNs. There were nine meetings of the steering committee beginning in December 2007 but only two since June 2009. Staff turnover in the AHTF and other circumstances resulted in an hiatus in the projected quarterly meetings in 2008 and the March 23, 2009 meeting of advisory committee was, as one representative put it, "long overdue". The attendance of provincial representatives and FN representatives fell off considerably it seems after the hiatus though some members participated through conference call and of course there were some individual meetings. There was a perspective advanced by Eastern Door participants and apparently shared by the steering committee members that the Eastern Door should deal with a range of birth disabilities and learning disabilities, not just FASD cases, though the latter would remain the core Eastern Door focus. There was also, in the articulated Elsipogtog perspective conveyed at these steering committee meetings, the view that the goal was to build an Aboriginal centre of excellence; this objective, while not apparently discussed at length in the steering meetings, generated much thought, not questioning the ideal, but with respect to how it might be effectively and properly achieved as will be discussed below.

### Perspectives of External Governmental Collaborators

Interviews were conducted in Halifax, Moncton and Fredericton with the principal governmental collaborators of the AHTF project. They were federal, provincial and UNBI representatives. Seven persons were interviewed, some twice and also with email follow-ups; with one exception, all interviews were "face to face". The respondents indicated that Elsipogtog's programs and organizational sophistication in the field of FASD and other developmental disabilities clearly were exceptional, not only for First Nations in Atlantic Canada but throughout the region and even in Canada as a whole (the

Lakeland Centre in Alberta was cited by the government interviewees as an impressive centre of excellence for FASD work and an influence on the development of the Eastern Door). One provincial respondent commented that that "Elsipogtog is way up there, virtually alone among the FNs regarding services and capacity" while all heaped praise upon the Health Centre's management and the FASD expertise and organizational skills of the Eastern Door's founder. A third provincial government respondent commented that there is nothing, certainly east of Montreal, comparable to the coordinated prevention, multi-disciplinary diagnostic team and intervention thrusts of the Eastern Door. The UNBI representative shared that view –"none of the other FN communities has anything like the programming of Elsipogotog [in FASD and development disabilities] … there is some awareness of the risks of FASD, spread word- of-mouth by mentors and home visits [personnel, such as the maternal nurse] but not much else".

The Eastern Door's comprehensive prevention, diagnosis and intervention program was deemed path-breaking regionally in all dimensions. For example, one very knowledgeable respondent observed that while there are other PCAP projects elsewhere in Atlantic Canada, that initiative, focused on both prevention and intervention, has actually only been rigorously implemented in Elsipogtog; that view was shared by the provincial and UNBI respondents. Interviews with Health officials in Nova Scotia, such as Capital Health, indicated also that there was there both limited public awareness of FASD and almost a complete absence of diagnosis and intervention capacity in the province. The Eastern Door's Family Support program was cited by all respondents as a key intervention program that has enabled much better utilization of community and provincial support services for the rehabilitative plan developed for each client and family subsequent to the careful assessment and recommendations of an impressive diagnostic team. The AHTF funding was seen as directed to institutionalizing the Eastern Door work (mobilizing and coordinating community and other social support services to enhance capacity and sustainability in this field), liaison with provincial health services, and through presentations and other activities, exploring and expanding its possible linkages to other FNs.

Respondents generally indicated that the Eastern Door should have a wide "development problems with children" orientation and that an undue focus and "hype" on

FASD was unwise; indeed, having such a broader focus was how they saw the Eastern Door to have been evolving, emphasizing the negative implications for the birth effects of alcoholic consumption, smoking and drug abuse, school children dealing with learning disabilities and so on. That said, all the respondents acknowledged that FASD is a major reality among First Nations such as Elsipogtog (as one put it, 'there is not the same level of awareness outside the First Nations") and that it is a special expertise of the Eastern Door. Provincial government respondents, noting the forthcoming provincial centre of excellence for FASD diagnosis and intervention / treatment recommendations, were especially appreciative of nuances for policy and support of having a highlighted core theme such as FASD while also being open to responding to developmental disabilities in general. A few of these respondents, cognizant of the challenges of collaborating with different local agencies where the philosophies and agency targets may be quite different from the Eastern Door's family focus and outreach approach, and in a milieu where the resources are scarce, noted that a broad mandate and a network of collaboration and liaison were essential to realizing the AHTF project's objectives.

The respondents considered that the concept of the Eastern Door as a centre of excellence, especially for Aboriginal communities, made sense in light of what has been put in place and achieved thus far. They considered that, like many other FNs, the FN partners in the AHTF project - Fort Folly, Indian Island, Bouctouche - have small populations and limited capacity for responding to issues such as FASD, apart from modest prevention awareness activity, and thus there is a major need for such a centre that can provide a culturally appropriate leadership in all three dimensions of prevention, diagnosis and intervention. A federal respondent noted that Atlantic region-wide meetings of tribal councils (including MAWIW and UNBI from New Brunswick) for Wellness, Child and Youth, have prioritized the need for programs to respond to widespread issues of FASD and fetal-based and developmental disabilities. While the federal respondents indicated much support for the centre of excellence concept, one commented that "the problem is political as each FN wants a piece of the action so it is difficult to get consensus and the government does not like to impose a viable alternative". Another respondent acknowledged that, in the Eastern Door, Elsipogtog had a case for being classified as a centre of excellence and that that objective and standing

was “probably necessary to in continue to receive substantial government support”. The respondent elaborated that the three prerequisites would be having a broad “developmental problems” focus, being well-institutionalized or integrated in the Elsipogtog community, and being linked up with other FNs in New Brunswick.

The federal interviewees considered that Elsipogtog’s Eastern Door could be a centre of excellence in its field with respect to both FN and Mainstream communities. They envisioned that the involvement with other communities would essentially be informational, highlighting awareness and prevention. Diagnoses and intervention / treatment would require much more resources with respect to both the communities involved (i.e., their intervention and treatment capacity) and the Eastern Door diagnostic team - in the early days of the Eastern Door, according to the coordinator at the time, there were two diagnoses per month but this was not sustainable in light of the thoroughness of the diagnostic approach and the value of meeting the same day with the parent-guardian to discuss the team’s recommendations, consider an implementation plan, and respond to parents’ questions and concerns. A key to meaningful coordination with other FNs, and their support for the Eastern Door as a centre of excellence was seen to be protocols and mechanisms established for linking these FNs to the Eastern Door expertise.

The provincial respondents stated that, to a significant degree, provincial health attention to FASD and related neurological developmental disabilities has been influenced by the developments in Elsipogtog, and that strong liaison between the Eastern Door and the provincial FASD team which has now recommended a provincial centre of excellence in FASD has been established. A senior provincial health official commented that the D-I of the Eastern Door has been the dynamic mover and information source behind the greater attention to FASD issues in the province and certainly the “sine qua non” of the Department of Health’s investment in FASD-related activity in Elsipogtog. One provincial respondent agreed with the centre of excellence concept but emphasized that “it would really have to be a centre, reaching out [to other FNs] in information, intervention strategies and so on  ... and broader than just FASD”. It was also noted that Elsipogtog has received “ten times as much funding as any other such community and that greater share is not sustainable” for several reasons including the

current economic squeeze in government and especially in the Department of Health. The UNBI respondent observed that "all 15 First Nations cannot be competing with one another but must collaborate more" and in that regard she could appreciate Elsipogtog being a centre of excellence in dealing with FASD and similar neurological disabilities. She shared the view of the provincial respondent quoted above, namely, that Elsipogotg has received much more provincial funding / resources than other FNs and would have to reach out and do presentations, orientation, / training and even perhaps diagnostic work for other FNs. As was noted in a subsequent interview, some FN leaders in other New Brunswick communities were decidedly less interested in the current Eastern Door initiative when informed that the Eastern Door as yet does not do diagnoses for other FNs' members.

Several provincial government respondents drew attention to the recent Department of Health's acceptance of the provincial FASD advisory team's recommendation for establishing a provincial centre of excellence in that field (an RFP has been sent out September 2010). The advisory team, strongly influenced by the Elsipogtog experience but drawing on FASD programs elsewhere in Canada too, recommended a community-based service delivery for FASD diagnosis and intervention / treatment, with the centre being supplemented over time with as many as five regional centres. This plan would contrast with a hospital-based service delivery such as exist in a modest way now outside the Eastern Door (doctors in Moncton and Mirimachi provide diagnosis and treatment recommendations for FASD). In the recommended approach, the provincial centre would work closely with non-profit and with Aboriginal liaisons and clearly the Eastern Door as a centre of excellence for FNs in New Brunswick was seen by the respondents as an effective partnership.

While the respondents were quite aware of the Eastern Door programs and the thrusts of the AHTF project, none were particularly aware of any of the emerging results of the project apart from what was gleaned from the few meetings of the advisory / steering group and not all respondents attended those and, moreover, there was turnover among the role players from the different governmental bodies. For the most part, while they appreciated that there would be some workshops presented, they were inclined to expect little involvement on the part of three participating FNs, whose attendance

reportedly at the advisory / steering committee meetings was spotty. The UNBI respondent seemed to sum up a more general view, noting that the three participating FNs were minimally involved in the project (see elsewhere for further elaboration and assessment of the participation).

Several respondents indicated that crucial to the success of the Eastern Door program is that clients in PCAP and Family Support are interviewed and provide feedback, that the views and collaboration of local service providers are assessed, and that an effective data management system is instituted. In these ways the perceived central AHTF objective - mobilizing and coordinating community and other social support services to enhance capacity and sustainability in this field in Elsipogtog – could be thoroughly assessed. One respondent observed that she has been informed that already there appears to be evidence of much less alcohol use among pregnant women in Elsipogtog. Another respondent, familiar with Elsipogtog, observed that it should be possible to track child development since both the elementary school and the Health Centre have excellent data available (e.g., the Health Centre started graphing height and weight in children's charts in 2004).

Some additional concerns or suggestions advanced by respondents were (a) the top leadership responsible for the Eastern Door is nearing retirement and they should be mentoring their replacements (actually there is a transition committee set up though it is unclear how it is faring); (b) the availability of resources is problematic; one respondent claimed that a few years earlier the Eastern Door had a coordinator plus two staff people for the crucial home visitor (i.e., Family Support) program whereas now the coordinator has to do some FS work and has only one staff member available for home visits; (c) community buy-in and competition among local services for limited governmental funds could be a problem, especially if funding is perceived as a "zero sum" situation; (d) extending the honed skills of the diagnostic team beyond children as is occasionally mentioned but yet to be done. Overall, there was a strong consensus that the Eastern Door program was a well-conceived program that was well-implemented and so the focus of these governmental and UNBI respondents was very much directed at the future namely, where is the Eastern Door and the province heading with respect to the FASD and related issues and how can other FNs be more meaningful involved.

## FUTURE DIRECTIONS AND A CENTRE OF EXCELLENCE

A number of specific suggestions for future directions in the Eastern Door program have been advanced in the summaries for each chapter above so here only the more central emergent themes will be cited.

### Ten Specific Suggestions

1. PCAP staff, conflict resolution and the use of motivational interviewing: given the necessary outreach style that is intrinsic to the valuable PCAP approach, there is a clear need for mediation training for PCAP staff, and, given the staff's considerable interaction with clients, the use of motivational interviewing and difference games appear crucial to help clients deal effectively with local service providers without alienating them. Mediation and conflict resolution training, as for example in the Elsipogtog Apigstigtoaen approach (perhaps provided by the current Apigsigtoagen trainers), could pay dividends in the navigation and advocacy work for clients.

2. PCAP workers' face to face meetings with clients are important and apparently a main if not the chief source of advice and support for many PCAP clients as there does not appear to be a whole lot of referrals to local agencies. What are the implications for the staff's interaction with clients? For their training as advocates and support people?

3. It is crucial for PCAP and FS programs to identify key measures (e.g., ASI) to be monitored in the client engagement. Monitoring and measuring change is crucial to having confidence about the program and appreciating how to analyses and improve the service; this is an area where there is a significant shortfall at present vis-à-vis the PCAP best practices elsewhere.

4. The recommendations for changes provided by PCAP and Family Support staff and clients (e.g., flex time, infrastructure resources) are congruent and well-taken so the attendant policy options need serious examination.

5. In the case of the Family Support program, for example, , the need for more attention to monitoring and measuring the changes over time in the attitudes and behaviours of the youths and parents is paramount since such data are crucial for regular internal and external evaluation. Apparently there is a considerable amount of pertinent data routinely gathered but resources are required to analyse what is available and identify gaps in data collection. Little organized, "machine-ready" data were available for this assessment.

6. The issue of a fulltime coordinator for the Diagnostic team: if the coordinator has to do significant outreach and has no secretarial help, then it impacts negatively on the Eastern Door's effectiveness since monitoring clients' progress, providing updates to the diagnostic team etc are very salient for achieving excellence. This unfortunately is the current situation as the FS coordinator also coordinates the Diagnostic Team's involvement. Should demand for diagnostic services increase as expected (see below), the need for a full-time coordinator would be even greater.

7. The assessment found an evolving /maturing Eastern Door (exemplified for example in its inclusionary theoretical and policy approach) and more acknowledgement and collaboration on the part of the salient established services like CFS, Nurses, and Psychological Services. Note that some tension is fine and is there for sure between ED and other community services BUT a collaborative evolution has been mutual and positive linkages have been spiked by PCAP, SOS and ECD. 'Aggressive' outreach styles may be necessary but can also be properly harnessed. To further effective institutionalization, there should be an operational committee of Elsipogtog

service providers for the Eastern Door. Along with conflict resolution provided by Elsipogtog's own Apigsigtoagen approach such an advisory committee to regularly input with the Eastern Door could be beneficial to all.

8. With respect to partnering with other FNs, implicit in the concept of an Aboriginal centre of excellence, there is a need to set out objectives and strategies and monitor the implementation of same. As noted, in the views of the federal and provincial governments as well as leaders of the other FNs, such collaboration by the Eastern Door with the other FNs is very important and, given political and economic realities, a necessity. The FNs might be different and have different priorities but in any specific area, to avoid tokenism, there is need to lay out a mechanism for benefiting them. Also there is a need to identify its resource requirements.

9. A strategic action plan for an Aboriginal centre of excellence is necessary. How to achieve it, what are the protocol and resource requirements, how to reconcile cost-effectiveness and equity – these are important policy issues as indeed they are in general for problem solving courts as centers of excellence in New Brunswick and elsewhere as noted above. In the case of Aboriginal communities that challenge is greater / magnified since the communities are smaller in population and scattered so imaginative solutions are necessary.

10. Clearly the resource issue emerged as paramount. More resources are required to effect the establishment of appropriate data systems and subsequently the monitoring and regular internal evaluation of the programs and services; a shortfall has been the reality, as noted in the text, in the follow-up to the diagnostic activity and in the functioning of the prevention and intervention services (i.e., PCAP and Family Support). Informed interviewees inside and outside Elsipogtog properly considered that long-term funding was crucial to secure partnership and collaboration within and beyond the community as otherwise, with virtually all collaborators on a short funding leash,

competitive and centrifugal factors loom large. Unfortunately, even while the Eastern Door initiative was proving itself more and more path-breaking in its community-based model of prevention, diagnosis and intervention – and reaping appropriate kudos from national and provincial authorities – the funding was being cut, not increased.

**Environmental Scans and Future Directions for the Eastern Door**

There are three major contextual developments that appear to be crucial to the evolution of the Eastern Door and underline how important the resource issue is to its future direction; these are:

1. The provincial health initiative – according to provincial officials in the Department of Health , there is pending an announcement of a New Brunswick provincial FASD centre of excellence. As indicated in the text above, the province appears committed to a community-based delivery model (versus a hospital delivery service), a model which places emphasis on collaboration with regional sub-centres and working with Elsipogtog as the Aboriginal centre of excellence for New Brunswick. To evolve into an effective Aboriginal centre for non-genetic birth disabilities and related development problems, the Eastern Door would require a significant and long-term increment in resources.

2. Increasingly, the criminal justice system (CJS) is acknowledging the need for a different response to accused persons and victims who have non-genetic birth disabilities such as FASD and related problems. Recently – 2010 - the Canadian Bar Association passed the following resolution:

   > "**BE IT RESOLVED THAT** the Canadian Bar Association supports the initiative of Federal, Provincial and Territorial Ministers responsible for Justice with respect to access to justice for people with FASD and urges all levels of government to allocate

> additional resources for alternatives to the current practice of criminalizing individuals with FASD".

The Bar's position was that when FASD disabled persons are convicted of a crime, their disability should be recognized and their sentence should "accommodate" the disability (ibid). The Bar did not advance specific solutions but its president emphasized the need to have general acceptance within the CJS that there is a problem and what is currently being done with FASD-affected offenders is not working. The federal government response has been positive; in August 2010 the Justice Minister acknowledged in the meeting of the Canadian Bar Association that the FASD issue represents "a huge problem" (Canadian Press, October 12, 2010)

3. As noted in the text, the New Brunswick Department of Justice and the Elsipogtog Band Council have reached an agreement to establish, as a three year pilot project, an Aboriginal Healing to Wellness Court at Elsipogtog. The resource requirement for diagnostic and treatment can be expected to be significant as indicated in the following quotation from the government's media statement:

> "The court will deal with crime and its underlying causes, such as mental health and substance abuse. Not all offences will be within its scope. For those who are eligible to participate based on offence type, they will be required to take responsibility for their actions and to comply with a treatment plan as ordered by the court. The plan will be supervised by medical and mental-health professionals as well as Elsipogtog elders. The progress of the accused will be monitored regularly by a provincial court judge".

**The Resources Issue**

A central issue, if not the central issue, that has emerged from this assessment of the AHTF project, aimed at the two chief objectives outlined in the introduction, namely furthering the institutionalization of the Eastern Door in Elsipogtog, and enhancing its potential as a centre of excellence for dealing with non-genetic birth disabilities and learning / development problems in general, has been the question of adequate resources.

There are many dimensions to the resources issue and the following six illustrate the complexity:

1. Federal and provincial positions on funding (e.g., cost-sharing issues, jurisdiction etc) underline the need for partnerships.
2. The squeeze on health budgets at all levels of government and the growing demand for more equity in access to centres of excellence underline the need to find smart solutions.
3. Controversy exists concerning whether current centres of health excellence and problem-solving courts (Mental Health Courts, Drug Treatment Courts etc) are smart solutions and how can they be better in this regard?
4. The Eastern Door as a smart solution has been acknowledged by the New Brunswick committee charged with determining the best vehicle for delivering FASD and other programs. The Eastern Door's community–based model of prevention, diagnosis and intervention has been deemed to be both effective and efficient.
5. An Aboriginal centre of excellence appears to be necessary and justified by both practical and constitutional / social policy considerations but it remains to determine how it could be established, effectively function, and what the protocols and resource requirements are, though it is clear that the requirements will be significant and have to be long-term for planning and implementation. Minimally there will be need for a second day of secondment for the Diagnostic Team members and definitely a full-time coordinator for arrangements, monitoring and updates.
6. The three arms of the Eastern Door – PCAP, Diagnostic Team and Family Support - are all crucial, integrative dimensions of a successful program; e.g., studies show that FASD children require greater levels of support and supervision to help them perform daily activities and to manage challenging behaviours.

In conclusion, this assessment has shown that an important, effective service has been established at Elsipogtog in response to a set of prevalent birth disabilities and serious social problems. The Eastern Door's evolution into a full-fledged community-based model of prevention, diagnosis and intervention has been significant and the AHTF project has contributed to this success. It is clear that a major step forward has been taken in integrating the ED's service with other services and programs in Elsipogtog though more needs to be done in that regard. Similarly, there has been progress in reaching out to the other First Nations though clearly much more has to be done in terms of defining - and implementing - how other FNs can profit from and network with the Eastern Door's expertise and services. These challenges will likely become more demanding in the light of reduced funding for some ED functions such as Family Support, and, as noted above, the growing demands from new developments at the provincial level in terms of responding to birth disabilities, and from the increased attention to birth disabilities and related problems in the justice system, both in general and in the Healing to Wellness court to be established in Elsipogtog. From a policy perspective, the Eastern Door is, to use a Churchillian expression, "at the end of the beginning". It is poised to make a much greater substantive impact, on the issues to which it has been addressed, in the community, in other Aboriginal communities, and in New Brunswick more generally. It appears to be up to the challenges but clearly more resources will be required as will strategic action plans to respond to the challenges.

## APPENDIX A

### SOME THEMES TO EXPLORE IN THE CLIENT INTERVIEWS

**NOTE: This interview is part of the assessment of recent Eastern Door initiatives. It is done independent of but on behalf of that program. All the information will be considered confidential and anonymous. No name will ever be used or cited in any report, oral or written. Just the overall results will be provided to the program directors. Your cooperation is much appreciated.**

**Involvement in PCAP:** Ask a general question about involvement – **how have you found your involvement in the PCAP program -** then probe with respect to the following

How did you become involved – referral by? Self-referral?
Why did you become involved?
What were your two most serious problems re pregnancy and/or parenting prior to becoming involved in PCAP?
How long have (or were) you been involved in PCAP?
Have you been involved in both individual (e.g., home visits) and group activities?
Your level of participation? (#of home visits, of group sessions attended)

**PCAP's navigating and coordinating roles:**

Ask about their awareness of and contact with **other supportive local social services and programs before becoming involved with PCAP and since they became involved**

Before PCAP – which ones were you involved with and how adequacy was the service?
Since PCAP – which ones and the adequacy of service?

**PCAP's social support role:** Ask the general question about the importance of PCAP's social support – **how important to you has been the support and assistance of PCAP and its services/programs** – and then probe with respect to the following

Before and Since PCAP - who were support people for the respondent?

**Before PCAP** – Close family members? A local service provider? Other?

**Since PCAP -** The PCAP home visit worker? (the Thursday PCAP group?) Close family members? Others local service providers?

**PCAP's advisory role** - Ask the general question about the quality of advice and helpful ideas that came through contact with PCAP staff, home visits and group sessions, - **has PCAP provided you good advice and helpful ideas for dealing with any problems you have had** - then probe with respect to the following

**Before PCAP** – did you seek counsel from others or local agencies before and during pregnancy? Was it available / accessible?

**Since PCAP** – have you received counsel from other local service providers? Other people? PCAP home visits? Other PCAP one-on-one contact? PCAP Thursday group sessions?

**How important has PCAP assistance been for you regarding the following**

Connecting you to other local service providers?
Providing Advice or Counseling?
Providing Social support?
Being an advocate on your behalf?
Being there (accessible)?
Other?

**Specific ways PCAP may have helped you;** Ask a general question **– what was the best way PCAP involvement helped you?** Then ask for each of the following areas

Parenting
Dealing with any substance abuse issues
Housing and Other material resources
Dealing more effectively with local service providers
Providing direction and a plan for me
Giving me confidence about myself

**Assessment of the design or implementation of the PCAP program**; Ask a general question re the ask about the best and least beneficial ways the PCAP program is designed from your point of view - **What do like most about the way PCAP is carried out? The least?** - and then ask their views on each of the following features

The referral process to PCAP
The referral processes subsequently facilitated by PCAP
The "difference game"
The Individual meetings with PCAP staff
The home visits
The Thursday night group sessions

**How important an impact has your PCAP involvement had an on any of the following aspects of your life?**

Personal family life
The trust I have in local service providers
The confidence I have in myself being able to do what I think I should
Any substance abuse problem I had
Any parenting problem I have or could have in the future

**Suggestions for improvements in PCAP**

In general, off-the- top, how would you think the PCAP program can be improved?

Then, ask about each of

the PCAP activities (the individual visits – the home visits - with PCAP staff? the group sessions? The difference game etc?)

The capacity of PCAP (# of staff, what staff can do?)

The type of PCAP staff member (office and outreach?)

The way PCAP relates to other local service providers (the referral processes, the level of PCAP's collaboration and similarity of views and strategies in services provided)

Would you recommend the PCAP program for others who have had similar experiences to yourself – Why or why not?

General Comments of the Interviewer

**APPENDIX B**

## PCAP PROGRAM; STAFF OVERALL ASSESSMENTS

1. In your own words what are the key overall goals, stated as outcomes, of the PCAP Program? (Briefly – in point form)

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
___________________
______________________________________________________________________
______________________________________________________________________
_____________

2. Have these goals been well appreciated by all central role players at the Eastern Door? Elaborate on any perceived variation

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
__________

3. What have been the strategies and procedures developed to achieve those goals? Have they been adequate to the task? Did new strategies emerge over time to improve effectiveness?

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

4. There have been diverse roles for the PCAP staff in relating to the young female clients such as being "a navigator directing them to local services", providing social support, and sometimes discussing their options and life goals with them. Are some roles more important than others? Which have been most successfully carried out?

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

5. What do you consider have been the major successes with this program? Why?

______________________________________________________________________

6. What do you consider have been the major challenges or problems with this program?

7. How have these challenges been addressed and / or should be addressed?

8. What do you think the PCAP clients themselves like most and / or think is the most important benefit of the program for themselves?

9. What are the two greatest challenges for the PCAP staff in seeing that the clients profit from their participation in PCAP?

10. What are the three most central local agencies you work with or access in your role as PCAP worker and has their response been helpful or not? Has it changed over time?

Local Agencies –

1.________________________________________________________________________

2.________________________________________________________________________

3.________________________________________________________________________

Two most central Regional or Provincial agencies –

1.___________________________________________________________________

2.___________________________________________________________________

11. In your view has the level of integration and coordination among PCAP and other local service providers improved substantially over the past year? What more, if anything, is required to achieve a satisfactory level of community coordination?

12. As you assess the situation now, what improvements, if any, can be made to the PCAP Program to enhance its effectiveness in the Eastern Door?

13. Any additional Comments?

## APPENDIX C

### SOME THEMES TO EXPLORE IN THE CLIENT INTERVIEWS

**NOTE: This interview is part of the assessment of recent Eastern Door initiatives. It is done independent of but on behalf of that program. All the information will be considered confidential and anonymous. No name will ever be used or cited in any report, oral or written. Just the overall results will be provided to the program directors. Your cooperation is much appreciated.**

**PRIOR TO INVOLVEMENT WITH THE FAMILY SUPPORT PROGRAM**

**Explore whether there had been a lot of problems with the child / youth in the years immediately preceding the involvement with the Family Support Program**:

The kinds of problems and how long had they gone on (since birth?)
Problems at school
Trouble at home
Trouble in the community

**Explore the person's view of the causes and any assessments provided her/him by local service providers including school officials:**

What did you think were the causes of your child's problems?

Did your child / youth ever receive an assessment from any local service provider (social worker? school psychologist? other service?). Was it helpful for you?

**Explore the person's social support back-up and the coping behaviour that she /he drew upon:**

Did the child / youth's problems aggravate other personal or family problems for you?

Did you find any useful, helpful ways to deal with these problems whether at home or school or elsewhere?

Did you have much social support for your coping with your child's problems?

From family members
From personal friends
Local service providers

**BECOMING INVOLVED IN THE DIAGNOSTIC ASSESSMENT AT EASTERN DOOR**

How did you come to be involved with the Eastern Door diagnostic service?

How did you become involved – referral by school? self-referral? Other?

Why did you become involved? What were your hopes and expectations?

What did you think of the assessment that the Diagnostic team made re your child's problems?

Was it clear and understandable to you?

Was it what you expected?

Did you have enough opportunity to ask questions or to comments?

Were the diagnostic findings presented to you in an appropriate way?

Did the diagnostic team identify community supports and other resources that could help?

Did the FS Worker review well the diagnostic report with you?

On a scale of 1 to 10 with 10 being the highest, how helpful was the diagnostic report and experience to you in suggesting how you might deal with the child?

**INVOLVEMENT IN THE FAMILY SUPPORT PROGRAM AT THE EASTERN DOOR:**

**Involvement:**

Why did you become involved?

How long have (or were) you been involved?

Involved in both individual (e.g., home visits) and group activities?

Level of participation? (roughly the # of home visits, the amount of other contact with Family Support staff)

**Family Support's navigating and coordinating roles:**

Ask about **before and since** involvement in the Family Support program with respect to their awareness of and contact with other local social services including special school programs

**Before** – which local services and / or school programs were you and your child involved with and how helpful / adequate were those local services or you and for your child?

**Since** – which local services and the helpfulness / adequacy of the service for you and for your child?

**Family Support's social support role:**

In coping with your child's problems, what have been the major social supports that have been most helpful to the child and to yourself?

**Before** Family Support involvement – close family members? Any local service provider? School programs? Other?

**Since** your involvement with Family Support - Close family members? Other local service providers? School programs? The Family Support home visit worker?

**What assistance has the Family Support service provided to you regarding (ask about each of the following)**

Connecting you to other local service providers?
Advice or Counseling?
Social support?
Being an advocate on your and your child's behalf in dealing with other persons and services?
Being there (accessible)?
Other?

**Specific ways the Family Support program may have helped you;** Ask a general question – what has been the best way involvement in the Family Support program has helped you? Then ask for each of the following areas

Parenting and family life
Housing and other material resources
Dealing more effectively with local service providers
Providing direction and a plan for your child
Giving me confidence about my child's future
Seeing Improvements already in my child's attitudes and behaviours

**How important an impact has been your involvement with the Family Support for any of the following aspects of your life**

Improvement for my child in coping with things (school behaviour? Getting along with others? Other?)
Personal family life
The trust I have in local service providers
The confidence I have in myself being able to do what I think I should

**Suggestions for improvements in the Family Support program**

In general, off-the- top, how would you think the Family Support program can be improved

Then, ask about possible improvements for each of the following

the Family Support activities (the home visits, helping you getting things worked out for your child with other local agencies, helping you understand better your child's problems)

The capacity of the Family Support program (# of staff, what staff can do)

The way the Family Support staff relates to other local service providers and to the school system (the referral processes, the level of collaboration and similarity of views and strategies in services provided)

Would you recommend the Family Support program for other parents / guardians whose child / youth may have similar problems as your own? Why or why not?

General Comments, Interviewer:

**APPENDIX D**

**Family Support Program: The Family Support Worker**

2. In your own words what are the key overall goals, stated as outcomes, of the Family Support Worker Program? (Briefly – in point form)

2. Have these goals been well appreciated by all central role players at the Eastern Door? Elaborate on any perceived variation

6. What have been the strategies and procedures developed to achieve those goals? Have they been adequate to the task? Did new strategies emerge over time to improve effectiveness?

4. There have been diverse roles for the Family Support Worker in relating to parents and children such as being “a navigator”, providing social support and sometimes “crisis management”. Are some roles more important than others? Which have been most successfully carried out?

**5.** What do you consider have been the major successes with this program? Why?

6. What do you consider have been the major challenges or problems with this program?

7. How have these challenges been addressed and / or should be addressed?

11. What do you think parent(s) or guardians(s) like most or think is most important benefit of the program for themselves? For their child?

12. What are the two greatest challenges for the Family Support Worker in seeing that the recommendations of the Diagnostic Team are implemented?

13. What are the three most central agencies you work with or access in your role as support worker and has their response been helpful or not? Has it changed over time?

Local Agencies –

1.______________________________________________________________________________________________________________________________________________________________________________________________________________________________

2.______________________________________________________________________________________________________________________________________________________________________________________________________________________________

3.______________________________________________________________________________________________________________________________________________________________________________________________________________________________

Two most central Regional or Provincial agencies –

1.___________________________________________________________________________________________________________________________________________________________________________________________________

2.___________________________________________________________________________________________________________________________________________________________________________________________________

11. In your view has the level of integration and coordination among Eastern Door and local service providers improved substantially over the past year? What more, if anything, is required to achieve a satisfactory level of community coordination?

______________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________

14. As you assess the situation now, what improvements, if any, can be made to the Family Support Program to enhance its effectiveness in implementing the recommendations of the Eastern Door and assisting the parent/guardian and child in coping with their needs?

15. Any additional Comments?

Interviewer's Comments: