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**Bulkley Valley**  
**Fetal Alcohol Syndrome**  
**Community**  
**Mind Mapping Project**

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**Smithers, BC**  
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## Introduction

The initiative for this project came from the Smithers Fetal Alcohol Prevention Committee in keeping with their mission statement:

*We acknowledge the value of all people and believe every person has the right to the highest quality of life. Therefore, we are committed to advocating for FAS prevention, support, and resources that promote changes to strengthen individuals, family groups, and communities in the Bulkley Valley.*

This committee was formed in 1997 and since then has done a number of projects in the community including:

- Yearly checks at the local bars to ensure they are displaying signs of the Smithers bylaw #1148 which states: *Beware. Drinking beer, wine, coolers and any alcohol during pregnancy can cause birth defects.*
- Advertising campaigns on Mother's Day and during the Christmas season
- Producing the "Please don't drink if you are pregnant" stickers
- Attending the Fall Fair parades
- Mall displays during Alcohol and Drug Awareness week
- Radio interviews during Alcohol and Drug Awareness week
- Newspaper articles every six months
- Building a resource library
- Handing out awareness pamphlets and discussing fetal alcohol syndrome on FAS Awareness Day
- Writing the proposal for the Needs Assessment project, getting the funding and hiring a coordinator
- Hosting a theoretical strategic planning session with Carol Legge in October 1998
- Hosting a workshop with Dr. Asante in October 1999

One of the goals established by this committee provided the basis for the issue identified for study. This goal is in the category of research and states, "To ensure that all suggestions for changes in the Bulkley Valley are based on accurate community based research to determine the community's perspective on the needs, concerns and possible solutions around FAS." The committee anticipated that this project would accomplish the following:

- It will provide a needs assessment for those affected by FAS
- It will provide an evaluation of the impact of FAS on the community as a whole

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They expected the benefits would be:

- It will raise the awareness of FAS issues in the community
- It will develop a common understanding of FAS
- It will define a community plan of action on How to address FAS
- It will provide a document that will help in the seek for further funding

The committee chose the mind mapping process as the most efficient, inclusive and economical means of obtaining an effective community response. They expressed the idea that, “The community based initial research will illustrate themes of FAS related community problems that need to be addressed. With the mind mapping results and the support of the community, the committee will be in a better position to access funding to deal with the prevalent issues. We believe this project will allow the community to become involved in a participatory capacity with the ongoing work of the Smithers FAS Prevention Committee.” They also state “ The outcomes will be measured by the mobilization of the community around the issues of FAS. The attendance at the mind mapping groups, the number of people involved in the Smithers FAS Prevention Committee will be indicators of the success of this project. The ability to access funding for specific projects will also be a measure of the success of the project.”

Based on these recommendations and goals of the Committee, the Mind Mapping Sessions began. There was also guidance from the Prince George Fetal Alcohol Syndrome network who went through this process in their community (Grounded in Hope, 1998). Key people in agencies throughout the community organised the people for the Sessions within their agencies. Nineteen Sessions were planned and seventeen were conducted.

The results from these Sessions were summarized and a Meeting/Luncheon based on these summaries was held with representatives from each Session. Thirty-five people from a wide cross-section of the community attended the final meeting. The results from this meeting form the basis of the community recommendations.

Although the results from the Mind Mapping sessions are presented in detail the participants have not been named in order to maintain confidentiality.

A postcard campaign was also conducted. Four hundred stamped and addressed postcards were distributed throughout the community. These cards asked the question , “ What does Fetal Alcohol Syndrome mean to you?” Fifty-two (13% return) responses were received and these are summarized as another part of the community response.

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## **Mind Mapping Sessions**

Mind Mapping is a participatory action research process. It is essential for the community to participate. For this reason it was chosen as the research process for this project. The process has been well defined by the Chris Leischner, 1999 while working with the Prince George FAS Network. This description follows below.

Mind Mapping is a tool for assisting and enhancing many of the styles of thinking and learning that we are required to do in our work. Though it has been primarily used as a learning skills tool, we have developed it as an information gathering tool where ideas can be elicited and then utilized to further develop a community building solution focused process.

### **How To Do a Map**

See the sample map shown in Figure 1.

1. Print in capitals for ease of reading and to encourage you to keep the points brief.
2. Use unlined paper (banquet paper works well and is inexpensive) since the presence of lines on paper may hinder a non-linear process. (If you must use lined paper turn it so the lines are vertical).
3. Use paper with no previous words on it.
4. Write the main idea in the middle of the page – it may be a word, a phrase, or a couple of juxtaposed ideas.
5. Put related ideas, words, or phrases around the main ideas using lines that radiate out from the central idea like spokes. When you get a new idea start again with a new spoke from the centre.
6. Go quickly, without pausing – try to keep up the flow of ideas. If you are using this in a group process, do not allow the members to ‘process’ the ideas, to make comments or to explain, just get the ideas on the paper. Do not stop to decide where ideas should go. (Ordering and analyzing are ‘linear’ activities and will disrupt the Mind Mapping process).
7. Write down everything that is thought of without judging or editing – this disrupts the flow.
8. You may want to use colour coding to group sections of the map.
9. One technique of Mind Mapping is to then further explore each idea with related ideas branching out from those ideas.

### **Advantages of Mapping**

Mapping is sometimes seen as a form of brainstorming. Both of these techniques work to encourage the generation of new materials, such as different interpretations and viewpoints. However, Mind Mapping relies less on random input and more on providing



Figure 1. A portion of a sample Mind Map

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opportunities for fitting ideas together. In this format no ideas take precedence and all ideas are connected to the centre.

Here are some advantages that will become clearer to you as you experience the Mind Mapping process:

1. It clearly defines the central idea by positioning it in the centre of the page.
2. It helps you to clearly indicate the relative importance of each idea.
3. It assists in 'seeing' the links among the key ideas more easily.
4. It positions all your basic information on one page.
5. As a result of the above it assists with making recall and review more efficient.
6. You can add new information without messy scratching out or squeezing in.
7. Because it does not lock the information into specific positions it allows you to see the information in different ways, from different points of view.
8. You can begin to see complex relationships among ideas.
9. It provides a foundation for questioning, encourages discovery and creativity by showing up contradictions, paradoxes and gaps in material.
10. Mind Mapping is a relatively easy technique to teach and implement. For this reason it can be utilized quickly, with different groups of people, and produces abundant information.

### **Smithers Mind Mapping Sessions**

The materials used for the Smithers Mind Mapping sessions are shown in Figure 2. The ink from the fine tipped felt pens should not mark through the paper. The red ink pen can be used to write the names of people who want to participate further directly onto the map and be visible. The reference book has all information at hand and a place to record names of participants and any important details or questions from the session.

To conduct a session:

- Plan and confirm the session with a key person in the group or agency
- Arrive early
- Set up the room, large table in the centre of the room with chairs pushed away
- Roll the banquet paper or newsprint onto the empty table
- Open session with introductions (record names) and a brief explanation of the process
- Find central focus of the group
- Conduct Mind Map
- Discussion, get names of people interested in particular issues (write in red )
- Explain continuation of process
- Hand out postcards

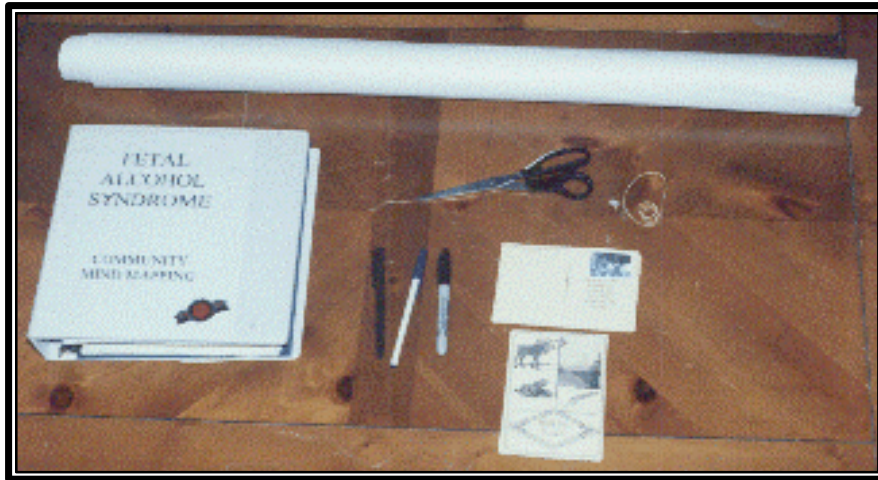


Figure 2. Materials used to conduct Mind Mapping Sessions: roll of banquet paper, reference book, scissors, elastic band, black fine tipped felt, red ink pen, blue ink pen and blank postcards.

### **Response to the Mind Mapping Sessions in the Smithers Area**

There were seventeen successful Mind Mapping sessions conducted in the Smithers area. There were actually two more scheduled and a number under consideration but these did not work out. It is hoped that these missed groups can be contacted later in the next stage of this process.

Each of the Mind Maps was summarized as written with no attempt made to clarify and thereby possibly change intent of the comments. Neither the names of the agencies nor participants are included in the summaries that follow in order to maintain confidentiality.

#### Group I

Central Focus: **INTEGRATED COMMUNITY**

#### **Subjects**

Women's Issues

#### **Topics, issues and solutions from your map bubbles**

Prenatal care  
 Support  
 Employment/ wage equity  
 Cultural inclusion

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Women's Issues	Counselling, especially on partner issues Removal of blame
Education (awareness & prevention)	Awareness Elementary school FAS education Public Health Nurse in schools School board support
Education (support & working with FAS)	Integration Youth programmes Community participants/ community issue School support for FAS
Support	For parents and family Need an FAS worker in the community* Dental care
Diagnosis	Statistics Avoid labelling/ stigma Understanding Positive/ acceptance Countering prejudice
Judicial System	Youth programmes Family justice forums Understanding
Day care	Social integration Observe postnatal motor delays
Alcohol	How to drink responsibly Media support Create culture of nonuse/attitude Alcohol and drug prevention
FAS Campaign	Show people the importance of FAS Organised campaign Partnerships/high profile groups

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FAS Campaign	Publicized Process/address issues Nonconfrontational Build support structures Buy into community issue Fun/music/easy involvement Solutions
Media	Positive
Services	Transportation Alcohol and drug counselling Pregnancy support Bring services to clients

**General Statements related to FAS made by your group:**

- Blame
- Isolation
- Marginalization
- Barriers
- Poverty
- Funding
- Self esteem
- Stigma
- Mental health
- Barriers
- Spirituality

**Group II**

Central Focus: **PREVENTION**

**Subjects**

**Topics, issues and solutions from the Map bubbles**

Education	Awareness of drinking during pregnancy Target high schools Workshops Training Information/written resources
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Outreach	Pregnancy Outreach Programmes Pregnancy Planning Not Drinking Alcohol and drug counselling
Support	Individual 1 on 1 Groups Mothers Those affected Healthy baby workers Certified Alcohol and drug counsellors Dedicated workers Drop ins Family support/ go out into the community
Employment	How to get a job Job search/ career/ resume/ cover letter/ presenting self Employer awareness
Community	Community accountability programmes Alternative justice resolutions Consistency
Alternatives to drinking	Exercise Cook healthy Role models Support groups Money for activities Native cultural alternatives
Advertising	Graphic posters and ads More symbolic/ tangible in association with FAS Radio/ cable/ posters/ newspaper/ hotline
Residential Schools	Power/ control/ modelling Lack of parenting skills/ family breakdown Government and bribery Children can't speak Lack of communication/ can't express themselves Sexual abuse/ drinking with the priests

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Residential Schools	Show support by counselling Help find a voice
Assessment	Awareness/ community/ courts Money for doctors for assessment Awareness of FAS factors
Reserves	Need to change Real world Anger/ hatred/ jealousy/ negative Frustrating Band politics/ outrageous rules Chiefs lead families

**General Statement relating to FAS made by group:**

- HIV
- Birth control misunderstood/ unprotected sex
- FAE/ not obvious except behaviour
- FAS/ behaviour/ small frame/ labels/ slow/ stupid/ older/ steal/ slow development/ mental deficiencies/ illness/ problem with brain/ physically disabled
- Struggle
- Challenge
- Lack of communication

Group III

Central Focus: **COMMUNITY BASED HOLISTIC APPROACH**

<b><u>Subjects</u></b>	<b><u>Topics, issues and solutions from the Map bubbles</u></b>
Prevention	Teach kids to make personal choices that affect their lives early in life
Diagnosis	Tools? Questions? Who has FAS? Not aware Recognition Support

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Diagnosis	Can form a community strategy for people identified Assistance at a young age Acknowledgment Referred
Resources	Educational material Referrals Diagnostic tools Services/ programmes Structured environment
Research	Key
Residential schools	Past/ anger/ blame/ guilt/ abuse Future/ healing/ move forward Strength How to heal
Ongoing funding	Inclusive/ working together/ community plan Communication Different groups/ different parts Not just project-based
Alcohol	Don't condone drinking First Nations more susceptible to alcohol Alcohol based culture/ "Drink after work" Underage drinking/ lack of self confidence Lifestyle/ drink/ sex/ pregnant Peer pressure
Support	For families Daycare Support groups Library Care plan Stimulate parts of the brain
Pregnancy	Don't drink during pregnancy Pregnancy planning Planned Parenthood

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Public Health	Population health Prenatal information Helping families Community development experience
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**General Statements relating to FAS made by group:**

- Cycle/ FAS/ drink/ pregnancy/ addictions/ denial
- Guilt/ blame/ lack of understanding
- Punishment
- Media/ alcohol focused

Group IV

Central Focus: **INCLUSION**

<b><u>Subjects</u></b>	<b><u>Topics, issues and solutions from the Map bubbles</u></b>
Awareness	Education Schools Fit student needs Different learning needs Doctors Judgement/ preconceived notions
Advertising	Warning signs Bar signs On bottles Not fun or benefits
Diagnosis	Recognition Relief
Communication	Is key* With general public May deal with someone with FAS
Support	Referrals Resources Learning needs Developmental needs

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Education	Someone to work with them Community Awareness
Pregnant Moms	Support workers Harm reduction
Money	Where it is needed
Responsibility	Fathers Parents People in power
Lifestyle	Parenting skills

**General statements relating to FAS made by group:**

- Slower kids
- Stress
- Misinformation
- Preventable
- Anger
- Lack of skills
- Client/ all ages
- Crime
- Grief
- Guilt/ blame
- Socioeconomic
- Discrimination

Group V

Central Focus: **LIFE CYCLE**

**Subjects**

**Topics, issues and solutions from the Map bubbles**

Education	Schools need to participate Prevention education in schools Men need to know
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Education	Educate kids about FAS Remove targeting Forgiveness Start people talking
Money	FAS ignored because of lack of money
Prevention	Ban alcohol commercials Warning labels Liquor stores need signs
Parenting skills	Daycare Childcare
Assessment	Awareness/ recognize signs Acknowledge condition Awareness of reasons for behaviour Understanding
Structured support	Street people Social support Support workers Treaty offices need to address problem on reserves
Residential schools	Not only a Native problem Integrated community healing process It's time to recover Healing pole at SSS Friendship Centre is a beacon/ colourblind
Money	FAS ignored because of lack of money
Research	Determine physical results What are other countries doing? Precise amount of alcohol Universities need to stop stupid research Research alcohol/ prevent addictions Does Desipramine work?
Justice	Educate judicial system on FAS Jail / support on release/ daily structure/ gentle rhythms Jail is not a suitable consequence

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Community understanding	Community based programmes Not regional programs
Drinking	Teen rituals/ drinking is part Abortion is better than FAS
Focus on gifts	Overcome negative aspects
Respite	To caregivers No cost
Employment	There are lower skilled jobs Recycling/ catering/ shredding
Home support	Poor housing/ poor environment Need a place to go Meeting place/ crafts/ laundry/ washing facilities/ cheap lunch Need decent standard of living
Services	Lifetime Free Burns Lake model Adult life skills
Groups	Integration into social groups/ eg Cadets Busy in good things
Doctor	Trained Bring up subject of FAS to every pregnant woman Assessments

**General statements relating to FAS made by group:**

- FAS is a lifelong limitation
- Want healthy babies
- Cycle
- Frustration/ depression/ hopelessness/ blackness
- Low self esteem

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Group VI

Central Focus: **PREVENTIVE EDUCATION**

<u>Subjects</u>	<u>Topics, issues and solutions from the Map bubbles</u>
Support	Pregnant women Families/ before and after birth Expand programs/ eg Pregnancy Outreach Programme
Education	Factual Public Awareness Breakdown stereotypes and stigmas Remove mother's guilt Teacher training
Cultural	Lack of public places to socialize/ alcohol free Need alcohol free events and programmes
Alcohol	Zero- tolerance
Money	Given to foster parents but not natural parents
Medical Intervention	Accurate and early identification
Government	Social cures are not the government priority Support/ more cost effective than the costs to court and medical system How to get through to their accountants
Schools	Need teacher training Counsellors do administration Not set up to do social work Only 1 alcohol and drug worker in the whole system Teachers don't continue on as students move through system
Community	Acceptance/ Raise level of awareness of all people and ability to respond Church support The Zone Need a Rec. Centre* Community systems/ anything that helps us take care of one another Know what services are available

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Merchants	<p>Consumers' world          Merchants are in public forum          People with agendas          People lean toward issues that touch their lives and families          Priorities are consumer demands, government regulation and trying to keep up with the electronic market          Are constantly asked to support all causes that are in the community and pick their "favourites"</p>
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**General Statements relating to FAS made by group:**

- FAS is a symptom of how we deal with the disadvantaged
- Regular system doesn't meet the needs of FAS kids (or any other kids) / hope they disappear/ end up on the streets/ poverty
- When damage is done, what can you do?
- Teen pregnancy high/ denial factor
- Institutions become the extended families

Group VII

**General statements relating to FAS:**

- Needs recognition and proper intervention
- It's been around a long time
- Don't drink when you are pregnant
- The cycle can be broken/ there is great hope
- More government is required
- No known safe level/ avoidance is best
- Your baby comes first/ think of him or her before you drink
- Values in the home
- Don't drink extensively at home
- Moderation has got a better taste
- Totally preventable
- An unasked for inheritance/ dissembles a life before it can begin. A preventable consequence/ lets work together to prevent FAS and heal its victims
- Break and addiction/ not a heart
- Employer can help by training workers
- If school children aren't diagnosed there is no funding
- History of parents is delicate

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- Offer counselling (drug and alcohol, financial, marital...) at work site
  - Educate managers about FAS
  - Routines are important
  - Workshops to prevent FAS and help families
  - Need to know about what it is
  - A secure home on a farm/ safe and happy
  - Foster parents help keep FAS kids out of trouble
  - Is a drink now worth your baby's potential?
  - Don't you want your child to be the best it can?
  - Education will help lead to prevention
  - Education of parents before pregnancy
  - How to stop boozing/ very difficult to do
  - Quit drinking during pregnancy/ anytime is better
  - Church, discipleship and training centre for FAS people
  - The cost of alcohol abuse is too high
  - Treatment/ people can't always get it
  - Follow-up to treatment
  - Pregnant women party even though the information is out there
  - Bartenders serve pregnant women
  - Women should avoid drinking, smoking and caffeine
  - You have to love and care and treat FAS people with respect and get to know how to handle them
  - God loves you
  - Prison/ correction institutes/ kids with FAS/ 1 kid never got out of prison
  - Put a raw egg in a glass of alcohol/ watch the edges cook/ I told my daughters that this would happen to their babies brains if they drank during pregnancy

### Group IX

Central Focus: **ALCOHOL**

#### **Subjects**

#### **Topics, issues and solutions from the Map bubbles**

Prevention

Need recreation  
AA  
Counselling

Support

Guys

Need to learn what women go through during pregnancy so they can offer support

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Guys	Not drinking/ keep stress down Maybe kitchen classes Awareness/ understanding
Diagnosis	
Schools	Teachers should be aware Need to give support to break cycle
Schools	Need money Teach children about FAS Get rid of labels
Prevention	

**General statements relating to FAS made by group:**

- No cure
- Funny looking kids/ FLK
- Learning difficulties
- Pixie kids
- Low body weight
- Facial disorders
- Behaviour problems

Group X

Central Focus: **DRINKING DURING PREGNANCY**

<b><u>Subjects</u></b>	<b><u>Topics, issues and solutions from the Map bubbles</u></b>
Alcohol	Make it illegal for mother to drink Do tests every week Someone else can get it for her Lie detectors Everyone in this town drinks
Posters	Showing how the baby could turn out Effects of alcohol on your life

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**General statements relating to FAS made by your group:**

- It's dumb to drink when you are pregnant
- How does it make the baby feel
- Effects on baby/ slow/ dumb/ deformed
- Why do people start drinking?/ Cool?
- Why would a mother want to drink when she has a baby in her stomach?
- How much would a person save without drinking for a whole year?

**Group XII**

Central Focus: **SUPPORT**

<b><u>Subject</u></b>	<b><u>Topics, issues and solutions from the Map bubbles</u></b>
Intervention	Follow through Early intervention/ Elementary School or sooner Need education support right away Early structure development/ need repetition Prevent habits forming
Education	Prevention
Foster Parents	Need realistic expectations Need to avoid burnout Cannot be taken advantage of Need cooperation of The Ministry Crazy Too many children in homes Kids are challenging Can't give to kids with difficulties Need to lobby Can work through Federation
Team Work	Important All agencies/ schools/ doctors/ parents/ Ministry Makes a difference in kids' lives

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Parents	Need support/ training/ expensive Volunteers/ Good Luck! Guilt Accountable Mothers and Fathers drank Recognition to parents of FAS kids Mentors/ live in with the families/ cheaper than foster homes Give money to single mothers instead of foster parents/ mentor Many are FAS/ clueless to other people Generational
Repetition	Important Same message Everybody work together
Assessment	Accurate Necessary for funding Act normal in so many ways They are not normal Did the Mother drink? Testing available Funding to test
School	Support 1 on 1 Teach aid training Stop sitting counting spots/ go outside and count birds Volunteers/ Union won't let them Bus support In school for a large part of their day/ behaviour/ trouble/ expelled Not their fault FAS kids know/ "I'm dumb"/ easier road to play dumb Muheim has only 2 kids with teacher assistants
Disabilities	Inability to comprehend Lack of consequence Lack of memory Compulsive Rules don't register Doesn't go away Shoplifting Can't instill a conscience into an FAS person

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Funding                      No money/ it falls apart  
                                      Bury it/ will cost less

**General statements relating to FAS made by your group:**

- High risk/ high needs
- Should be illegal for Mother to drink
- Prevention chart with Mother

Group XIII

Central Focus: **INTERVENTION**

**Subjects**                      **Topics, issues and solutions from the Map bubbles**

Diagnosis                      Early is necessary  
                                      Not a problem until school year  
                                      Problem as “Family Secret”/ taboo/ stigma  
                                      Only when kid becomes “bad” does it show  
                                      School funding/ need diagnosis  
                                      If FAS children were identified they would get support  
                                      Multiple diagnoses  
                                      Court/ repeat offenders

Assessment                      Screening FAS  
                                      Follow-up with information/ assess/ plan

Consistency                      Community  
                                      Interagency  
                                      Province  
                                      Hear over and over that children have been moved around

Preschool Quality              Very important intervention  
                                      May be only continuity in child’s life  
                                      Could be doers in intervention  
                                      Ties in with learning style and understanding  
                                      One constant but not recognized  
                                      Social services needs to know that this is a constant

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Birth Control Education

Woman shouldn't drink when she is pregnant  
Not always a woman's issue  
Family issue  
Fruit juice to celebrate pregnancy

Community

It affects us as a community  
Need consistency  
Chain of command  
Liaison with other support programs  
Interagency communication/ process/ all communities

FAS Parents

Time schedule is different  
Don't keep appointments  
Lack of judgement  
Young parent/ low functioning  
Living in a family setting/ progression of independence/ reaches 19  
removal/ out of care/ back into cycle/everything falls apart  
Someone moving into the home as support may be invasive  
Intergenerational  
How can FAS parents help FAS child?

Foster care

Continuity is difficult  
In and out of different cares  
Children get lost in shuffle  
Workers (everyone) changes

Prevention

Pregnancy Outreach Programme

Learning styles

What method of teaching allows children to show they retain learning?

**General statements relating to FAS made by your group:**

- Support and understanding are key
- Alcohol is culturally acceptable
- Frustration/ easy to give up

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Group XIV

Central Focus: **DON'T DRINK IF YOU ARE PREGNANT**

<u>Subjects</u>	<u>Topics, issues and solutions from the Map bubbles</u>
Support	For family For child Mother Counselling From fathers Nonjudgmental support
Parenting Programmes	
Information	Not enough CAP class Other students
Drinking	Peer pressure Wanting to belong Drink to stage to get happy Special occasions/ weekends/ birthdays/ anniversaries/ summer Would the people in Church give wine to pregnant women? Kids listen to their parents when they come home from bars
Advertising	Not enough ads saying you shouldn't drink "You should drink because you'll have more fun" When you are drinking you'll go to Tropical Islands Ads that make drinking look bad
Pregnant friends	Friends don't want her to drink Responsibility for each other People will look at you funny if you drink when you are pregnant
Law	Can the mother be in trouble for drinking? Fetal rights vs. maternal rights
Alcohol	Portrayed as fun by the media Ads should be anti-drinking/ make it look bad Parental example Warning labels on alcohol How easy is it not to drink? How much drink does it take to kill your child?

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Foster parents	FAS kid is different
Diagnosis	
Man's role	Not just a woman's child Is he there? Responsibility/ Does he want to take it?
Life of a child	What can happen? Lifestyle Can the baby be addicted at birth? Does every child have the same difficulties? Lifelong damage
Life of a child	Learning disabilities Violent behaviour Personality disorders

**General statements relating to FAS made by your group:**

- Can FAS lead to alcoholism?
- My aunt drank when she was pregnant and her 3 kids are fine
- Assumptions
- My Mom drank when she was pregnant with me and I'm kind of slow in school, do I have FAS?
- Myths
- Challenges

Group XV

Central Focus: **Support**

**Subjects**

**Topics, issues and solutions from the Map bubbles**

Implications	Cultural/ loss of culture as a whole Racism/ seen as a native disease Community/ effect on system as a whole Strain on support systems Further substance abuse/ further damage
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Intervention	<ul style="list-style-type: none"> <li>Early</li> <li>How to get it?</li> <li>Before they are entrenched</li> <li>In courts</li> </ul>
Education	<ul style="list-style-type: none"> <li>Educating community</li> <li>Lack of knowledge/ teachers</li> <li>Special programmes</li> <li>Prioritizing it as a problem</li> </ul>
Education	<ul style="list-style-type: none"> <li>Make it more visible</li> <li>Understanding</li> <li>Eradication/ need to help the people who have FAS</li> <li>Failing at something could help them with what they can do</li> <li>Positive path</li> <li>Education for pregnant parents</li> </ul>
Medical	<ul style="list-style-type: none"> <li>No cure/ keeps doctors out of it</li> <li>Not diagnosed at an early age</li> <li>Physiological problem</li> <li>Medical or health funding</li> <li>Cure?/ Is there a pill that will cause brain growth</li> <li>If was a cure there would be no incentive to stop drinking</li> </ul>
Diagnosis	<ul style="list-style-type: none"> <li>FAS undiagnosed</li> <li>Don't know how many people have FAS</li> <li>Don't always know who they are</li> </ul>
Labelled	<ul style="list-style-type: none"> <li>lazy/ stubborn/ trouble maker</li> <li>FAS "tagged"</li> <li>Real stigma</li> <li>Told they will never get a job/ are capable</li> </ul>
Preventable	<ul style="list-style-type: none"> <li>100% preventable</li> <li>Personal responsibility</li> <li>Don't have the same compassion</li> <li>Seen as a moral disease/ self inflicted</li> </ul>
Drinking	<ul style="list-style-type: none"> <li>Some women drank during pregnancy and their kids are fine</li> <li>So it's OK to drink</li> <li>Does not affect everybody</li> </ul>
Expectations	<ul style="list-style-type: none"> <li>Not always clear</li> <li>Supporters need to work with what there is</li> <li>Not expect to make changes</li> </ul>

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Time	Recognized fairly recently Not so much time to study it May be enough time/ no interest
Frustration	Unable to articulate Need education about how to live with FAS Treated differently Realistically/ it is hard for them to learn May look normal so there is an expectation for them
Frustration	Retention is nil Literacy
Training	Skills training for support workers Techniques for support and help Skill/ to work with or support them
Barriers to progress	What works with some clients does not work with FAS Slow progress/ no progress Don't get anywhere
Lifestyle	Contributes to FAS Women take the brunt of it Husbands don't help Isolated communities/ no support Low income Jail/ they get support

**General statements relating to FAS made by your group:**

- Break the cycle
- Ban the sale of alcohol and cigarettes for 2 generations

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Group XVI

Central Focus: **THE BRAIN**

<u>Subjects</u>	<u>Topics, issues and solutions from the Map bubbles</u>
Diagnosis	Needed for subclinical abnormalities
Support	Need to know how to support families
Art Therapy	Beneficial to this population
Research	How to measure safe amount of alcohol during pregnancy
Awareness	Posters
Education	System Those with FAS/ behaviour/ problems related to this
Mental Health Workers	Could deal with stress, guilt and grief of Mom over FAS child
Training	Need education to know how to deal with issues Need to know what resources are available Need to know what is being done
Affected Adults	Need housing/ social skills/ education Need independence/ employment skills

**General statements relating to FAS made by your group:**

- Book/ The Broken Chord
- Cycle/ many generation perpetuate the syndrome
- Grief
- Guilt
- Dealing with generation 1 or 2 after diagnosis
- Are sperm affected?
- FAS/ alcohol use continued/ could disguise mental illnesses
- Prejudice
- Bullying
- Abuse
- Problems with attachment/ significant developmental markers

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Group XVII

Central Focus: **FETAL ALCOHOL SYNDROME**

<b><u>Subjects</u></b>	<b><u>Topics, issues and solutions from the Map bubbles</u></b>
Prevention	Education Pregnancy Outreach Programmes Strategies for Moms
Awareness	Posters Let Moms know that alcohol will hurt babies Exposure Reminders
Education	Start in primary school before the kids start drinking
Diagnosis	Know that your problems are based on your mother's drinking Need quicker access to diagnosis in smaller communities Intervention to break cycle Recognition makes a difference in count
Knowledge	How women say "no" to alcohol

**General statements relating to FAS made by your group:**

- Caused by drugs and alcohol during pregnancy
- Causes brain damage, behavioural problems and physical harm
- Babies are victims with consequences not of their choosing
- Failure to thrive/ lack of attention
- Misdiagnosed as schizophrenia
- Get rid of blame

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### Group XVIII

The incidence of FAS occurring in children in Smithers is mild. They do not have the Central Nervous System or Cardiovascular problems of acute FAS.

Diagnosis made with “Diagnostic Guide for FAS and Related Conditions, 1997”

From: The Four Digit Diagnostic Code  
FAS Diagnostic and Prevention Network  
University of Washington, March 1997  
Children’s Hospital and Medical Centre  
4800 Sand Point Way NE, CH-47  
Seattle, WA 98105  
Phone (206) 528-5157  
FAX (206) 527-3959

Common characteristics of FAS children:

- Small heads
- Wide set eyes
- “funny” hands
- small upper lip
- no philtrum

Also have:

- small bodies
- mental problems
- all 100% hyperactive

Diagnosis is simple

FAS – alcohol is the causative factor, not chromosomal. Probably not caused by alcohol damaged sperm.

Get the message to Moms before they get pregnant. The worst damage occurs when women drink between 0-24 days gestation, before they are usually aware of the pregnancy.

Heart and hand malformations are difficult to measure – the process is too invasive.

100% have attention problems. Desipramine, a tricyclic antidepressant is specific to FAS – it allows children to store information time/sequence better.

This is a complicated problem.

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There is new evidence indicating that an FAS mother who does not drink may have FAS daughters. Could it be long-term ova damage?

Computer Programme – “Solo Works”

- sound, touch and information
- multisensorial
- helps FAS kids learn

The “Friend “ programme in Seattle works to prevent FAS. One friend on the streets works with teens to help them avoid alcohol.

Teaching students with FAS/FAE:

A Resource Guide For Teachers. Prepared by Special Programmes Branch. 1996.  
BC Ministry of Education, Skills and Training.

### Group XIX

Central Focus: **SUPPORT**

<u>Subject</u>	<u>Topics, issues and solutions from the Map bubbles</u>
Education	Building self esteem Helping them develop to their potential Increase capacity to learn Develop potential from young age Teach caregivers Need money Parent education Courses need to be open to everyone
MCF Existing Programmes	Resources to foster parents Services for developmentally disabled
Foster Parents	Training Opportunities Respite Schools recreation/ kids recreation

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Foster Parents	Day programs Support groups Finding foster parents who will take FAS kids/ challenge for MCF
Adults with FAS	Community education around behaviour
Integration	Services/ schools
Employers	Job placement Investments at this level do businesses good Less shoplifting Pivotal relationships
Rural Community	Isolation/ lack of services More acknowledgment of problem here We need to create local support systems Identify then support
Schools	Upgrade teachers' qualifications No strategies in regular curriculum No special courses available Day programs for troubled kids Behaviour sends kids outside school system If they can't keep kids it affects the parents Recreation/ FAS kids cannot recreate as well
Good Testing	Early assessment Provide intervention Numbers may be under-reported Alternative methods of teaching
Natural Parents	Prevention of FAS Respite Need to know even average people struggle Adequate schooling Frustration/ challenges Infant routing changes/ stages Teach routines to kids
Criminal Justice System	Housed in jail without learning Exposed to other behaviours

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Alcohol	Media Sponsoring sports events Hype vs. costs
Stigma	Label is heavy to carry Label may bring services Not wanting child identified/ parents have to admit to drinking Fault Misunderstanding/ misinformation
Barriers	Money for programmes Advocating for particular programs FAS/ new wave of program money requests Competition Limited resources
Families	Generations Drink/ unprotected sex More likely to drink
Services	Need to do a piece of something Need to be integrated (e.g. Schools)
Support	No-one supports FAS Usually parents get support going/ FAS parents cannot No skills/ lack of understanding Training No charity group for FAS Work for meaningful inclusion of children Make the “here” a better place Everyone benefits

**General statements relating to FAS made by your group:**

- FAS kids/ repetition/ same mistakes
- FAS is preventable

As each Mind Map summary was completed a draft was sent to the agency concerned for correction and validation. When all agencies had replied this part of the process was finished.

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# Final Summary Meeting

## The Meeting

When the Mind Maps had been summarized and the validations sent in by the participating groups a Final Summary Meeting was planned. A lunchtime meeting was chosen in order to get as many people as possible to attend. One person from each group was invited, but more wanted to come in fact from seventeen groups forty people registered and thirty-six showed.

The meeting room was prepared to encourage positive thoughts about fetal alcohol syndrome issues and to help maintain focus on the goal. The Community Mind Map was on display and colourful affirmation statements were posted around the room. These statements came from the Mind Maps or from 'It Takes a Community'. The statements were the following:

Statements from the participants:

- Communication is key
- Integrated Community
- Prevention
- Support
- Inclusion
- Community Based Holistic Approach
- Life Cycle
- Preventive Education
- Alcohol
- Drinking During Pregnancy
- Intervention
- Don't Drink if You are Pregnant
- The Brain
- Fetal Alcohol Syndrome
- The Cycle Can be Broken
- Birth Control Education

Statements from "It Takes a Community"

- If disclosures are made without an informed and caring support network, the new awareness could precipitate a family crisis
- Equally important as prevention activities are intervention strategies that help families and communities now living with the presence of FAS

- 
- All children are heavily influenced by the conditions in which they grow up. A child, whether normal or challenged with FAS can have either a positive or negative upbringing
  - Resource workers coming to terms with the special needs of the community members sometimes look upon persons with FAS as teachers who challenge communities to rethink existing perceptions and remember old values and teachings
  - A key element of community healing is the understanding within the community that social and cultural wellness and progress depends on taking immediate action...
  - Preventing one child from being born with FAS more than earns you your life's salary
  - Canadian and US health authorities recommend abstaining from alcohol during pregnancy and breastfeeding
  - Traditionally, pregnant women and nursing mothers led a healthy lifestyle with lots of physical activity and a nutritious diet
  - "Behold, thou shalt conceive a son; and now drink no wine or strong drink" Judges 13:7
  - In the early days and months, infants with FAS may develop more slowly than other infants. An immediate concern is some infants may have difficulty regulating basic functions such as sleeping and feeding
  - FAS is a thing that you can't rub off or wear off. It's something you have to carry with you for the rest of your life. It's hard.
  - Fundamental to any intervention action is the belief that nobody sets out to damage their child on purpose
  - Parents, teachers and other professionals involved with the FAS child need to form a strong alliance to maximize the effect of their efforts and minimize the effects of the condition
  - Not understanding the nature and affects of FAS often leads to constant criticism, punishment, school failure and the downward spiral of isolation and low self-esteem
  - After about age 12, measured IQ scores for youth with FAS remain constant or decrease because their abstract thinking is slower to develop than their peers
  - As much as possible, the first priority is to provide a stable home and family life for the child
  - Children need to know the actual facts of FAS and how to prevent it before they begin to be sexually active and before they begin to use alcohol and drugs
  - The potential value of FAS knowledge that caregivers have to share cannot be overestimated – and sharing knowledge of strategies that work is one of the best ways that caregivers can help each other
  - The family and community are challenged to help children with FAS find a place in the community and world at large

- 
- The people caring for persons with FAS need skills, knowledge, good will and support to be most effective
  - Trying to parent a child with FAS without knowing the implications and how they play out developmentally is like trying to find your way around Toronto with a road map of Vancouver

The most common topics of the Mind Map summaries were selected for the subjects to be discussed at the meeting. This was done using a computer word count on Microsoft Word by the following method:

- Go to edit/ Find
- In 'Find What' type in a commonly used word
- Find next
- Click here and count as many times as the word comes up

This method gave an accurate count for the most commonly used words in the Mind Maps. The most twenty common words were used as the subjects to be selected from at the meeting for discussion.

These top twenty subjects were:

- Education/ Prevention
- Diagnosis/ Assessment
- Support
- Alcohol/ Drinking
- Community
- Intervention
- Foster Parents
- Parents
- Women
- Money /Funding
- Programmes/ Services
- Court/Justice
- Behaviour
- Cycle
- Communication
- Lifestyle/ Cultural
- Teamwork
- Stigma/ Guilt
- Research
- Employers/ Employment

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These subjects were written on flipchart paper and posted on the walls of the Meeting room. Everyone was given three red spots to stick on their top three choices from the twenty. The top five were then selected as the subjects for discussion at the meeting. These were:

- Education/ Prevention
- Support
- Money/ Funding
- Diagnosis/ Assessment
- Intervention

Everyone chose their favourite subject and sat at a table to work with a group. They were asked the following question:

*“What can we do, with respect to the given subject, to address the issue of fetal alcohol syndrome?”*

*It may help to think about these questions:*

- *What are our long-term goals?*
- *What are our short-term goals?*
- *What are some feasible actions that would work in this community?*

*And to consider:*

- *The capacities of this community*
- *Community events we can work with*
- *The available people*
- *The available people*

As everyone began the group work lunch was served.

### **Five Responses to the FAS question**

#### **1. Support**

- Outreach programmes to rural communities
- Mentorship programme
- FAS/FAE family support worker to help with family/child long/short term planning “ongoing”

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### Community Service Improvements

- FAS/FAE respite to parents/ foster parents
- FAS/FAE training to parents/ social worker/ teacher/ employers/ government workers at BC Benefits
- Advocate/Association Committee be formed
- Mentoring programme
- Assistance in the justice/ legal system to FAS/FAE people (education)
- Educational options to FAS/FAE adults
- Support groups for adults with FAS/FAE
- Guidance in external brain – for life
- Support in Family home – access to services
  - information
  - behaviour technology
  - training
  - support groups
- School support – i.e. : teacher assistants
  - training teachers
- Support needs to be – individual
  - family
  - school/ work/ community
- Special needs – disabilities
  - re: funding by government
  - FAS/FAE needs to be recognized

### 2. Money/ Funding

- 1% of tax revenue from the sale of alcohol should go to FAS/FAE work
- Reluctance to be diagnosed/ diagnosis should be community centred
  1. Determine first normal parameters for FAS/FAE
  2. Identify FAS/FAE in community – assessment/ diagnosis
    - difficult because of human rights and political issues
- Long- term goal – elimination of FAS through diagnosis/ assessment
  - education kindergarten to adult
  - FAE gets funding
  - education/ research
- Short- term goals – funding proposals
  - neurological evaluation
  - every child has rights
- Support for those who have alcoholic problems

- 
- Pilot in Prince George – making better choices
    - alcohol intake
  - “No new money – have to use existing programmes and money”

### 3. Diagnosis/ Assessment

- What
  - involve physicians
  - others in community
  - train people to spot and refer
  - include schools
  - develop a team approach/ community centred
- How
  - subcommittee of FAS to develop assessment team
  - need an easy route to channel people through to assess
  - be able to differentiate between FAS/ FAE
- Capacity
  - need various tools for different ages
  - need various screens to get people/kids to help sooner
  - we have educated front-line workers (schools/ D&A workers...)
  - we have strategies for front-line workers when FAS suspected
- Diagnosed
  - may not mean the person qualifies for help
  - don't need to have a diagnosis to start getting help
  - can be key to getting appropriate/ effective help
  - other than physicians should be able to make diagnosis
  - team approach to diagnosis
  - FAS committee
  - access to diagnosis – need to make it easier
    - for adults too
  - acknowledge severity of FAE
  - education of workers, especially school
  - Dr. Moisey/ Child Development Centre/ FAS Committee school educated front-line workers, create framework
  - give Smithers Community Services Association strategies
- Capacity
  - we have a tool we can use, FAX to Reno to lady who produced it, she will discuss it with us and we can keep doing this until we are comfortable using it on our own

- 
- Short- term
    - identify Doctor and network
    - team development
    - to make strategies available to all front-line workers
    - train people working with FAS clients
    - improve regular communications, re: resources, training & strategy
  - Long- term
    - existing framework that works easily for referral and assessment
    - case conferencing so everyone involved in the individual's life is working on the same functional plan
  - Look into barriers for Doctors identifying as diagnosis
  - Learn from other communities
  - Identify key people in community to do particular skill assessment to minimize number of people referred to Doctor

#### 4. Intervention

- Long- term
  - educate to eliminate need for interventions
  - foster parents, re: how to work with FAS clients
  - aides – connect with supported child services to continue with school and teacher assistants
- Intervene at young age – grade 6/7
  - sexuality
  - learn about alcohol
- Educate
  - young FAS children to learn about FAS before they are adults
  - Healthy Babies/ Healthy Families pregnancy education
- Adult FAS
  - family support
  - need to educate court system to recognize the basic premise that FAS youth/ adults don't have the same ability to know cause and effect
  - alternative justice programme

- 
- Supports for adult
    - home support extension
    - budgeting – show how to shop
    - “external brain”
  - Short-term/ Long-term
    - team approach to intervention
    - “everyone on the same page”
  - Short-term
    - foster parent education
    - school funded programme
    - sexuality and FAS teaching at the same time
    - advocate for money for support
    - person for alternative justice follow-up
  - Society needs to deal severely with alcoholism
    - money to deal with root causes
    - include a youth programme, e.g.: caught with alcohol must attend effects of alcohol – alternative justice
  - Long- term
    - user fee on alcohol
    - designated treatment of alcohol related illness and disability
  - Relearning of parenting skills
    - teaching in culturally appropriate ways
    - mentoring of FAS adult parents in parenting
    - leading with example/ role modeling about not drinking
  - Youth access to alternative entertainment – recreation
    - activities

## 5. Education/ Prevention

- Increase Awareness
  - education programmes around affects of alcohol on relationships, health (personal), fetal health ... starting early in primary school
  - provide material/ background information to parents so they can discuss disruptive and detrimental effects of alcohol, again covering effect on fetus/ unborn child (for families where alcohol is already an issue, this is unlikely to be done, where importance of the previous point – school programme)

- 
- Increase Responsibility - make people responsible for their drinking, e.g.: school teenagers drinking at school party – instead of suspending adolescents have them prepare a presentation on why he/she was reprimanded and again talking about what alcohol does to a person
    - offer free safe places for kids to meet, Smithers has a lot to offer for physically inclined kids (sports) however, there is a need for a place for kids to just hangout with each other
  - Involve kids in developing programme (prevention) for kids, e.g.: development of a travelling theatre show on FAS on alcohol/ development of pamphlets/ media blitz...

### **Summary of the Five Presentations**

The ideas generated by the five groups had considerable overlap and can be summarized as follows:

- Prevention and support of FAS/FAE require a team approach
- Assistance is needed in the justice system
- Education about the effects of alcohol needs to begin in kindergarten and continue through to adulthood
- There needs to be more teen programmes and youth must be included in FAS/FAE education and the prevention process
- A portion of the revenue from alcohol sales should be used for FAS/FAE education, prevention and support
- There needs to be support for families, foster parents, and individuals with FAS/FAE by trained workers
- Mentoring programmes and pregnancy outreach programmes work and should be continued and expanded
- More people need to be trained to accurately diagnose FAS
- More government funding must be made available for FAS/FAE issues

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## Postcard Survey

Four hundred postcards were made up and sent out into the community. These were preaddressed and prestamped and asked the question “*What does fetal alcohol syndrome mean to you?*” A sample blank postcard is shown in Figure 3 and completed postcards are shown in Figures 4 to 8. They were given out by people who participated in the Mind Mapping Sessions, by those in contact with FAS people and some were left in conspicuous places to be picked up. This survey was regularly mentioned in the local newspaper and on the radio. Of the 500 postcards distributed, 52 were sent back complete, a 13% return.

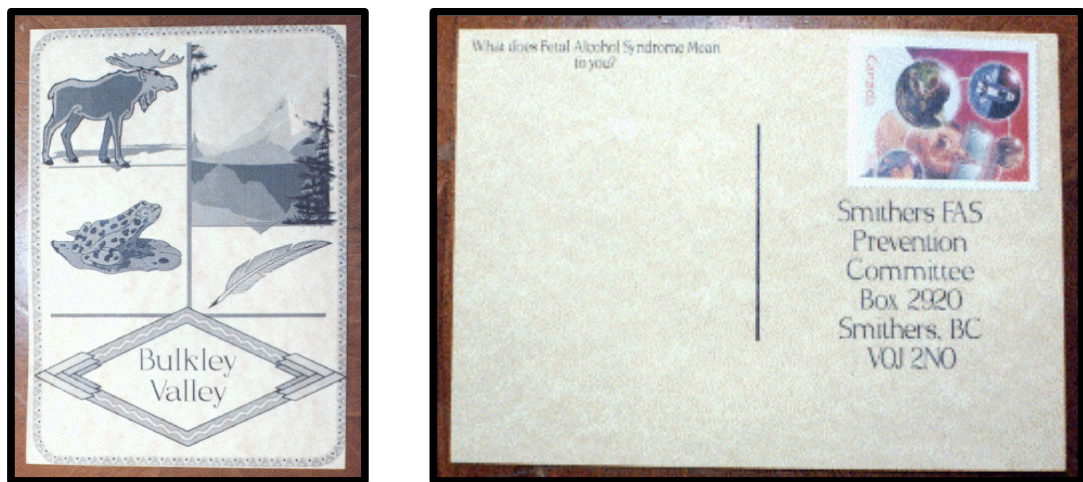


Figure 3. Each side of a sample blank postcard with the question “What does Fetal Alcohol Syndrome mean to you?”

The results of the postcard survey have been summarized as follows:

- Support of parents
  - More education for pregnant parents
  - Support for women who drink during pregnancy
  - Mothers needs to be alcohol and drug free during pregnancy
  - Partners need to stop drinking/ campaign with that message/posters “Alcohol can affect your unborn child, Dad”
- Society problems
  - Drain on taxpayers
  - Drain on social support
  - Gives employment to support people
  - Strain on justice system
  - Drain on health care/ medical system

- 
- Society problems
    - Disruption in school
    - Home/ school/ society financial cost

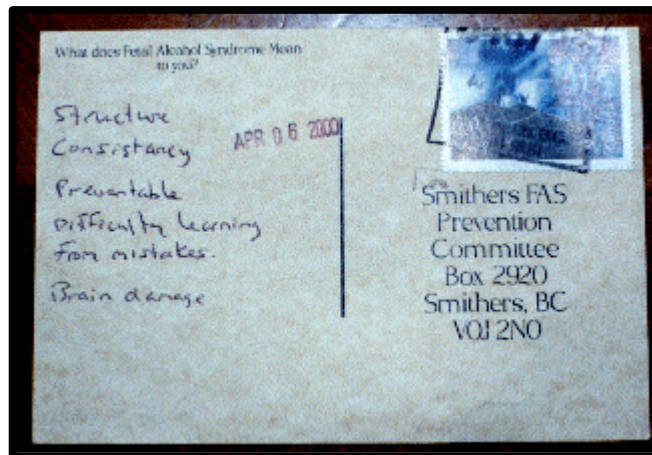


Figure 4. Completed postcard.

- FAS kids need
  - Structure/consistency
  - Help and understanding
  - Respect
  - To learn about FAS

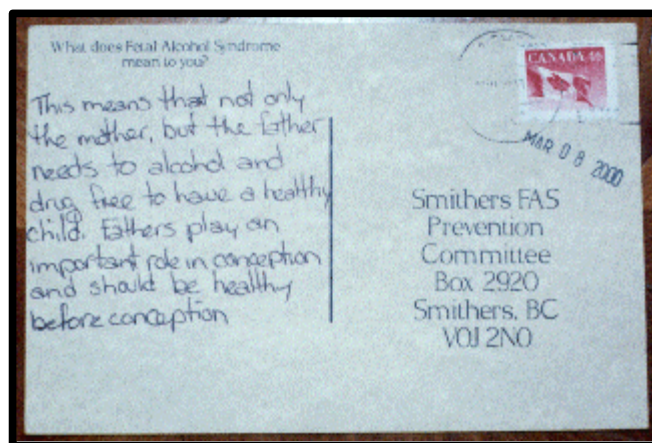


Figure 5. Completed postcard.

- 
- Alcohol problem
    - Increase the cost of alcohol
    - Increase drinking age
    - Alcohol addiction is a problem
    - Make it illegal to sell alcohol to pregnant women
    - Destroys lives
    - Don't drink at all
    - Less alcohol
    - "Ban the booze. Save our society"

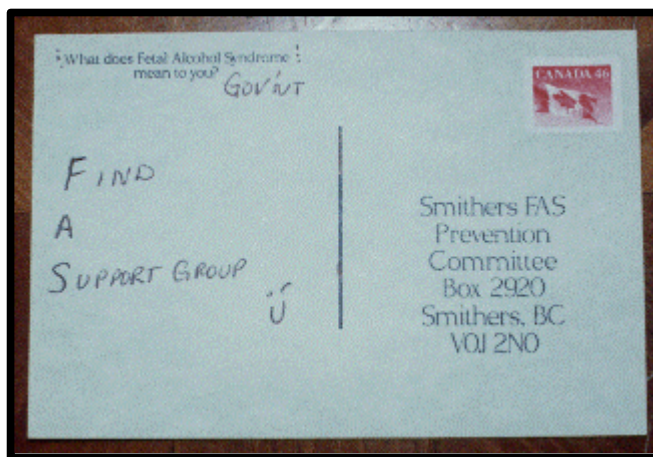


Figure 6. Completed postcard.

- Anger and resentment toward mother
  - Preventable if mothers did not drink during pregnancy
  - Not a very good mother
  - Irresponsible parenting
  - Sterilize mothers who drink during pregnancy
  - Alcohol indiscretion during pregnancy
  - Selfish of mother
  - Charges should be laid against mothers who drink during pregnancy
  - "Your baby doesn't have a choice to drink or not and it definitely isn't your place to make that choice"
  - Social and moral overindulgence of uncaring or uneducated females

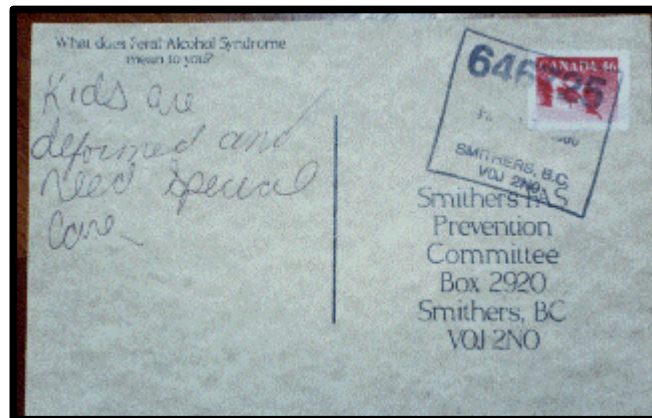


Figure 7. Completed postcard.

- FAS kids
  - Lack skills
  - Look different
  - Have difficulty learning
  - Have mental/physical problems
  - Suffer
  - Are left out
  - Hurt for life
  - A lifetime of frustration
  - “Destruction of the life of an innocent”
- FAS is caused by drinking during pregnancy
- FAS is completely preventable
- Families need
  - Resources
  - Respite

- 
- Problems
    - Guilt/ blame
    - Misunderstanding
    - Tragedy
    - Trouble
    - Sorrow/ sad
    - Struggle

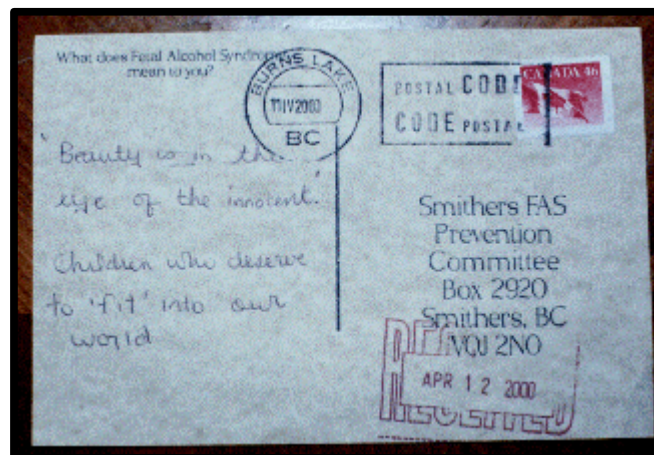


Figure 8. Completed postcard.

- Community need for
  - Information
  - Education
  - Intervention
  - Money to assist
  - Increased awareness on the affects of alcohol
  - Support for foster parents
  - More support systems
  - Money for support
  - More counsellors to meet the needs of FAS individuals

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## Summary

The Mind Mapping process was proven to be a very efficient and successful method of surveying a community to determine what its members know and think about a specific issue. In particular, with respect to the issue of fetal alcohol syndrome in the Bulkley Valley a wide range of people from the community showed a good response.

The problems encountered during this phase of the process were not major. One flaw was the lack of representation of some groups and agencies in the community. People who did not join in were too busy, this was the common reason for their not participating. Two Mind Mapping sessions that were scheduled did not happen because the participants did not show up. This means that some important areas of the community were not surveyed. This includes the courts, the RCMP and the school system. There may be ways to include these groups in a later stage of this process.

Overall, the common sentiments of this community with respect to fetal alcohol syndrome can be summarized as follows:

- A team approach involving a strong network between all community agencies , families and individuals needs to be developed in order to provide prevention FAS and support of those with FAS.
- Education regarding FAS/ FAE needs to begin early in life and continue through teen years to adulthood, actively involving all participants.
- There is an alcohol problem in this community and it must be addressed. There needs to be community education and information made publicly available to increase the awareness of the effects of alcohol.
- Mothers and families need a lot of support and education during pregnancy to avoid the incidences of FAS/ FAE.
- There is a need for more trained people to work with families and individuals living with FAS/ FAE.
- Diagnosis must be a community responsibility as support for and treatment of those with FAS/FAE needs to be recognized without guilt or stigma.

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## Financial Statement

### Budget

Total contract fee		5000.00
Advertising – job posting	53.54	
Babysitting	30.00	
Film and processing	15.18	
Gift certificates	30.00	
Meals – breakfast, catered luncheon	333.20	
Postage	295.32	
Final report – paper, covers, binding	88.95	
Seed money – for continuing FAS studies		
Stationery – pens, paper, rolls of paper, postcard paper		
*Wages – 175 hours @ 20.00	3500.00	
<b>Totals</b>	5000.00	5000.00

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**Budget Notes**

\* Wages for 175 hours:

<b>Jobs</b>	<b>Hours</b>
Fetal Alcohol Prevention Committee Meetings	6.75
Final Report – compiling, writing and printing	23.25
Interim Reports	1.00
Making Postcards	8.00
Mind Mapping Sessions – planning , conducting and writing up	93.75
Miscellaneous – phone, email, FAX, purchasing, paperwork, radio interview and budget	15.25
Summary Meeting / Luncheon – planning and hosting	27.00
<b>Total Hours</b>	<b>175.00</b>

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