

Enhancing FAS/ARBD Interventions in the Prenatal and Early Childhood Stages in Canada

Prince George FAS Community Mobilization & Policy Development

Background

The Northern Family Health Society in Prince George, BC is well known for providing effective outreach services to at-risk pregnant women and families. Direct service delivery programs and activities include a BC Ministry for Children and Families Pregnancy Outreach Program, Health Canada's Community Action Program for Children (CAPC) and the Canadian Pre-natal Nutrition Program. The CAPC program is a Fetal Alcohol and Drug Effects Prevention program.

Additionally the NFHS is well known for its leadership of the Prince George FAS Community Collaborative Network and its project activities. The Network's goal is to develop a community policy response for the prevention of FAS through a community mobilization process.

Description of FAS Project:

(FAS Prevention Project: Connecting Community Circles- funded by Health Canada Population Health Fund 1997-2002)

In April of 1997, the Prince George Community Collaborative Network engaged in a community consultation initiative that focused on solutions to the prevention of FAS. Mind mapping was used as a means of diagramming our community's voice. Though this process did not always stay solution focused it provided us with an overall composite of the concerns and ideas that our community members held. It was a relatively quick and informative way of hearing from over 150 different community individuals. The information we gathered was staggering and the subsequent analysis was sobering. It was clear where our community of Prince George wanted to direct their energy in FAS prevention.

By 1998 we had completed a "blueprint" for our next steps in developing and implementing policies and solutions for the prevention of FAS based on the Mind Mapping information. (*Grounded in Hope: Our Community's Response to FAS*, 1998). This document gave direction to our Prince George FAS Network, a partnership of over 50 varying organizations and committed grassroots parents and caregivers.

The first step was to facilitate networking and communication among FAS Network participants and across all community sectors. Second, was implementing a Communication Campaign that would promote the guiding principles of women-centered care. And, third was the development, implementation and evaluation of an effective dissemination and transfer process of FAS community development. This entailed the documentation of learning's, accomplishments and outcomes of the Network's efforts to be used by other coalitions and communities in their FAS community development.

There are currently six Northern BC communities partnered with the Prince George FAS Network and the Network has five viable action committees working towards the community identified goals and policy development. Visit our website at (www.nfhs-pg.org).

One of the goals of doing FAS community mobilization & policy development work is to enhance the

CAPC/CPNP programs.

Perhaps the issue of how our work in community and policy development impacts on FAS and the work of CAPC/CPNC are best summarized in the words of a parent of an FAS affected child when she said,

" We know what we want. We need help now. We need respite now. We don't need or want more research and studies. We are dying out here. Since we have had the Network we understand what you [the Network, frontline workers, researchers] want better but it still doesn't change what we know we need. We now have a real resources center, with a co-coordinator and a list of accomplishments."

Development of Key Activities / Practices:

FAS Community Development

An example of an activity that was pivotal in beginning FAS community development in Prince George was the occasion when we held a FAS education workshop in 1992.

At the end of that workshop four of the parents came to me and said "we need to do something more in our community", so we formed a committee called the FAS Action Committee. Members included a public health nurse active in the Special Needs Adoptive Parents Association, a foster parent, another adoptive parent, a social worker, infant development consultant, and myself the coordinator of the pregnancy outreach program.

It was the parents who grounded the work of the committee. These were people who had previously demonstrated their desire for change by advocating for their child or by writing letters to the editor for example. We actively included and maintained these individuals in the Network specifically by mentoring them in the Network's activities to ensure their comfort and safety.

One of the first initiatives undertaken by the FAS Action Committee was an FAS community awareness campaign with grant funding from regional Alcohol and Drug programs. At this time, we made a decision to change our committee's name from FAS Action Committee to FAS Education Committee as members felt we would be more likely to be successful in receiving prevention funds. The campaign message was *Thanks for Caring. Friends, Family and Community: Supporting Mother and Child*. There was no message specific to FAS, but underlying the slogan was the subtitle-supported by the Fetal Alcohol Syndrome Education Committee.

FAS Policy Solutions

Our Pregnancy Outreach Program community advisory committee has also had a key role in moving our community forward with respect to the development of FAS related policies in our community. The membership of this committee included health and social service providers who also work closely with our client group (Native Friendship Center street worker, public health nurse, social worker, infant development consultant, parent advocates, pregnancy outreach worker, nutritionist, physician, alcohol and drug counsellor, hospital native liaison worker). The goal of this committee is to explore ways of improving the conditions in the community for our families. We work to address service gaps and barriers to accessing services in our community.

An example:

I was working with a client who was heavily using. She was pregnant with no prenatal care and in agreement to "detoxing". I accompanied her to the detox unit. They denied her a bed- apparently she had behaved badly during her previous stay. I explained that she was pregnant and asked that she be given priority of care. They said their hands were tied. Looking for another solution, I called the maternity ward to see if I could have her admitted there. I had been successful with this option in the past. However, it was a different charge nurse and she refused to admit her. Meanwhile my client became angry and agitated at the situation and left. I couldn't blame her. Monday morning the street workers called me to tell me that she had survived an overdose over the weekend. Monday morning we rallied together the street worker, the nurse from the needle exchange, the native friendship center alcohol and drug counsellor, a worker from one of the transition houses and a public health nurse who was committed to this issue. We landed on the doorstep of the hospital and demanded a meeting with management and the chief of staff. We were prepared to go to the media if they chose not to meet with us. At that meeting we listed protocols that we recommended be adopted. As a result of this opportunity our detox unit was the first in BC and western Canada to have written into policy "priority of admission for pregnant women."

The policy response was a direct result of this incident. Had we missed this opportunity, women may have been time and time again subjected to similar treatment. Additionally, our hospital agreed to adopt a policy of admitting pregnant women for detox on the psychiatric ward, as the staff on this unit are better able to respond to the needs of substance using women, and as a last resort, admission to maternity.

Now if we have a client who wants to be admitted to detox at 4:30 on Friday and the charge nurse who knows the policy has left for the day, we can refer the admitting worker to the policy manual. This is the only way of ensuring that agreements are sustainable. This started the ball rolling in looking for other ways to influence policy in our community.

Community Collaboration

We saw that there could be a benefit from reorganizing our community in some way to have more agencies understanding and responding to the issue of women and addictions and harm reduction. We needed to look at ways of finding individually tailored care for pregnant women requiring intervention. We wanted to look at different models and philosophies of approach.

The FAS Education Committee invited policy makers and program managers to the table to consider and discuss different ways of collaborating. We researched The Coalition for Alcohol and Pregnancy in Boston, Breaking the Cycle- Toronto and the Sheway program in Vancouver - all models for a collaborative community approach to responding to the issue. We submitted a letter of intent to the BC Health Research Fund to support this initiative. They urged us to submit letters or evidence of support from women with addiction issues. When this happened myself and others felt relieved! Something hadn't felt right...we had been moving ahead without having women participate in a meaningful way in the process. This is when we collectively made a decision to rein back and find out what grassroots women, youth and families would want to see happen in our community to meet their needs.

Prior to embarking in a grassroots consultation process we realized that if we were going to do the grassroots consultation we had to have the policy makers and the program managers at the table. There was no point in proceeding with the process unless there was an agreement that they would respond to what the grassroots were saying. The group discussed taking a population approach to

policy development in our community. There was a consensus and commitment to responding to this issue. There was also an agreement to formalize a larger FAS coalition that was named the Prince George FAS Community Collaborative Network (1997).

We began community consultation using a *mind mapping process* (described as a community development research method on the website). Front-line service providers were trained in facilitating focus sessions using mind mapping. This was an exciting and simple way of involving grassroots actively in the process of identifying solutions that would be grounded in our community.

Health Canada began to hear about the work that was being done in our community, involving diverse sectors in determining FAS policy solutions. They provided a population health seed grant to support documenting the historical action and a strategic plan for moving forward in our community.

Population Health Approach to FAS

We looked historically at what had happened in our community over the past 10 years. We documented it in a framework that would enable replication of the process in another communities. This led to an understanding of the context of the FAS action to date and gave voice to our communities' direction. We did a thematic analysis of the mind mapping data and went back to the participants to do a validity check. We asked, "Is this what you said?" They reaffirmed the data and gave more input and recommendations. We synthesized the information into a document that would give direction to the community. This document and the process that created it was our first attempt to work "upstream" in FAS work. It represented what our community wanted, and how our community wants to do it.

Key Project Activities / Practices that contribute to our Success:

Guiding Principles of the Prince George FAS Network

The Guiding Principles of the Prince George FAS Network are consistent with the population health - community development approach. These principles are useful in CAPC and CPNP programs as they move communities ahead in enhancing FAS/ARBD prevention and interventions in a community.

- To commit to a gendered perspective as an organizing principle.
- To develop a vision and goals which includes primary prevention as the number one goal but does not exclude selective and indicated prevention interventions.
- To commit to the principles of participatory action.
- To achieve consensus on the working definitions of "grassroots", "policy", "community", "prevention", "population health", and "participatory action research".
- To achieve consensus on women's right to choice and a common ethical perspective of the Network.
- To achieve a consensus to redefine the concept of prevention to include a broad continuum of prevention-intervention strategies.
- To work towards a common contextual understanding of "drinking and women" that includes health determinants.
- To develop and commit to a client-centered approach that embodies the principles of harm reduction.
- To ensure the continued education and skill development of Network members by providing ongoing training activities inclusive of the "grassroots".
- To provide communication and training opportunities that are accessible to the "grassroots"

and that encompass the principles in clear language.

At one point we realized that our membership and momentum of committees was in question, we'd forgotten to continue educating our membership and the community about FAS within the broad context of issues in our community. We were told by people, "while FAS is on your plate everyday, for us it is just one of the many problems that we are dealing with. We have a limited budget and resources so we can only come to the table so often". We thought about this wondering why it was perceived to be such a little issue when, for us, it is such a humungous issue? We said, ah huh we've been forgetting to do continual strategic awareness of FAS, within a population health context. We seemed to have this instinctive desire as human beings to zone in and individuate things so that they are in manageable boxes. When we do this however we forget the big picture and we also forget to remind people of the bigger picture. If we work together and do one piece at a time, take opportunities when they present themselves, be responsive and flexible and remember the bigger picture, change is sure to come.

Building Relationships

The importance of building and maintaining effective relationships is key in our community development work.

Partnerships are based on shared authority, risk, responsibility and accountability. Building such partnerships in Prince George has required that all members have a joint investment in outcome and access to resources. Through partnerships we have found solutions to complex problems; we have shared opportunities, knowledge and ideas. We find we make the best use of limited resources, can share costs and hopefully eliminate duplication of our efforts. Building strong partnerships requires skill, knowledge and experience. It also requires a less territorial way of looking at our work. Collectively, our Network has a useful concentration of all of these. The Prince George FAS Network has spent a good deal of time cultivating membership that is involved and committed to shared vision, goals and objectives. We have a detailed action plan, effective communication processes, efficient use of resources and a commitment to evaluating and realigning our project as needed.

We have found that small things make a difference in fostering relationships in community. For instance, we found with diversity of membership, that language differences existed. We worked to recognize that there was more 'sameness' than differences to the "labels" in our language. We dialogued these 'samenesses' and explored new ways to be inclusive in our choice of language for discussions. This helps to ensure all levels of comprehension at the table.

As well, we intentionally hold our meetings in a circle. In the circle everyone is equal and everyone's contributions are valued. This may seem like an insignificant detail; however, the use of a circle is consistent with our philosophy and principles and it sends a clear message of our commitment to equitable, respectful work.

Shifting Attitudes

Impacting community shifts in attitude is still our biggest challenge. We can remember when our Regional Director of Alcohol and Drug programs didn't understand how FAS related to their services. She didn't understand where A & D programs fit with this issue. After becoming involved as a member of the FAS Network she became one of our biggest champions in moving the issue forward. However, she is the first to admit that it took her awhile to shift her attitude and develop an understanding of the issue. Now she sees that a high percentage of people in treatment are youth and adults living with FAS and that a woman who has had a child with FAS is more likely to have

another child with FAS. So, people in treatment need to be educated about FAS and need to have free and easy access to birth control if they are still substance using.

Community awareness and education are seen by many as key prevention strategies. When looking at how that education will be done or what awareness will be communicated in a community, we found that we were facing the difficulties inherent in major attitude shifts. People in our community, especially the service providers, needed to be engaged in discussions around the causes of substance misuse that leads to FAS. Attitudes towards women, drinking, FAS affected individuals and pregnancy were our major stumbling blocks.

To ensure effective policy and program development, the underlying causes of substance misuse and Fetal Alcohol and Drug effects needed to be made visible and then dialogued. We have worked long and hard to educate and bring awareness of alternative ways of thinking and believing about this issue.

In part, the medicalization of substance misuse has resulted in the use of disease-oriented language. This in turn has contributed to an attitude among workers and policy makers that allows for only a narrow definition of prevention. We found that the lack of ability on the part of medical and social service workers to reframe from a "problem" to a "solution" based approach was in part responsible for their inability to shift their practice responses to be more responsive and respectful. The global move of social services away from holistic and humanized concepts in their work and attitudes in the past decade is an obstacle in effective prevention and policy development.

Shared vision and common understanding

Having a shared vision of a healthy community is an important foundation for doing the Fetal Alcohol Syndrome work that will be required in our communities. Women are the primary targets for blame when the issue of FAS comes to the forefront. We hosted four different workshops with the goal of helping our community move towards viewing health as a more inclusive concept that considers the collective well being of our community and what we can do for each other and with each other. This kind of community action is a progressive, change-oriented process that has assisted our community members in identifying, valuing, managing and choosing healthier options for themselves, their families, their clients and the community.

We had a conference called *Reframing a Social Issue; Families, Substance Use and FAS*. The goal was to promote a population health approach to FAS. We reframed FAS from an individualized addiction issue to a social issue with its roots in poverty, violence, literacy and abuses. We included workshops such as Men's role in FAS Prevention, Politics and FAS. Some people really struggled with that. They asked "what does that have to do with FAS?" It would be interesting to follow those individuals and see if they make the connection in the future. We're so accustomed to picking people out of the bottom of the falls and not making the connection of what works in an upstream population health approach. We see only the person swimming downstream. It is our job in facilitating the FAS Network to help people make these connections and give that perspective to shift attitudes. We do this through our naming and reframing of language, the kind of communication campaigns we do, and by putting on workshops that are a little "out of the box" to broaden the issue.

FAS Community-based Policy Solutions

There was nervousness on behalf of some of the policy-makers in wondering what the grassroots would say that they needed and whether or not they could respond. But, in actual fact what we found is that they want and need the some thing. It is just said in a different way. It wasn't that complicated.

The biggest part of what they wanted was a change in attitude and how they are treated. The agency's and service providers' attitudes and a more collaborative approach between systems doesn't require extra dollars. It simply requires doing work differently, seeing women and families differently. This was a clear message from the grassroots.

Caregivers said we just want teachers, store-keepers and our neighbors to understand our kids. We don't want them to see our kids as stupid, non-compliant, bad kids. We want people to understand that our kids are children with a disability. We want people in our community to understand that it is an invisible disability and that we need their support. Caregivers and parents aren't asking for "preferential treatment" but "differential treatment." Differential treatment simply means that you have to start looking at the situation differently, rethinking a way of doing things differently for the child to be successful. We need to realize that it is not about doing things harder but instead it is about doing things "different". These solutions require no extra dollars and yet they require an entire shift in attitude.

FAS as a Community Issue

A prime time for our FAS Collaborative Network was an interagency networking event we held called *Developing a Community Approach to Supporting Pregnant and Parenting Women with Substance Use Issues*.

Until this time any events we held were primarily called "FAS" workshops or meetings. We found that by changing the focus from "FAS" to "Community Supporting Women with Substance Use Issues" changed the dynamics. We also found that holding the event in a circle facilitated a more collaborative environment for participants. We had people from outlying reserve communities and the aboriginal community clamouring to attend when they had appeared to be missing in the past. This was a real learning for us as we realized how important language is ... Perhaps they had been uncomfortable coming out to an FAS event previously because of the blame and the shame and the history in their communities, knowing that many of them had family members affected.

Community-based Harm Reduction

The most significant learning at this event was that harm reduction during pregnancy isn't just about reducing or abstaining from alcohol and drugs but about providing mothers with enough food to eat during pregnancy, being sure they can access transportation to get to their doctor's appointments and having women feel safe in accessing programs and services.

This event gave people the broader picture ... it took the issue of FAS and expanded it into a broader context of poverty, violence, and trauma. It took the issue away from a women-blaming stance. It reinforced the importance of having community service providers, agencies and citizens on the same page with women-centered basic guiding principles. Previously, providers had the impression that you had to be an alcohol and drug counsellor to be able to assist women with addictions and to prevent FAS in our community. The issue of FAS was de-medicalized and demystified.

Redefined Prevention in FAS work

Redefining prevention of FAS was another important process for the FAS Network. This prevented the splintering of energies. Previously, members would say, "I'm not interested in prevention or I'm not interested in intervention". Splitting the community was not going to be advantageous for moving FAS action ahead. By redefining prevention across the lifespan, we were able to touch the many

dimensions of women's, children's and families lives. This was another big Ah Huh, for us.

The redefining of alcohol and drug treatment and the acknowledgement of different women-centered philosophies of approach was another epiphany. Treatment is not just about going to an alcohol and drug counsellor, or into a treatment centre. It is about emotional, physical, spiritual and mental healing and discovery. The D.E.W. (Days, Evenings Weekends) medium intensity program based on Charlotte Kasl Davis's work "*Many Roads, One Journey*" was a big part of our shift in thinking. Participants were also introduced to the TWEAK and TACE, A & D screening tools and others to help identify women at risk. There was recognition that everyone in the room, whether working as a nurse in the nursery, labour and delivery, a street worker, or in a women's transition house, was valuable in assisting women to reduce or abstain from substance misuse. We didn't need to be an expert to do this work.

Also key was the fact that the counsellors in the room working in the area of detox, alcohol and drug outpatient services and residential treatment were giving permission for others to do this work. They assured us "We can't do it all so you won't be tripping over our toes. By the time women get to treatment providers the need is for intervention at the far end of the continuum, we would hope that others are providing prevention and early intervention." This was a new awareness of a desire to share this load and an understanding that there was no need to worry about territoriality. We are all doing important elements of this work.

FAS Roadmap to Services

This event also led to identifying the need to develop a roadmap to FAS related systems; agencies and persons within agencies providing FAS related services in our community. This was the beginning of our FAS roadmap of services in our community that encompassed prevention, intervention, and support to families. We realized what was needed was a user friendly roadmap ... if you phone the number you would get assistance at that point of entry and not be passed on to another agency. Parents were a successful part of our community reorganization as they placed the calls that located the services for the road map.

Building Community Capacity

We identified that people were at different levels of understanding and skill levels within the Network. We realized that if we were going to develop a common base of guiding principles that come from the same place in terms of our knowing and therefore our doing, that it was really important that people have the opportunity to continue their education and development. We committed to ensuring that such opportunities happened. Giving back to each member of the Network, always refilling their cup, never sending them away empty. This has been key to their continued participation so that they keep coming back to the circle and are committed to the process, a sense of belonging. It is about meaningful participation and involvement. Meaningful is sometimes misinterpreted as what can we get out of participants and not enough about what can be shared in consultation with full and meaningful participation between all affected segments of the community.

FAS Communication Campaign

We recognized the need to have a continual Communication Campaign, a continual way of raising the community's awareness about the issues, about keeping FAS front and central in people's minds, but also from the right angle of understanding. Not from the women- blaming stance, "If the woman would just stop drinking then she won't have a baby with FAS." This gave root to the Creating

Solutions research with the BC Health Research Foundation. If we are going to look at this issue broadly and be true to our principles, we have to look at substance use and how we can help women to understand their substance use within the context of their lives, the community and society. How do we tell people, including service providers and citizens, in a simple way what substance misuse is about, so that they can start to understand it from a population health perspective? Women's substance misuse is rooted in so many other issues. If we can get a contextual understanding of this then we are going to enable the community to see that FAS is a symptom of something else and put it into perspective so that they know the connection whether you are a drug and alcohol worker, a neonatal nurse, or social worker or just 'Jill public'.

The job of educating the community is never done. We have to keep plugging away at this community. We continue to ask ourselves how do we keep people coming to the table? Keep them interested? Our action committees are highly committed and action oriented. We discovered that it is easy to get caught up in the task- oriented focus of doing FAS work. We realized at one point that we had lost sight of the continued need for a communication campaign ...the education, the awareness, the development of solutions and policies have to be in motion together. People change. There may be five people actively working in a committee, then, two new members join the group who may see things differently. This means taking steps backwards for a while before taking giant leaps forward again. It is important to take the time to get everyone on the same page of understanding. This is hard to do. It requires patience, faith and a belief that even though you are stepping backwards and things feel out of control that it is going to get us where we want to go.

As a result we stepped back and reviewed our communication strategy. We had another workshop to create a more general message that could be used to identify our Network and by all the action committees in their community work. We are currently seeking funds to implement this campaign.

Influencing Policy

The Women's, Infants and Children's Treatment Center Program is being built in Prince George. The Creating Solutions researchers met with the director to share their research recommendations with respect to programming. They asked her to consider that a lot of women in treatment will be FAS affected and have a limited learning ability. Traditional cognitive therapy may not be effective. They discussed with her the need to adopt a variety of approaches to individually tailor treatment for women with differences. They suggested providing shorter modules to enable women to easily move in and out of the "discovery" process (we call recovery), as the needs of their families dictate. Example: This would allow a "stages of change" approach. Women may only get through the first module if they are in the contemplative stage or if they are unable to continue due to other circumstances. This would not be perceived as failing to complete treatment.

Because of efforts of the FAS Network some people in our community are beginning to shift their attitudes and incorporate identification of women at risk, harm reduction and women centered approaches into practice.

We are now in the process of conducting key informant interviews to document what integrated practices of FAS prevention and support looks like in human service delivery. We want to develop the findings into an interagency collaborative FAS best practices model. This is part of our historic development in the policy development work that our FAS Network has embarked on. This is how our community has reorganized and developed interagency protocols to collaboratively address the issue within a population health context.

Regional Development

Building community capacity required that we also assist other communities in their learning process. Living in the North however and contending with dangerous weather conditions, isolation and inaccessible roads; we had to find other ways of communicating despite geographic and climate problems. To do this and to build a stronger community, we developed a website primarily geared to community development but also inclusive of our Prince George Networks activities and research results. We also made the commitment to mentor other communities by traveling to those communities during warmer weather and accessible times of the year.

One important aspect of working with other communities is the ability to determine their readiness for change and development. On the website, we created an extensive *Indicators of Readiness* checklist. In completing this checklist, which could take up to a few days, communities were stimulated to discuss significant issues such as available resources, guiding principles and who really is involved or not.

A large part of learning is the ability to reflect on our activities and gain insights and wisdoms. We found when we started to be approached by other communities to initiate FAS development, we needed to be able to articulate and demonstrate what we had done and were doing.

As we began to document these learnings to share with other communities, we realized we were achieving two goals. One, to mentor other communities in population health approaches and two, to assist our community in taking a good look at our practices; the good and the bad.

Restorative Justice

Restorative justice and FAS is the most recent issue that our Network has chosen to focus on. A new action committee has formed and a proposal is being developed to bring restorative justice principles into the work with FAS affected individuals in conflict with the legal system. This proposal developed for the National Crime Prevention Center is based on the principles of crime prevention through social development, a foundational strategy that addressed the underlying causes of crime and is basically a population health approach applied to the justice system.

We have come to understand that no matter the discipline; health, social work, justice or even business, the terminology may be different but the principles are the same. In demystifying the language and finding common ground for our "upstream" work we are better able to affect the FAS/ARBD interventions in prenatal and early childhood.

Staff Support and Training Needs:

Celebrating

We have found that one very important component of ensuring sustainability and continued commitment to our FAS Community Development work is to celebrate our successes. So often we are unable to see the tangible results of our efforts and instead focus on all the work that is yet to be done. As a coalition, we have learned the importance of coming together every three or four months to share and celebrate our circle of knowledge, progress and successes. In doing this, we are able to help those new to the circle or those just reentering to adjust, get caught up and see the rewards, intrinsic as those are, to the difficult and dedicated work of our volunteer FAS Network

When we completed the Grounded in Hope document we had a big celebration with strawberry shortcake and decorations and some fun. We wanted everyone who had been involved to know how important this step was and to recognize the massive efforts that were required to get to where we were. We reviewed the document and the recommended directions, got a renewed commitment and promises for continued involvement, then we all took a break over the summer, agreeing to meet in the fall.

At each of our large Prince George FAS Network meetings we have had a recognition ceremony of some kind. The first event recognized the assistance and support of various organizations in our community who had contributed to the work of the Network. The organizations' representatives were awarded certificates. At the second big event we recognized our parent supporters. These were parents who had been fundamental to the development and to the integrity of our Network. They were awarded plaques given with our gratitude for all their hard work.

Inclusive Membership

In our FAS circle everyone is equal. Everyone has a lot of strengths and assets to bring into the circle. Many times people will say, "I'm not sure why I'm here, I don't have much to offer." We always challenge them about that by asking them what they bring in the way of life, volunteer, or work experience? For example, a foster parent who has fostered kids with FAS for six years has knowledge and skills beyond any imagination.

Our membership is as inclusive as possible. It is understood that people will come and go. That can be one of the frustrations but it can also be viewed as one of the strengths, because people know that they can move in and out of the circle. It doesn't matter who they are, they have something valuable to bring to the circle and always the circle can expand to include grassroots affected, service providers, parents and policy makers. In order to have this work we encourage participants to mentor new members. We try to keep the language simple and the process understandable. New participants are encouraged to talk to their neighbour if there is something they don't understand. We use fun ways of doing this such as distributing whistles for people to blow if someone uses a big word or an acronym that they don't understand. This keeps it real, fun and ensures the information is useful to everyone equally.

Another learning was that action committees identified that an hour isn't long enough to meet and they appreciate fewer meetings for a longer time that are more like a workshop format. It seems to better meet the needs of participants. Often we will hold meetings from 10:00 to 1:00 for example, 2 to 2 1/2 hours. We combine learning for participants with strategic planning for the Network, and networking and sharing over lunch.

We knew that there would be many "busy" policy makers who would be unable to commit to a continued attendance at our Network meetings. But we also knew that we needed to keep them aware of our initiatives and informed about the direction we were taking. For this reason we decided to keep the membership in the Network fluid. We continually encouraged new members and old ones returning to attend a meeting every so often without it affecting the overall momentum of the group. In the interim we keep them informed by sending them newsletters and updates, by means of fax, email and our website.

Evaluation Activities:

We have chosen to measure our success and learning goals with a participatory evaluation that is consistent with our principles of shared power and knowledge. This method in itself can be conceived

as community building, as it requires the active involvement of Network members. This process is initiated at the beginning of the project being evaluated and continues throughout the duration of our work. Participatory Evaluation (P-E) is a collaborative activity, which allows people to take a more active role in defining their outcomes. This approach builds on strengths and values the contributions of everyone involved. This is consistent with the inclusive nature of community development. However finding individuals with the expertise to do participatory evaluation is problematic. The one individual in Prince George who is skilled is over-committed and there have been some difficulties meeting deadlines. The use of Participatory Evaluation was to help us to further recognize the complexity and depth to which policy influence and affects the work of those living with the effects of FAS/ARBD as well as our work of continuing to shift and channel the work of those who deal with this issue in service and government agencies.

Fostering Sustained Community Change

We have found patience to be one virtue that requires a lot of special effort. For many of us who are task oriented we assume that the outcome is the most important event. Not so, in community, the process is the most integral part of building capacity and developing a sustainable community that feels empowered. Community work requires less of a "me" orientation and much more ability to go outside of us in believing in the process and having faith that everything happens for a reason. We do not have mistakes in our work, only learning opportunities. We do not have failures in our development, only more information on which to build our vision and help others know where they may or may not wish to go in their work.

There are six key elements to fostering sustained community change. In doing FAS related work they are even more important because we are working with individuals and families who are disadvantaged and seldom given their sufficient due for their knowledge and years of experience. In other word, they have been devalued by many of the community members who say they are there to help. Don't shortchange anyone of these (either the people or the elements). (Labonte et al, 1999)

1. **Relationship building** - trust, accountability, power sharing and social support. Families of FAS affected are often continually in crisis or at the very least, stressed by the added work that a disability can bring. They require more support and understanding than most people are prepared to give.
2. **Effective Participation** - control of decisions by those affected, involvement in action, inclusive processes and democratic decision making. Without meaningful involvement, most grassroots people will fall away from the process of community development. Remember that because their role has often been minimized they will require mentoring into genuinely equal partnerships with professionals.
3. **Leadership Development** - including partnership development and coalition building that is inclusive of those FAS affected and their families. Building capabilities for FAS affected individuals and their families can take place in leadership development. We simply need to adjust our thinking around what "should" be done and what "can" be done.
4. **Resource Mobilization** - financial resources, internal and external capacities are built and support from **all** others is considered a resource.
5. **New Energy** - vision, concrete outcomes and improved conditions. A most exciting piece of FAS work is the continued new information and research that we learn that makes us rethink our ways of doing our work. For instance, at a workshop in Winnipeg, a presenter had us questioning the benefits of harm reduction after she suggested that reducing harm would in fact reduce the severity of FAS to perhaps FAE. But did this really assist the affected individual because now they would have fewer services or claims to resources to help deal with a similarly debilitating disability?
6. **Reflection** - Learning, evaluation, accountability and analysis. Without a doubt, our ability to reflect on our work has allowed us to connect the various pieces of our intervention and

prevention work into a mosaic of strength and promise.

Internet - A community organizing tool

The Internet is more than a learning environment. It is a community-organizing tool. This technology increases the availability of a wide diversity of ideas as well as facts. The information that is shared is seldom "filtered" by our media, corporations or government. We believe the Internet provides great promise as a forum to influence political discourse and thereby affect policy and practice in the area of FAS.

We also see that equal access to this tool is a relevant issue that must be addressed. Our Network has worked to ensure computer and Internet access to our families and to FAS affected individuals. Inter-connectivity is a prerequisite of being a part of a community and larger society. Access to this technology can assist our families in feeling connected and supported.

The challenge will be learning strategies that assist this group of users with gaining success with this often-frustrating technology. Fundamentally, our work is directed by the belief that through building in successes, those without power, FAS affected and their families will be empowered.

Regionally, individuals in remote, rural and isolated areas can tap into our local knowledge, resources and experiences. We can share ideas; information and importantly we can dialogue our successes in prevention and intervention work for FAS.

References

www.nfhs-pg.org

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