

**Finding Alternative Solutions:
A Mentoring Program for Youth and Young Adults with
Neurological disabilities**

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Prepared by
Jennifer Kyffin, Project Coordinator

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PART I: INTRODUCTION

Fetal Alcohol Spectrum and Community Exclusion

The difficulties experienced by individuals with Fetal Alcohol Spectrum (FAS)¹ present obstacles in academic, social and economic spheres. Marginalization is a common occurrence as individuals with neurological disabilities struggle to understand the increasingly complex social patterns of adolescence and young adulthood combined with greater expectations associated with school, life skills, and employment. Moreover, according to McCreight (1997), as teens and young adults struggle with peer and community acceptance they may also begin to realize the extent and permanence of their disability, and may experience what Streissguth (1997) calls secondary disabilities.

Unsuccessful transitions into the larger community, according to Streissguth (1997), lead to disabilities that the individual is not born with, and which could be ameliorated with adequate intervention. Common secondary disabilities among individuals living with FAS/pFAS are depression, disrupted school experiences, employment difficulties and trouble with the law. For many young people with neurological disabilities, their inability to process complex cues and to independently connect cause and effect, make it almost impossible for them to learn and develop life skills simply from experience and natural consequences as most children and young people do. Instead, they may repeatedly engage in patterns of challenging behaviours. Unfortunately, society seldom understands that the behaviours they are witnessing are the result of disability.

Contact with the Legal System

In her presentation on *FAS and the Legal Process*, Julianne Conry, UBC professor of Educational Psychology and Special Education, stated that “On any one day in BC there are 306 youth in custody, 94 in remand, 1000 on bail, 4450 on probation and 10 in the Input Assessment Unit”. Of these numbers, 23.3% are youth with FAS and partial FAS (*FAS – A Community Responds: A Conference With a Difference, February 1999*). This figure corresponds to those in a 1997 study of a Burnaby young-offender facility, which reported that 24% of prisoners had alcohol-related birth defects (The Globe and Mail, April 1998). In fact, the frequency of alcohol-affected offenders led a CBC commentator to describe the situation as “the sleeping giant” in a feature report entitled, *Life Sentence* (CBC National, 1997). These findings demonstrate all too clearly, the relationship between people with FAS/pFAS and their interaction with the legal system.

¹ For the purposes of this document, the term “Fetal Alcohol Spectrum” (FAS) describes the scope of prenatal alcohol effects that includes Fetal Alcohol Syndrome, Fetal Alcohol Effects and Alcohol Related Neurodevelopmental Disorders.

Barriers To Participation

In the Cowichan Valley, contact with youth and young adults with neurological disabilities confirm difficulties in their day-to-day lives. Long standing feelings of isolation, feelings of being misunderstood and unsupported, and being anxious about school and jobs are just a few of the experiences identified by young people living with FAS.

Despite the fact that the Cowichan community has many employment and recreational services, young people have difficulty accessing and utilizing these programs. They say that peoples' expectations of them can be unrealistic because their disability is often hard for others to recognize. And without the additional guidance, structure and support to modify unrealistic expectations, under-employment, mental health concerns and high-risk behaviors may result.

In addition to feeling the pressures of unrealistic expectations, young adults living with FAS identify education as an essential component to creating understanding that respects differences. Giving presentations, participating in workshops, and writing educational materials are some of the ways that people with FAS can increase understanding and gain recognition as experts of their own experience.

2. Background and History of Mentorship Program

The Finding Alternative Solutions Mentorship Program follows on the work of the "Seeking Alternatives" project and the lengthy community development process undertaken by the Cowichan Valley FAS Action Team.

The Cowichan Valley FAS Action Team is a community coalition of parents, family members, service providers, advocates and volunteers that promotes action that will prevent fetal alcohol spectrum (FAS) and maximize the potential of persons living with FAS. The Action Team monitors programs and services responsible for FAS concerns at the local, regional and provincial levels, and advocates for their accountability.

History of the Cowichan Valley FAS Action Team:

In 1993, the Duncan Special Needs Adoptive Parent (SNAP) Support Group was formed under the umbrella of the provincial SNAP Society in Vancouver. For three years, family members worked together with professionals in the community to provide advocacy, education and mutual support around the many issues associated with FAS. In February 1996, they joined with other community members to set up a steering committee and launched a united campaign against FAS. One year later, the group spearheaded their first major initiative, a province-wide conference in Duncan entitled "FAS/E: A Community Challenge". In May 1997, the Cowichan Valley FAS Action Team was organized to oversee the implementation of action plans that were developed at the conference.

A follow-up workshop held in November 1998 with service providers, ministry personnel, family members and advocates, led to discussions as to how we could better support people with FAS through prevention and intervention measures. The ultimate goal was to prevent these individuals from getting into trouble with the law in the first place; to ensure that if they *did* come into contact with the legal system, they were treated with justice.

Seeking Alternatives

In response to the needs identified in this community consultation process, a one-year, community development project was designed to identify and mobilize existing community resources to support people with FAS.

The Seeking Alternatives project helped to build a more responsive community environment through workshops intended to bring together young people with neurological disabilities, family members, caregivers, service providers of various disciplines, and advocates of community safety and crime prevention measures.

In addition to broad community education aimed at crime prevention, the Seeking Alternatives project provided a unique platform for young people living with FAS to voice their ideas and concerns.

Beginning in May 2000, community research and consultation was undertaken in order to develop a program with the kinds of supports necessary for the amelioration of secondary disabilities associated with FAS (Appendix A, Responsive Community Integration). The consultation process clearly indicated that people whose lives are affected FAS do not merely wish to be consumers of specialized services—they want to be recognized as valuable individuals who can help to build the necessary supports that will enable them become productive members of their community.

Finding Alternative Solutions

After the initial consultation process, the Mentorship Program began to run a volunteer weekly support group in October 2000 to further explore the issues faced by young people living with FAS with the aim of developing a program for youth and young adults living with it.

During 2001/2002 the Finding Alternative Solutions Mentorship Program has attempted to build on the accomplishments of past projects, expand understanding of FAS as a community issue, and to encourage other sectors of the community to become involved and to take greater responsibility for inclusion of people living with FAS.

PART II

OVERVIEW OF THE PROJECT AND PROCESS

The purpose of the Finding Alternative Solutions Mentorship Program is to address the barriers of marginalization and socio-economic exclusion experienced by many youth and young adults with FAS. The work of this project is based on a positive, alternative approach that reflects the skills and potential of young people to grow, to succeed and to educate others.

1. Project Goals

The primary goals of this project promoted community inclusion of people living with FAS through:

- Enhancing the quality of life for youth living with FAS and other neurological disabilities.
- Developing a sustainable community infrastructure that supports work experience for youth with FAS and other neurological disabilities.
- Enabling youth with FAS and other neurological disabilities to access, evaluate and influence community supports.
- Conducting activities that promote community education, awareness and understanding of the challenges, gifts and talents of young people with neurological disabilities.

2. Mobilizing the Project

The first four weeks of the Mentorship Project focussed on developing the supports and structures necessary to begin project implementation. These activities included:

- Hiring a peer consultant and developing a comfortable working and learning environment.
- Securing program and office supplies and signs
- Continuing to orient our Peer consultant, Leila Wilson. Leila works in the office 12 hours each week over three days.

- Letters of introduction and posters about the drop-in were distributed throughout the community.
- Members sent faxes and emails, and placed classified ads in order to advertise drop-in group.
- Outreach to community organizations serving youth including foster parents association, Community Options Society, Call To Action Youth Team, and Cowichan Tribes Youth Services to promote mentorship program

3. Project Activity Streams

To achieve the project goals, three activity streams were implemented over the ten-month project. These activity streams are intended to give young people concrete opportunities to contribute to strategies that address FAS at a personal and at a broader community level.

3.1 Social/Life Skills

The Mentorship Program encourages young people to build confidence and pursue their potential through participation in, and development of, life skills programs, recreation and employment opportunities, and educational and community enhancement projects. The team focus of the program fosters relationship building, empowerment and equality by encouraging young people with FAS to educate each other and the community about the strengths, challenges and strategies associated with FAS and successful community integration. The outcome of this approach is the development of a network of community supports that are more inclusive of people with FAS.

Social and Life Skills activities are intended to enhance the quality of life for young people living with FAS in the following ways:

- providing healthy activities and building positive social connections and self-esteem
- supporting young people to act as peer mentors and assist with outreach, education and program facilitation

These program objectives were achieved through the following activities:

- a weekly support group to foster trust and abilities in a supportive, non-judgmental environment.

- opportunities such as cooking, budgeting and time management encouraged through group discussion and activities.
- community enhancement projects that promote team work, leadership skills and a sense of civic pride and accomplishment

Over the ten-month project, 4-5 young adults formed the core group that attended activities on a regular basis. Other young people participated more sporadically, dropping in on occasion to join in activities or to seek support or assistance to access services. Under the guidance of the coordinator, project activities were undertaken by young people living with FAS and included group meetings, recreational outings, community enhancement projects, work experience placements and public presentations.

a) Drop-In Group

Social and Life Skills activities over the ten-month program occurred in several ways. In the earlier stages of the program, the regularly scheduled Monday drop-in group proved invaluable in developing trust, friendships, and group cohesion. With the guidance of the coordinator, participants in Finding Alternative Solutions Project established a cooperative framework for the group meetings. Some key components of the group agreement included:

Check In

Done at the start of the meeting to give each member a chance to say how they feel, and mention anything that might affect their participation in the group. This helped set the tone for respectful listening and sharing.

Creating a Safe Environment

Each session, facilitators remind members that what they have to say is important because it lets others know that they are not alone in how they feel. Expectations remain consistent.

Confidentiality

Members agreed not to talk to anyone else about each other's stories without their permission. Won't hold any information against any person in any way.

Respect

Helping each other to feel that its OK to have different opinions, choices, difficulties and strengths.

Listen

No talking when someone is speaking

Develop and encourage awareness of basic body language

Everyone is important to the group

Everybody has something to give to the group
Hearing what each other have to say

Support to others

Encourage speaking and discussion
No put downs

Review

Ongoing review of how we are respecting the group agreements. Lots of praise and encouragement to help remember.

If required, change or add group agreements by consensus.

Closing Round

Closure at the end of each meeting
Share appreciation
Chance for suggestions for next time

Scrap Book

A collective reflection of the program—thoughts, art, feedback etc.

Some Topics Covered in the drop-in group were:

1. Self and Self Esteem
2. Exploring Feelings
3. Dealing with Stress and Anger
4. Daily Hassles
5. Body Image/Awareness
6. Trust and Friendships

Interestingly, as a stronger sense of belonging and confidence in the group developed, attendance became increasingly sporadic. The group still kept in contact and was very supportive of one another—but they were less likely to attend the Monday drop-in time. When we explored this, factors including work, school and less reliance on group support were reasons for not coming to the drop-in group.

To help increase drop-in attendance during the summer months, we facilitated several meetings at local water spots and at members' favorite coffeehouses to encourage participation. Despite these efforts, drop-in group participation was a challenge.

When Monday meeting attendance declined, mentorship team members still maintained contact through telephone calls, making appointments and dropping in at other times throughout the week. Often, members just wanted to have an

informal meeting with the coordinator and at other times, the contact was for more specific support around an immediate situation or crisis.

With this kind of 'hit and miss' contact pattern, it became increasingly apparent that the 'drop-in' group was fine so long as it remained a drop-in. Program activities needed to reflect the capacity of those in the program, which means that scheduled events take a back seat to immediate situations. In response to this, we relaxed around the Monday drop-in attendance and remained flexible to other types of non-scheduled contacts from team members.

Other issues that arose in maintaining the drop-in group related to group dynamics. We had a few new people come to the group who were not *good fits* due to high needs related to addiction and mental health issues. Several of these people are '*periphery members*' who do not attend group or group activities regularly but who access occasional one-to-one support through the program.

Another important reason for the decrease in weekly drop-in attendance can be attributed to the teams' desire to move from a 'support group for each other' to an 'educational group for the community.' Beginning in the fall of 2001, project activities focussed more upon community activities to educate the public about FAS.

b) One-on-one Support

One-on-one time with team members proved to be an important part of the program services. The amount of individualized support fluctuated with each person and depended on many life factors such as stress levels, other supports available, coping skills etc. Despite variation in frequency and intensity, one-on-one support proved to be a consistent need among group members living with FAS.

c) Recreational Activities

Recreational activities provided a fun way to team build and to develop leadership skills and confidence.

An overnight camping trip to Lake Cowichan was extremely successful and 7 participants enjoyed activities that included tubing, swimming, snorkeling, basketball and barbecues.

Other recreational activities included tennis, swimming, hiking, movies, potlucks, and going out for coffee.

d) Community Kitchens

Community Kitchens is a locally operated program established to support people to budget, shop and prepare healthy, inexpensive meals for individuals and families. In partnership with Ministry of Children and Families and local churches who donate their kitchen spaces, Community Kitchens operates over 20 kitchens

throughout the Cowichan Valley. These kitchens are comprised of 5-10 people who come together twice each month to plan and prepare food to take home.

We participated in Community Kitchens meal budgeting and cooking classes on throughout the project and used the meals for potluck gatherings, traveling and for economical meals at home. Team members learned to price compare using flyers and coupons and learned the basics safe food preparation and storage. As well, after each community kitchen session, team members donated meals to a person in the community.

e) Fundraising and Awareness Raising

- Two car washes were organized and implemented by team members to raise awareness about FAS and funds to support people living with it.
- We had a display at the Duncan Mall on August 20th. We talked to about thirty members of the public and drew attention from many, many more.

f) Community Enhancement Projects

Mentorship team members were involved in several community enhancement initiatives throughout the Finding Alternative Solutions project.

Together Against Violence Month

Mentorship Team members created a display booth and organized and attended a conflict resolution workshop for November 25th, 2001 at the Together Against Violence Community venue. Students from the Frances Kelsey Students Against Violence everywhere (SAVE) program also attended. This was facilitated by the Regional Youth Coordinator from the Ministry of Public Safety and focused on Developing skills to acknowledge and resolve differences peacefully.

The James Street community Enhancement project

Members helped facilitate focus group discussions with many groups of youth throughout the Cowichan community to learn more about personal safety issues that youth face everyday.

Issues such as violence, drugs, alcohol, bullying, intimidation, racism, vandalism and theft were among the concerns identified in this consultation process (Please refer to Appendix B, for project information). As a result of this youth-led consultation, "Paint the Park Event" was held June 15, 2001 in order to address some of these safety concerns; through:

- Painting park equipment with anti-violence messages to beautify the park

- Creating and distributing educational information about issues related to youth violence and crime prevention
- A barbecue held by student council of Cowichan Secondary
- Prizes donated from local businesses and food proceeds going to the Bethel Baptist Youth Group

Youth/Senior Mentoring Project

Mentorship team members served on the BC Crime Prevention Association's Youth/Senior committee, planning and participating in several community enhancement project designed to reduce crime associated with the fear and misunderstanding between youth and seniors.

Some of the activities undertaken in the project included:

- A holiday event at the Finding Alternatives Office bringing youth and seniors together to make wreaths and centerpieces
- A holiday hamper drive that collected food and toys from students at Cowichan Secondary. Hampers were then prepared by youth and seniors and were delivered to isolated seniors and families in the community by teams of youth and seniors.



3.2 Employment

The Mentorship Program worked to collaborate with community agencies and potential employers to coordinate appropriate employment opportunities that reflect the interests, abilities and goals of mentorship team members.

In addition, the Mentorship Program provided monitoring and on-going practical support by maintaining contact between the employed young person and the community employer.

The Mentorship Program utilized increased social development and increased community awareness created through project activities to create employment opportunities for individuals living with neurological challenges.

Work Placements

Our focus on employment was ongoing and challenging. We accompanied members to the youth services employment center to assist with seeking employment, and worked on action plans that included education, training and employment (see Appendix C, for Action Plan example). Action plans helped to begin the process of exploring and identifying career and personal goals and objectives that evolved with each individual throughout the program. Some examples included career plans and actions that included “looking for a job that I would be good at” and working with an individual to take the first steps necessary to meet the criteria for a culinary arts program.

We coordinated appropriate employment opportunities for a few of our members with community development projects including:

- two twelve-week placements with the Call To Action Community Enhancement Project
- two ten-week, part-time placements with the Youth/Seniors Project
- one temporary placement with the Cowichan Chesterfield Society
- occasional jobs with the Health Canada Community Outreach Project

All of these project work placements had a community enhancement focus and the capacity to be inclusive of individuals living with an invisible disability. As such, employers were educated about the challenges of living with FAS and how these could potentially relate to employment situations. The Mentorship program monitored these work placements and provided on-going practical support by maintaining contact between the employed young person and the community employer.

As well, work experience placements were found for several members and included work with the United Way and Providence Farm.

Some of the employment outcomes achieved through the program are:

The mentorship program worked towards the development of a sustainable community infrastructure that supports work experience for youth with FAS and other neurological disabilities through:

- development of transferable employment skills such as team work, event planning, data collection, documentation methods and focus group facilitation
- providing support, outreach and education to community partners to involve youth with neurological challenges
- assessing strengths, challenges and employment interests of youth with neurological disabilities and collaborating with community partners to identify work experience opportunities
- providing contact support to youth for the duration of work experience placement.
- maintained communication and gathered feedback from community partners, youth and their families.
- evaluated and utilized feedback for continued program improvement

b) Disability Benefits

Two of our members were assisted to apply for Disability Benefits. Both were successful in their applications thanks to a lot of family support, peer support and improved relations with, and education of, staff at the Independent Living Resource Center. Several other members have files in progress but are experiencing barriers due to lack of diagnosis.

While Disability benefits are not meant to replace employment opportunities, they do provide a better safety net than the standard BC Benefits. In this way, members who have difficulty finding and keeping employment, have the option to volunteer or work part-time according to their abilities—rather than being penalized for their disability.

c) Educating Employers and Employment Counselors

The Mentorship Program met with Coast Salish Employment and Training Society to discuss how to work together to educate employers and employment counselors about the vocational issues related to people living with FAS. Coast Salish Employment and Training Society has a focus on supporting people with

disabilities and contracts with 19 aboriginal agencies/programs between Victoria and the Northern parts of Vancouver Island including, Gold River and Tahsis, as well as other remote communities such as Kuper Island.

We agreed that there is a need to create awareness about FAS among these employment programs and their staff (especially in remote areas), and we discussed the possibility of a one-day Island conference with a focus on strategies for education and employment. This idea eventually evolved into the "Strategies for Success" educational event held at Providence Farm on May 3, 2002.

Mentorship members also discussed employment issues during the presentation to the Adult Learning Centre and Cowichan Valley Trade School staff.

d) Employment Challenges

Coordinating employment for people living with FAS is challenging. The dual role of supporting the person living with FAS and educating the employer can be precarious in a competitive labour market.

Often, people living with FAS talk about negative work experiences. The reasons for negative work experiences can range from low pay, long hours, lack of transportation or a stable residence, complicated work tasks, misunderstandings, feeling picked on, feeling stupid and afraid to ask for help, forgetting schedules and feeling overwhelmed.

Disability Disclosure

Another employment issue for the FAS affected person is whether or not to tell a potential employer about the disability. Young people with FAS say that it is hard to tell employers about any kind of difficulties because they fear they will jeopardize their chances of getting and keeping work. On the other hand, young people with FAS require extra support to accommodate their processing differences. Deciding whether to tell an employer about FAS is a difficult decision for many young people with FAS. People in the Mentorship Program felt that it is usually a no win situation.

Difficulty Understanding Expectations

Last year, one of the mentorship team members was let go from a retail position because according to his boss, "he was not doing as he was asked." The employer, who knew very little about FAS, stated that she had several meetings with the employee to re-explain the job's duties. After repeated reassurances from the employee that he would do it right, the employer became increasingly annoyed with unchanged performance levels.

In this situation, the employer presumed that the person with FAS was demonstrating willful misconduct. In contrast, the employee felt that everything at work was going fine; in fact that several important meetings with the boss had

gone quite well. The young man with FAS mentioned that his boss had said a few things that he did not understand, but he just nodded in agreement to avoid being difficult.

It was not long before the young man with FAS was completely surprised when he was let go from the job. By this time, attempts to negotiate with the employer proved unsuccessful. The employer felt that she had given “more chances than usual due to his FAS.” She did not understand that he needed simple instructions, tasks assigned one at a time, written reminders, follow-up about task completion before moving to the next one, and lots of encouragement related to efforts—not just results. She didn’t understand that one small distraction could derail his thought processes and result in an entire morning’s work not getting done. She did not have any practical strategies to accommodate his processing and performance differences.

Differences in Scheduling and Prioritizing

In addition to actual job tasks, day-to-day hassles of life can also prove to be major barriers to employment for people living with FAS. Scheduling tends to be problematic for people with FAS who are challenged in planning ahead. More interestingly, it’s not just about the ability to plan ahead; it’s also about priorities.

Our culture works on an industrial model where time is segmented in ever increasing smaller pieces: Years, months, weeks, days, minutes, seconds and so on. But people with FAS have very little motivation to choose the ‘scheduled version of life’ over the ‘in the moment version of life.’ Formulating decisions about life’s abstract concepts such as being on time, predicting tomorrow’s consequences, planning for next week’s pay cheque, next month’s raise, and yesterday’s bills, can be as elusive as a rainbow’s end to the person living with FAS. The priority is now because it is actionable, which means it is real.

This is why work schedules can be difficult for people with FAS. Things come up. And when they do, they take precedent over things that were planned. Even when there is a day timer with good notes in it, because whatever is written down is an abstract concept. If something ‘real’ comes along: an invitation to lunch, the need to borrow money for cigarettes, a cool lake on a hot day, or an unexpected visit from an acquaintance, then it is likely that now becomes the priority.

Easily Overwhelmed

Even when unexpected things don’t come up—everyday things can overwhelm. People living with FAS have to work harder to weed out environmental stimuli. This can be tiring and emotionally draining. Imagine turning on all the appliances in your home and then trying to hear only the sound of the phone. Imagine a world that doesn’t turn off or tune out. This is how one person with FAS describes her experience of the world. And it means that typical work and daily life routines can be experienced very differently for people living with FAS.

Changes in routine, learning a new skill, making and remembering appointments, organizing work wardrobes, and planning transportation can be details that create high stress levels for people with FAS. And these stressors are exacerbated if they are unable to express their difficulties or ask for help. Rather than face embarrassment, they remain silent, experiencing the consequences of their actions, or lack of them, whenever they inevitably happen. In this way, people with FAS may have a sense of life happening to them rather than a sense of agency. And this sense of helplessness is exacerbated when other people's expectations are too high.

In the work environment, where the concept of employment tends to include notions of competition, consistency, reliability, flexibility, punctuality, and efficiency, it is no wonder that people with FAS have difficulty finding and keeping employment. Even when employers have information about FAS and are supportive, they are faced with the reality of profit margins and operational costs. This makes it difficult for many employers to redefine their concept of employment to include room for a more fluid model of cooperation, support, spontaneity, flexible hours, and accommodations for inclusion.

e) What Would Help

Employment opportunities for people with FAS need to be flexible. Part-time opportunities, working as part of a team are good options because responsibility is shared. When an employee is unable to work, other team members can complete tasks. Of course one drawback to this approach happens when team members resent "picking up the slack." But this can be prevented, in part, by having a mix of team players with varying abilities and by giving realistic goals to members with FAS.

Many potential employers have the capacity to successfully employ a person with FAS but they lack the knowledge and strategies to accommodate them. Action towards reducing prejudice and stereotypes about FAS, and indeed all disabilities, is a positive step towards creating a vibrant, inclusive community. Towards this end, public education is critical. And public education developed and delivered by people living with FAS creates the most impact and provides a concrete example of how people living with FAS can contribute positively to their communities.

3.3 Education and Awareness

Finding Alternative Solutions promotes community education and awareness through participation in workshops and presentations, and through the development of written educational materials. Team members' real life perspective at workshops and community presentations provide invaluable educational experiences. The group also produced articles in newsletters, booklets and pamphlets to educate young people, community organizations, employers and ministries about the challenges of living with FAS.

The project conducted activities to promote community education, awareness and understanding of the challenges, gifts and talents of young people with FAS through:

- community workshops and conferences
- presentations to organizations working with youth and young adults
- written educational tools such as newsletters, media and press releases, and booklets about FAS

a) Attending Meetings and Events

Throughout the project, team members were encouraged to attend community meetings and events to promote education and awareness around FAS.

FAS Provincial Consultation Group

On March 4th, 2002 three representatives of the Cowichan Valley FAS Action Team Society attended the provincial FAS Consultation Group Meeting in Vancouver, BC. The meeting provided excellent opportunities to network with other communities throughout the province and to exchange ideas and practices. The meeting brought many island representatives together for the first time and sparked the formation of the Vancouver Island FAS Network. Representatives of the Cowichan Valley FAS Action Team Society will attend the first meeting of this group on Monday, June 10th in Nanaimo, BC.

“Our Turn To Talk”

A group interview was given to researchers from the University of Victoria's Research for Social Change Unit who are interested in learning more about adults living with FAS and their experiences—especially related to employment, the justice system and parenting. Participants were paid for their time and were provided with informed consent (meaning they could stop at any time and only had to answer if they wanted to).

The researchers were struck by team members' commitment to reduce stigmas about FAS caused by misinformation and lack of understanding. As a result Corey LeBarge worked in collaboration with the Finding Alternative Solutions Project to develop a proposal for an educational video that will feature team members and their perspectives about FAS. Application for project funding was successful and mentorship members will assist in the production of “Our Turn To Talk” Adults Living with Fetal Alcohol.

- Three representatives from our program attended a series of community meetings to address homelessness in the Cowichan Valley Region. Participation from mentorship team members helped to illuminate some of the relationships between FAS and homelessness.

- Team members participated in a teleconference call facilitated by Western Breweries involving people such as Dr. Christine Lock, Dr. Assante and Dr. Koren. The dialogue gave excellent information about diagnosis and prevention. We have been added to the FACE (Fetal Alcohol Canadian Expertise) network mailing list.

Information booths and fundraising events provided additional opportunities for members of the mentorship program to educate the community about FAS.

- Car washes were held on June 28th and August 11, 2001 reaching over fifty people.
- We had a display booth at the Cowichan Exhibition to acknowledge International FAS day, September 9, 2001.
- At a display at the Duncan Mall on August 20, 2001 volunteers talked to 30 members of the public.
- We had display/info booth at the Together Against Violence Resource Centre on Station Street during November, 2001.

Quick evaluation sheets available at these events asked people if they had ever heard of FAS, what they previously knew about it and what they had learned from their contact with the project. They provided us with the following feedback:

Any amount of alcohol is too much.

Only one drink can harm the baby during any trimester and 'binges' are the worst!

Many women are unaware in the first month of their pregnancy, so they drink unknowingly...posing risk to the fetus.

b) Workshops and Presentations

Cowichan Tribes

On Thursday, May 31, 2001, the *Finding Alternative Solutions* Mentorship Team facilitated a three-hour workshop in collaboration with Healthiest Babies Possible and Cowichan Tribes. "*Fostering Success for Kids and Youth with FAS*" drew approximately twenty-five foster parents, community health workers and service providers from the Cowichan Valley.

A pre-workshop questionnaire (Appendix D) was used to determine what type of information would be most beneficial to workshop participants. Presentations and educational packages were then developed accordingly.

Cowichan Tribes generously provided the venue, refreshments and honoraria for speakers.

Cindy Giles and Sara Billings from the Healthiest Babies Possible program of Hiiye' yu Lelum (House of Friendship) facilitated a station-to-station activity originally designed for use in local schools. This 30-minute interactive activity provided participants with basic facts about FAS.

Jennifer Kyffin, program coordinator of the *Finding Alternative Solutions* FAS Mentorship Program, explained how FAS and partial FAS are diagnosed. She provided information that will help participants to distinguish between primary disabilities, those directly resulting from prenatal exposure to alcohol, and secondary disabilities that are the result of the interaction between the primary disabilities of the person and their unique life experiences. Jennifer emphasized that secondary disabilities can often be prevented when families and communities build supports for persons living with FAS or partial FAS.

A short video presentation provided a change of pace. An excerpt from the CBC television program "Moving On", originally aired on May 13, 2001, featured members of the Mentorship Team.

Mentorship Team members, Leila Wilson and Isaac de Bree shared "*Strategies for Success*," in a four-part presentation that included strategies for managing anger, dealing with difficulties listening, motivation tactics and supporting the person with FAS to cope with change. The information they shared from their personal experience of living with partial FAS and FAS was well received by people attending the workshop.

Cowichan Valley Trade School

On Friday, June 1, 2001, Leila Wilson, the Peer Consultant and Jennifer Kyffin, the Project Coordinator provided an in-service presentation to staff at the Cowichan Valley Trade School. As a contractor with the Ministry of Economic and Social Development, the Trade School is responsible for delivering employment information sessions that are mandatory for all financial assistance applicants.

Approximately twelve employment counselors attended the one-hour information session with the aim of learning basic characteristics associated with FAS and strategies to support individuals living with it.

Responses to the question, "***Will the information shared in this workshop be helpful to you in your work***" included:

“Yes, I will certainly be more able to refer our clients to your services. It also gave me much information on how to communicate more effectively with FAS clients and students.”

“Yes, as we try to supply training for the unemployed your workshop helps identify behavioral problems which were not understood before.”

After the presentation, Trade School staff made a request for the *Finding Alternative Solutions* program coordinator and peer consultant to critique one of their information sessions for people on income assistance. An assessment of this community service was undertaken and the process that we developed formed the basis of on-site assessments and FAS Audits for Inclusion.

Student Services—Malaspina College

On January 22, 2002, Leila Wilson, Peer Consultant and Jen Kyffin, Project Coordinator with the *Finding Alternative Solutions* Mentorship Team, provided a short presentation to Student Services personnel at Malaspina College Cowichan Campus.

In the one-hour presentation, Leila shared the results of her on-site assessment of Student Services. Leila also talked to staff about her experiences as a college student in the past and shared strategies that she had found helpful. Her stories provided valuable insight into the challenges faced by someone with an invisible disability.

Volunteer Tutors—Malaspina College

On January 14, 2002, five members of the *Finding Alternative Solutions* Mentorship Team provided a two-hour presentation to volunteer tutors at Malaspina University College's Cowichan Campus.

A pre-presentation questionnaire was used to assess how much the tutors already knew about FAS and to determine what type of information would be most beneficial to them in their role with students. The presentation and educational packages were then developed accordingly.

Jennifer Kyffin, program coordinator of the *Finding Alternative Solutions* FAS Mentorship Program, explained how FAS and partial FAS are diagnosed. She provided information that will help tutors to distinguish between primary disabilities, those directly resulting from prenatal exposure to alcohol, and secondary disabilities that are the result of the interaction between the primary disabilities of the person and their unique life experiences. Jennifer emphasized that secondary disabilities can often be prevented when families and communities build supports for persons living with FAS or partial FAS.

A short video presentation provided a change of pace. An excerpt from the CBC television program "Moving On", originally aired on May 13, 2001, featured members of the Mentorship Team.

Leila Wilson, the project's Peer Consultant, shared "*Strategies for Success*," that included strategies for managing anger, dealing with difficulties listening, motivation tactics and supporting the person with FAS to learn and cope with change. Leila also suggested simple and practical ways that the physical environment could be made more accommodating for a student with partial FAS or FAS. Isaac de Bree also shared strategies with the tutors as he spoke about his experiences when attending college.

The information shared from the personal experiences of people of living with partial FAS and FAS were particularly appreciated and all participants described themselves as either more knowledgeable or much more knowledgeable about FAS after the presentation.

From a thank you cards received after the presentation:

"Thank you for your thoughtful, clear and helpful presentation on Tuesday. We appreciate knowing what works well and finding out what we can change in our services to students."

"We were honoured by your presence and your generous gifts of time, energy and enthusiasm. Thank you for putting FAS/FAEinto perspective. Your focus on dealing with difficulties face, rather than the labels, gave strategies and perspectives that are positive and empowering. As an in-service for tutors, your presentation was excellent – pertinent and useful, as well as warm and eloquent."

BC Crime Prevention Association Regional Training

On April 5th, 2002 Leila Wilson and Jennifer Kyffin delivered a workshop to crime prevention practitioners entitled "Strategies For Success with FAS." The workshop provided an overview of FAS, highlights of the Finding Alternative Solutions Project, and personal strategies presented by Leila Wilson.

"Strategies For Success" Educational Event at Providence Farm

On Friday, May 3rd 2002 one hundred teachers, counselors, employment coaches, human services workers, health practitioners and other community members attended a day-long educational event sponsored by Finding Alternative Solutions, Hiiye'yu Lelum Society and Coast Salish Employment and Training Society.

The keynote speaker was Deb Evensen, an educational specialist with extensive experience developing intervention techniques for families and children living

with FAS. As well, employment and prevention issues were explored in afternoon workshops facilitated by Healthiest Babies Possible and RISE Up Employment Services.

The event also included a panel discussion featuring four mentorship team members who discussed their personal experiences living with FAS.

c) Media Releases, Newsletters and Articles

Three local media releases featured the Finding Alternative Solutions Program. One article featured an interview with mentorship team members who discussed their concerns about negative stereotyping caused by statistics and the media. As well, the team produced the FASt Forward newsletter featuring articles, poetry and information that focuses on reducing the myths about FAS and creating awareness and understanding for greater inclusion of people with disabilities. Isaac deBree wrote his life story which was published in January 2002 Special Needs Adoptive Parents Newsmagazine, Volume 18, Number 1 (Please refer to Appendix E for media releases, newsletters and articles).

d) Educational Materials

Educational materials were developed for workshops, presentations and distribution throughout the community. The following educational materials were developed for the project:

“Strategies For Success,” an easy-to-understand package that contains handouts on Managing Anger, Difficulties Listening, Motivation Strategies and Coping With Change (Appendix F)

“Understanding Secondary Disabilities” was developed to provide basic information about the role of the community as a link between primary and secondary disabilities associated with FAS (Appendix G).

The Mentorship Program Brochure outlines the Finding Alternative Solutions Project and some of the challenges associated with living with FAS (Appendix H).

“Fetal Alcohol Spectrum: Fetal Alcohol Syndrome and Fetal Alcohol Effects” is a large print package developed as an introduction to FAS. This package is intended to accompany Finding Alternative Solutions Workshop Presentations (Appendix I).

“Finding Alternative Solutions” is a large print package that outlines the goals of the project, identifies some of the basic challenges associated with FAS and describes the program activities undertaken to promote crime prevention through building community inclusion (Appendix J)

e) On Site Assessments (FAS Audits For Inclusion)

FAS Inclusion Audits are a simple tool to involve community agencies in addressing gaps and inefficiencies, and in celebrating successes. The process is intended to support individuals with FAS to better navigate complex systems and access services through the development of action plans for inclusion within community organizations.

In order to identify and develop an effective action-based method for increasing community inclusion of people living with FAS, the Finding Alternative Solutions Project contacted organizations in the Duncan area in an effort to identify and develop key components of an education and training model for FAS inclusiveness.

Key Assets and Areas of Potential

The community consultation process helped to identify key assets and areas of potential:

- Community organizations want to be inclusive of families and persons living with FAS/E, but lack the knowledge and skills to recognize and accommodate them.
- Community organizations will benefit from site-specific assessments that address the unique physical, social and institutional characteristics that impact each organization's capacity to be FAS inclusive.
- Education and training that responds to the specific needs of each organization will maximize learning, skill development and the implementation of inclusion strategies because of its relevance to day-to-day activities and because of its focus on practical applications that can be reasonably achieved.
- In-service training that is site-specific will increase organizational participation and results because it is more accessible and relevant for staff, administration, and volunteers than generalized, off-site training.
- Training within community organizations will create a ripple effect of sustainable, positive impact because trained staff can then transfer their skills to others within the context of the workplace and the larger community.

- People living with FAS are the greatest resource in providing relevant information, skills and strategies for inclusion.
- Follow-up assessment and support can increase long-term gains through the development of new strategies as new challenges emerge, and through sharing of best practices.

Action For Inclusion

Based upon the information gathered from people living with FAS and through the consultation process with service providers, a pilot education and training model was developed and delivered to three Duncan area organizations: the Cowichan Valley Trade School, School District 69 Adult Education Centres, and Malaspina University-College.

Assessing the 'FAS friendliness' of services, Leila Wilson visited the above organizations and attempted to access their services. Leila asked for information and participated in appropriate processes, examining the services through the lens of her knowledge and personal experience of living with FAS. This was compiled into a report, along with other feedback obtained from staff about their general knowledge of FAS.

In-service training sessions were then developed to address the specific issues of each organization. Leila suggested practical ways that services could better serve people with neurological disabilities. Her ideas included simple improvements to signage and effective ways to give directions to someone with a neurological disability, and because people with FAS often have difficulties concentrating in busy environments, she also suggested that interviews would be more effective in quieter, less cluttered spaces.

An external evaluator obtained the following feedback after the completion of on-site assessments and in-service training sessions:

"Thank you so much for doing the assessment of Student Services at Cowichan Campus. Very helpful, with specific changes that we feel we can (mostly!) put into place."

"An excellent report with many ideas and suggestions that are easy to implement."

"Physical setup of my office can be improved (to be more FAS/E friendly)."

"Knowledge gained here can be circulated among the staff, lessons adjusted etc. We will be able to implement practical changes."

“The site assessments were powerful because they were concrete and manageable.”

4. Evaluation

An external evaluator provided formative evaluation throughout the project using qualitative and quantitative data. A separate final evaluation report will be submitted to the National Crime prevention Centre,

PART III. DISCUSSION

Challenges and Lessons Learned

Throughout the ten-month project many challenges presented themselves as valuable learning opportunities. In fact, some of the difficulties we faced helped us to look at things differently, to try new approaches and to change our direction.

The Mentorship Program was very broad in scope, which was beneficial because it allowed us enough latitude to experiment with several areas in order to determine what is most effective to build community inclusion for young people living with FAS.

We were initially surprised and somewhat disappointed by the low numbers of youth dropping into the weekly FAS meetings. As we continued however, we realized that these low numbers are due to the huge lack of diagnosis and understanding around FAS. If people don't know what FAS is, don't know that they or someone they care about is living with it, then they won't seek services. Other factors such as negative stereotypes of people with FAS also influence people's willingness to self-identify. So the reality is that many people in the Cowichan Valley live with undiagnosed FAS and simply try to cope in the community.

Addressing this challenge helped to shift our perspective so that instead of focussing on direct services offered in a structured support group, we began to focus on building capacity in the community through education. And while this idea is not new—our approach is. This is because our project is founded on the belief that people with FAS are experts. Their personal experiences serve as a road map through our community and help to identify what and where the obstacles are, and how to remove them.

So, despite the fact that we moved away from a support group structure, we still achieved many of the objectives of the mentorship program because the process of delivering community education involves support, life skill development and social and employment opportunities. For example, one way that life skills were enhanced was when team members attended meetings and events as FAS delegates/advocates. These activities give team members recognition for their experience and provide high levels of satisfaction. This is a win, win situation because the community benefits tremendously from this kind of exchange.

Employment challenges also proved to be ongoing in the Finding Alternative Solutions Project. We found that several of our team members only want to work part-time and they want to work in the capacity of FAS educators. As one member put it, "I got tired of getting fired and problems with employers so I decided I'd rather spend my time getting out there and educating people to make it easier for others to keep a job." This way of tackling employment issues makes sense because it does not squeeze disabled people into uncomfortable job descriptions. Instead, it promotes community action that will lead to greater employment opportunities for people with FAS.

Moving Forward

Our community wants to hear from people living with FAS. Our on-site assessments and in services provide *relevant and practical* skills and strategies that local organizations and workers can do to accommodate people living with invisible disabilities. As well, it provides meaningful work for our team members who are valued for their expertise and unique insights instead of trying to have to "fit into" a job description.

In response to the positive support for this educational approach, the Cowichan Valley FAS Action Team society has proposed the *Action For Inclusion Pilot Project* which will develop practical, site-specific strategies that prevent community exclusion experienced by people living with FAS/E. It will provide concrete alternatives to crime, illegal and unhealthy activities by empowering individuals with FAS/E to conduct comprehensive, on-site FAS Audits and training that will build skills within community organizations necessary for greater FAS/E inclusion. It will assist young people living with FAS/E to realize their potential and have it realized by others, through their contribution to positive and sustainable change in the Cowichan Valley Regional District

APPENDIX A

Mentoring Youth with Neurological Disabilities: Responsive Community Integration

Jennifer Kyffin

University of Victoria

August 25, 2000.

Developing a mentoring program for adolescents with neurological disabilities grew out of a need to understand and interpret the challenges faced by youth with alcohol related neurodevelopmental disorders (ARND) in a way that promotes a positive relationship between the individual and the community. The primary challenges caused by organic brain differences, the additional disabilities associated with psycho-social maladjustment, and the influence of the community upon them comprise a dynamic system that develops in relationship with one another. Seen in this way, community integration does not emphasize changing the individual living with ARND, but promotes working together to build bridges to a community that is accessible, inclusive and supportive.

Building a responsive community requires flexible supports across many levels. This means that the community plays a part in mediating cognitive, behavioral and social difficulties by encouraging strengths and minimizing weaknesses. In order to identify possible interventions for youth with ARND, it is helpful to explore primary disabilities such as attention, memory and processing differences, and then consider how these interact with secondary disabilities associated with unsuccessful community integration.

According to Streissguth (1997), primary disabilities are those that arise from organic brain damage and reflect the CNS dysfunction inherent in the FAS or FAE diagnosis. Structural brain differences may or may not manifest in set of physical features including small palpebral fissures and epicanthai folds, deficient philtrum and growth retardation. More importantly, structural brain differences affect cognition. Using MRI, Mattson and Jernigan, (1994) found that the brains

of alcohol-affected children were microencephalic with a 20% smaller cerebral area, and that the basal ganglia, (which is involved in spatial memory, goal directed behavior, attention, language, and ability to transfer from one task to another), was disproportionately smaller than children who were not prenatally exposed to alcohol. In a later study (1999), Mattson and Riley found that explicit memory deficits found in the individuals with ARND were comparable to patients with Huntington's disease, which is a sub-cortical dementia noted for basal ganglia degeneration. Although there may be some problems with comparing such different groups, their similarity in functional memory and structural damage to the basal ganglia provide convergent evidence that may help to develop intervention strategies for both populations. It may also help encourage supports for individuals with ARND that reflect a disability rather than a set of behavioral and social problems.

An important link to understanding social difficulties that tend to increase with age is that fact that structural brain differences interfere with attention across the life span and will be exacerbated as societal expectations increase. According to Streissguth (1997), attention difficulties are present at birth and failure to habituate to light on the first day of life is the outcome most highly related to prenatal alcohol exposure among the hundreds of outcomes tested. An infant's initial inability to tune out stimuli may manifest later in life as difficulty with tasks that require attention. In school, distractibility, restlessness, lack of persistence and low overall achievement scores are commonly reported characteristics of children living with ARND (McCreight, 1997).

Lack of appropriate academic and social interventions for youth with ARND may be a result of diagnostic complexities. Unlike other developmental disorders such as Down's Syndrome, individuals with ARND may have no facial dysmorphology and IQ's that suggest they are not performing at their full potential. In the absence of expected positive symptoms, there may be a tendency to attribute difficulties to delays in maturational processes, impoverished home environments, or other extraneous factors (Kerns & Don, 1997). In addition, alcohol-affected youths may present a kind of diagnostic paradox because "serious intellectual shortcomings [are] masked by a lively friendliness or a very effective superficial skill in language" (cited in Streissguth, 1997 p. 75). Thus, creative compensation for cognitive differences may actually increase marginalization and impede appropriate diagnoses and intervention. As one Nanaimo elementary teacher commented, "I have a chatterbox in my class who is socially engaged to the point of intrusion and who engages in academics through creative acts of evasion. She can't sit still and she can't pay attention long enough to absorb the important information, but she seems bright and remembers a lot of extra details" (personal communication, May 18, 2000).

This description of the ability to effectively attend to relevant features while ignoring the non-essential ones, is what Koopman (1983) refers to as selective attention. Without this ability, stimuli create a jumbled environment that is difficult to filter, process or store effectively. Weiner and Morse (1994) suggest that alcohol-affected individuals have selective attention difficulties because they suffer from sensory hypersensitivity: their brains are unable to sort incoming

sensory information. According to this view, multi-modal sensory integration is compromised and this disruption prevents further processing required to organize information.

The inability to selectively attend to relevant information and the lack of tertiary processing does not mean that individuals with ARND can not learn, but that they learn differently. Additional learning supports that emphasize repetition, showing and doing, that employ all the senses to convey uncomplicated instructions, are some of the ways to help students. As one young adult stated in a discussion about her challenges with partial FAS, “Don’t tell me what I can’t do, show me and support me with what I can do” (personal communication, July 13, 2000). Unfortunately, accessing specialized resources for students can be difficult because, as one public school teacher explained, “referrals to the learning assistant often yield a less-than-helpful report which summarizes the child as “just slow” with little or nothing in the way of strategies for interventions (personal communication, May 18, 2000). Lack of diagnosis means that children with ARND may face additional barriers upon entering the school system because teachers may not be able to clearly identify ARND and specialized interventions are not typically available.

And even in instances where selective attention is optimized, it is helpful to understand that the attended information may not be generalized because alcohol-affected individuals have problems with relational thinking. The ability to see relationships between and among events in a sequence is what Koopman (1983) refers to as temporal processing. The notion of temporal processing is

similar to Piaget's (1972) idea that learning involves drawing from the concrete nature of something as well as attributing relational meaning to sequential actions. For example, a child can learn about something directly, the fact that a stone in one hand weighs more or less than a stone in the other hand. However, when a child places stones in some order and realizes that the stones amount to the same total number regardless of how they are placed, then something other than the property of the stone is abstracted. In this way, the child's own action creates a relationship with meaning which is then internalized so that the child no longer needs a concrete object or a specific event to understand a particular concept and to perform appropriate actions across different situations.

So besides memory and attention, learning also requires the capacity to link one's self to the properties of the object or to the actions upon it, thereby abstracting and then internalizing meaning that can be used in other situations. Simply stated, learning requires agency—a meaningful connection between the self and predictable outcomes in the environment. Difficulties in perceiving relationships means that the individual with ARND is disadvantaged in developing meaningful connections between self and the environment. This lack of connectedness is perhaps the most notable hidden disability for individuals with ARND because it creates isolation.

The episodic nature of life can have profound affects on the individual with ARND. In a film called David with FAS, when asked to discuss his own difficulties, David, a creative twenty-two year-old remarked, "I get sidetracked a lot because I'm locked up inside the short circuits of my brain"(1996). David also

reported abusing alcohol, an inability to manage daily routines, severe depression, self-destructive behavior and suicidal ideation. His parents discussed their grief about having to let go of expectations, when at eighteen, David was diagnosed with FAS. His mother commented that “David’s connectedness is absent; the fabric that weaves our life is missing” (from David with FAS, 1996).

The cognitive and emotional difficulties that David and his family describe present obstacles in both academic and social spheres, especially as the child reaches adolescence. Although primary disabilities do not cause secondary disabilities, the interaction between organic brain difference and social factors can. Increasingly complex social patterns combined with the faster pace of high school may marginalize youth with ARND as they struggle to fit in and be accepted by peers. In addition many teens with ARND have IQ’s which provide them with enough insight to feel frustrated and socially isolated as they begin to realize the extent and permanence of primary disabilities. Cases such as these constitute a paradox in which cognitive difficulties impede the individual from developing agency and social connections required for successful community integration, but they do not concomitantly protect the individual from the pain associated with awareness of their disability.

Unsuccessful transitions into the larger community, according to Streissguth (1997) lead to disabilities that the individual is not born with, and which could be ameliorated with adequate intervention. Common secondary disabilities among ARND individuals are; depression, suicide attempts, disrupted

school experiences (expulsion or suspension), incarceration for crime or alcohol and drug programs, and trouble with the law. When considering the example of the cognitive paradox previously mentioned, secondary disabilities may reflect two different approaches to coping with the youth's increased awareness and self-identification with ARND. Viewed in this way, frustration and denial of primary disabilities may manifest in anti-social behavior such as criminal activity and substance abuse. In contrast, depression and suicidal ideation may be a more affirmative response to the personal implications of living with ARND.

In either case, the frustration associated with lack of services and programs for youth with ARND is clearly heard by parents and caregivers. As one parent of three adopted children with FAS reports, "We grieve the lack of necessary, on-going assistance for our children (DeBree, 2000). Another mother during candid conversations around drugs and crime revealed the need for structure, support and productive activity for her adolescents. When reflecting upon her young adult sons' cycles of poorly planned criminal activities and repeated incarcerations she stated that, "I'm just so tired—and too old to be dealing with irresponsible kids, but mine are never going to grow up" (personal communication, June 2000).

In Canada, alcohol-affected youth, according to Conroy (199-), are estimated to comprise at least 25% of all young offenders. Furthermore, "on any one day in BC there are 306 youth in custody, 94 in remand, 1000 on bail, 4450 on probation and ten in the Input Assessment Unit" (cited in Cowichan Valley FAS Action Team, 1999, p. 3). The frequency of alcohol-affected offenders led a

CBC commentator to describe the situation as “the sleeping giant” in a feature report entitled, “Life Sentence” (CBC National, 1997).

And these disproportionately high figures are not new. In his 1983 report to the Solicitor General, Koopman found that learning disabilities among different populations of juvenile delinquents ranged from a low of 22% to a high of 90.4%. Although Koopman did not specifically distinguish between learning disabilities and ARND, he did characterize many of the presenting cognitive difficulties. Like alcohol-affected youth, these offenders had compromised analytic skills, an inability to integrate the past with the future, difficulty with relationships between and among things, and a non-linear view of time often accompanied by an inability to project themselves into the future (Koopman, 1983).

In addition to difficulties with analytic tasks that require attention and concentration, Stangeland (1990), interested in the role of cognition in behavioral and emotional adjustment in juvenile delinquents, found that mathematical tasks were difficult for delinquents as compared to non-delinquents. Support for this finding comes from Streissguth (1997), who found that the most common reason for incarceration among ARND individuals is theft. In addition, Normand and Rutman (1996), explain that many alcohol-affected youths and adults have little understanding of how money works due to difficulties with arithmetic, and may spend money recklessly or ‘borrow things’ in order to replace money which is lost. The high rates of theft and incarceration, according to one parent, is because “stealing is as an effective way to instantly gratify needs and does not involve planning not to get caught” (personal communication, July 12, 2000).

Of course, these findings do not suggest that cognitive impairments cause delinquency as is evidenced by many adolescents who have ARND and do not break the law, and by many without the disability who do. In fact, research by Malmgren, Abbott, and Hawkins (1999) warns against presupposing that learning disabilities cause crime. They further suggest that one possible explanation for the high rates of incarceration is that youth with ARND commit crime at rates similar to those of non-affected youth, but that they are more likely to be caught and may be treated differently once they are within the justice system. Unfortunately, critical analysis of the possible links between ARND and criminal activity is sometimes discouraged, such as cases where the press suggest that drinking during pregnancy causes the fetus to become a criminal, and that community organizations should be “fighting crime in the womb” (Rusland, 2000). However, despite inaccurate media portrayals that suggest that ARND causes criminal behavior, it is not unreasonable to consider the possibility that academic failure, difficulty with relational thinking, lack of connectedness, and inability to integrate past and future, may impede community integration and increase the likelihood of delinquent behavior.

In addition to committing crime, youth with ARND are also more likely to become victims (Burgess, 1994). The pain associated with living with ARND may be another sleeping giant who unfortunately does not awaken. Of particular note, Lemoine (1992) in a follow-up study of some of his patients from his ground-breaking 1968 study, and found that out of the twenty-eight original participants who were classified with less severe ARND (partial FAS), two had

committed suicide and five others had attempted it. Other studies investigating learning disabilities and suicide have also yielded startling results. For example, McBride & Siegal (1997) reviewed a study by Peck that investigated all Los Angeles suicide victims in 1985 who were under the age of fifteen years, and found that fifty percent had been diagnosed as learning disabled. This is a disproportionately high figure given the fact that only five percent of children in the American school system are diagnosed with a learning disability.

In light of these high percentages and the fact that Canada is ranked among the highest countries for youth suicide rates, McBride & Siegal (1997) conducted a study that analyzed handwriting of all adolescent suicide notes in Ontario for 1987, 1988, and 1989. Their results indicated that notes of adolescents who committed suicide showed deficits in handwriting comparable to those found in samples of learning disabled adolescents. Although there is no conclusive evidence to suggest whether or not these suicidal learning disabled individuals were prenatally exposed to alcohol, it is not unreasonable to consider their prevalence among this population given the fact that this exposure is the leading cause of learning disabilities in North America.

In addition to academic and social difficulties, there may be other cognitive anomalies peculiar to alcohol-affected individuals that place them at a higher risk for unsuccessful community integration. One such characteristic that is persistent across the life span is a lack of appreciation for the concept of time. Time for the alcohol-affected person is an abstract concept that is constantly changing and as McCreight (1997) reveals, the person with ARND lives in the

moment. Showing up late for work, not paying bills on time and failing to plan ahead are some of the more obvious difficulties faced by an individual whose internal clock is permanently altered.

The likelihood of recidivism is also increased without additional supports to mediate this inability to organize, plan and track time. A Corrections Officer recently described her frustration in dealing with a young male adult who kept missing probation appointments. She remarked that he was friendly and polite and indicated that he wanted to cooperate, so it seemed odd that he kept avoiding her. Finally, she became annoyed and asked him why he had repeatedly missed scheduled appointments. To her complete surprise, the young man casually stated, "Well, I'm here now." This response combined with other unusual behaviors, such as not remembering his live-in girl friend's last name, led her to investigate the effects of prenatal alcohol exposure. She stated that she believed that his history of repeated crime was possibly associated with a disability and that she wanted to find alternatives to the usual sentence of community hours in order to help break the cycle of repeated offenses (personal communication, July 3, 2000).

The notion of restorative justice is not a new one. It is founded on the principle that a relationship exists among the offender, the victim and the community and that a focus on repairing harm and reintegration to the community will ultimately benefit, more than a retributive approach, all those involved. Elements of the restorative justice approach are found in community agencies such as the John Howard Society, which provides alternatives to the

criminal justice system by offering programs that emphasize accountability. Unfortunately, this diversion program is not designed to assist individuals with neurological disabilities and as such, it is only accessible to first time offenders.

What is needed is a community outreach program that provides alternatives to criminal activity for youth with neurological disabilities. The program would promote successful community integration by working with community partners to develop and maintain services and supports, and by working to empower youth with FAS to influence and access these supports. Activities supporting this initiative would include life skills programs and supported work experience intended to bring young people with neurological disabilities together with a responsive community.

Other communities have had success with programs designed to respond to the needs of individuals with ARND. In Cranbrook, Community Healing Intervention Program (CHIP), has had success over the last seven years in providing structured day programs that included photography, rock climbing, paid work opportunities and a safe non-judgmental place to go for food and friends. "The most important contributions," according to program social worker John Barnes, "are the relationships that we build" (personal communication, August 9, 2000).

Building relationships is the essential challenge in providing alternatives to secondary disabilities including challenges with employment. The Focus Employment program in Burns Lake, British Columbia offers some innovative approaches to preparing individuals for the work place. Operated from New

Caledonia College, students attend small group classes every day and develop organizational and social skills in a very structured environment. Students can work in the program's catering business and are assisted in locating potential employers within the larger community. According to Linda Schmidt, the program coordinator, one considerable challenge is finding work placements outside the school setting. "It is difficult to get employers to hire our students—even on a part-time basis" (personal communication June 15, 2000).

This difficulty reflects the employer's fears about hiring a person with a disability. Concerns about insurance and liability, about extra training required to learn the job, and other problems that may arise need to be disarmed before the alcohol-affected individual begins any kind of work experience. It is vital that the potential employer is informed about ARND and given enough information and support in a way that emphasizes their role as building community strategies to support neurologically disabled youth.

But developing community partners is only part of the solution. Work experience opportunities also require direct service to the individuals with ARND. Initial identification of the youth's strengths, area of interest and challenges can be matched with the most suitable community partner for work mentoring opportunities. The next stage will match the youth with a screened, volunteer job skill mentor, who is trained to accompany the youth during skill acquisition and to assist with on site training. The job skill coach will encourage the youth in establishing comfortable work routines and act as a liaison between the staff, employer and the youth. In addition to providing one on one support to the

youth, the job skill mentor will encourage feedback from the community partner and report to the program coordinator. Consistent contact with the youth and employer shall be maintained beyond the initial training period and will vary case by case. Questionnaires and other feedback from all participants will provide program evaluation and influence work mentoring program development.

In addition to work experience, the challenges of primary and secondary disabilities faced by youth and their families reveal the need for community programs that provide life skill and recreational opportunities for youth with ARND. The Powell River Association for Community Living has been in operation for over ten years, providing support to young adults affected by alcohol. Program coordinator, Corrine Hunter explained that participation was inconsistent in the beginning. "We began a youth drop-in group and sometimes we would just sit and wait and no one would show up, but once word got out and people knew we were reliable and supportive more people started coming." The program now hosts several youth and young adult drop-in groups that are co-facilitated by local teens and university students who volunteer their time. Group activities include darts, cards, movies, playing pool and fun outings. Life skill components are also included through educational guest speakers and active community service. In fact, members of the girls only group called the "Divas" have helped to put on a Santa's breakfast, have raised money for the local women's transition house, and volunteer in a home for the elderly. Most recently, community teens and leisure service students organized a cycling club for

individuals with ARND and Corrine reports that it has been a wonderful success over the summer months (personal communication, August 2000).

Possibilities to provide recreational and life skill opportunities can be achieved by modifying and expanding upon successful models like that of the Powell River Association for Community Living. A youth drop-in group, advertised through community agencies, parent support groups and information handouts distributed at the Duncan Days fair is scheduled to start in October. The purpose of the drop-in group is to provide youth with neurological difficulties opportunities for positive social connection and activities in a safe structured environment, to encourage exploration of beneficial community services and assist youth in accessing them, and to promote involvement in further development of appropriate resources. Peer mentors, recruited from the local college and university, may participate as part of a course practicum or as a way of earning credits toward tuition through a partnership with the local chapter of "Youth Community Action" or they may elect to volunteer their time. In any event, all staff and volunteers will be trained after successful completion of the program's screening process.

In sum, the mentoring program will develop a network of community supports that respond to the needs identified by the primary and secondary challenges facing families and youth living with ARND. The program will utilize contributions from peer mentors and vocational and community liaisons, to provide life skill, recreational and work experience in a supportive, structured environment. The program will focus on strategies that prevent problems before

they arise, that promote concrete alternatives to social isolation and illegal activities and that encourage and assist young people with ARND to integrate into, and influence the structure of, an increasingly responsive and accessible community.

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