



ACTION FOR INCLUSION: FASD INCLUSION SYSTEM

**Year 2 Project Report
April 2005**

COWICHAN VALLEY FAS ACTION TEAM SOCIETY

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The Cowichan Valley FAS Society acknowledges the National Crime Prevention Centre of Public Safety, Ministry of Children and Family Development, and Emergency Preparedness Canada for providing funding for the Action for Inclusion project. We also acknowledge our many community partners who have contributed to the success of the Action for Inclusion Project over its first two years, and recognize the valuable contributions made by our Board of Directors, team members living with FASD, staff, volunteers, and community members.

EXECUTIVE SUMMARY

The Cowichan Valley FAS Society's Action for Inclusion Project has successfully completed the second year of project activities. The **Action for Inclusion: FASD Inclusion System** project is a three-year educational and training project designed to increase the capacity of communities throughout British Columbia and Canada in their ability to accommodate people living with Fetal Alcohol Spectrum Disorder (FASD).

To date, this project has worked with community organizations throughout the Cowichan Valley Regional District and other parts of Vancouver Island and British Columbia to assess their knowledge about FASD and to build their capacity to accommodate people impacted by it. The Action for Inclusion Project's goal is to develop practical, site specific strategies that prevent community exclusion experienced by people living with FASD. The project aims to enlighten community service providers about the daily challenges of people with FASD and to provide them with education and skills that promote inclusion.

Specifically, the project objectives are to:

- Help promote more positive attitudes about, and employment for, people living with FASD, by involving them in project activities that educate the community about FASD inclusion strategies.
- Build FASD inclusion strategies within Cowichan Valley Regional District community organizations by involving at least eight of them in the FASD Inclusion System process.
- Educate other communities about the model through the development of the Action for Inclusion network, hold a provincial workshop, present at a national conference, develop a project web site, and create educational resources and tools.
- Transfer the model to four BC communities and two Canadian communities beyond BC.

During Year 1 of the project, staff living with FASD worked under the guidance of the project manager to complete on-site assessments of eight service providers throughout the Cowichan Valley Regional District. In-service training modules that addressed the specific needs of each organization followed. Assistance with strategy implementation, the development of a web site, and a regional strategy session to brainstorm and share best practices rounded out the FASD Inclusion System process in its first year.

In Year 2, we transferred the Action for Inclusion System model to four British Columbia communities by providing consultation, training, and follow-up support. Based on the collaborative process and outcomes, we developed written action plans for local implementation. Feedback about physical, social, and institutional changes around FASD inclusion was obtained through follow-up and evaluation. The information was shared at a national FASD conference and via the project website and newsletter.

In Year 3, we plan to build on the previous two years' accomplishments and work to transfer the inclusion system model to two other Canadian communities beyond British Columbia. The project will continue to provide follow up and support to implement inclusion strategies with the four BC communities, and the eight Cowichan Valley organizations already engaged in the Inclusion System process. The project will produce a manual and educational film about the FASD Inclusion System process and will continue to involve people living with FASD across all levels.

1. INTRODUCTION

Despite the fact that the Cowichan Valley Regional District has many community programs and services, people with Fetal Alcohol Spectrum Disorder (FASD)¹ often have difficulty accessing and utilizing them. This is because without specialized knowledge, the disability is often hard for others to recognize, and without the practical skills and strategies to draw upon, programs and services cannot adequately accommodate people with FASD.

For people living with FASD, our communities' lack of recognition and appropriate supports can create misunderstanding and exclusion. Primary disabilities caused by prenatal exposure to alcohol are often misinterpreted as willful misconduct, laziness, dishonesty or stubbornness, when in fact, people with FASD are struggling to process instructions, need assistance organizing, have chronic memory problems, and experience sensory overload that causes frustration and impedes their ability to focus and process information.

In response to the clear need for more community awareness about the reality of living with FASD, as well as the need to provide strategies for service providers to support those living with FASD, the Cowichan Valley FAS Action Team Society created the **Action for Inclusion project** to develop practical, site-specific strategies that address community exclusion experienced by people living with FASD.

The project aims to reduce the likelihood of resorting to illegal and unhealthy activities by empowering individuals with FASD to participate in positive ones. Under the Action for Inclusion system, people living with FASD work with project staff and community organizations to develop and implement inclusive practices and policies. Organizations receive on-site FASD assessments ("Walk Abouts") to determine inclusion issues followed by responsive training that will build skills necessary for greater FASD inclusion. Through their contribution to positive change, people living with FASD become integral to the development of community strategies which benefit all community members.

In the Action for Inclusion project's first year, eight community organizations throughout the Cowichan Valley Regional District participated in the Action for Inclusion system. In Year 2, four communities in other regions of British Columbia received training about how to implement the FASD Inclusion System (also known as "FASD Inclusion Audits"). In Year 3, we will focus

¹ FASD is an umbrella term used to describe a range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioural, and learning disabilities with lifelong implications.

on transferring the model to two Canadian communities beyond BC. In addition, we will develop an educational film about the FASD Inclusion System process and a companion Action for Inclusion manual.

The overall goal of the project is to enlighten community service providers about the daily challenges facing people with FASD and to provide education and skills to promote changes that accommodate people with FASD.

The **specific objectives** of the project are to:

- Help promote more positive attitudes about, and employment for, people living with FASD, by involving them in project activities that educate the community about FASD inclusion strategies.
- Build FASD inclusion strategies within Cowichan Valley Regional District community organizations by involving at least eight of them in the FASD Inclusion System process.
- Educate other communities about the model through developing the Action for Inclusion network, holding a provincial workshop, presenting at a national conference, developing a project web site, and creating educational resources and tools.
- Transfer the model to four BC communities and two Canadian communities beyond BC.

In Year 1 of the project, our activities focused on:

- Involving people living with FASD in the development and delivery of program activities and materials;
- Building a working relationship with key organizations to foster the development of an FASD Inclusion System framework with each organization;
- Organizing and facilitating initial meetings and planning sessions to identify educational needs and goals of community organizations;
- Documenting levels of understanding and gaps in knowledge about FASD of the participant community agencies and organizations;
- Developing a web site that provided project information and highlighted persons living with FASD;
- Producing media releases to inform the community about the Action for Inclusion project and to raise awareness and education about FASD in our community;

- Conducting on-site visits (WalkABOUTs) in community organizations to assess physical and social factors that impact accessibility for people living with invisible disabilities;
- Developing and delivering in-service training and educational workshops that responded to the needs related to FASD inclusion identified at each organization; and
- Preparing written reports that identified FASD inclusion issues and made recommendations for solutions.

In Year 2 of the project, our activities focused on:

- Transferring the FASD Inclusion System Model to four other BC communities;
- Continuing to involve people living with FASD in the development and delivery of program activities and materials;
- Continuing to develop and deliver in-service training and workshops in response to the FASD inclusion needs identified at each organization in Year 1;
- Providing follow up support for key organizations to foster the development of an FASD Inclusion System framework;
- Organizing and facilitating FASD training meetings and planning sessions to identify educational needs and goals of community organizations;
- Completing written reports that identified FASD inclusion issues and made recommendations for solutions;
- Developing written action plans for implementation of inclusion strategies identified;
- Developing and distributing a follow up questionnaire on implementation of individualized inclusion strategies;
- Updating our Society's web site and publishing a quarterly newsletter.

2. PROJECT ACTIVITIES AND SUCCESSES

Objective 1: Teach other Canadian communities how to develop and implement the FASD Inclusion System Model.

What is the FASD Inclusion System?

The FASD Inclusion System is a simple tool designed to make community organizations more accessible to people with invisible disabilities. It involves learning about physical, social and

institutional factors that impact accessibility for people with FASD and then developing practical strategies to address them. By making our community organizations more accessible to people with invisible disabilities, we make them more accessible to everyone. With new knowledge and skills, organizations will be better equipped to accommodate people with neurological disabilities such as FASD. As well, staff, volunteers, administrations, and the broader community will all benefit from the inclusion strategies we help them develop. The Inclusion System is designed to increase accessibility and enhance work environments.

The **Inclusion System** process is comprised of five key components:

- **Building Structure** is the first step in the Inclusion System process, and involves working to create partnerships with community organizations, identifying who needs to be involved, forming a working committee, and bringing people together to build consensus around goals and objectives.
- **Assessment** involves working closely with each organization to: make assessment plans, identify educational needs, conduct on-site visits and develop recommendations.
- The final stages of the Inclusion System, **Education and Training, Implementation and Evaluation**, focus on developing education and action programs that respond to what has been learned in subsequent stages.

In order to move through the five components of the Inclusion System process, we complete the following steps:

STEP 1: DEVELOPING AN INCLUSION SYSTEM PLAN

The Action for Inclusion project works with each organization to develop a plan for the Inclusion System process. We agree upon the areas, programs, and services that will participate in the process, and upon the times to visit and provide training sessions at each organization.

STEP 2: ON-SITE VISITS (WalkABOUTs)

Young adults living with FASD (accompanied by project staff) visit each organization at a pre-arranged time(s). During these 1-2 hour visits, they explore factors in the environment of the organization that impact accessibility. For example, they explore building design, noise levels, signs, lighting, and other communication systems. During the Walk About, team members ask questions, take notes, or tape record information about their experience.

STEP 3: FOLLOW-UP WITH STAFF

After the on-site visits, Action for Inclusion project team members meet with the organization to provide more opportunity to ask questions about the Inclusion System process and about our team members. At this time, we also distribute a brief questionnaire, which helps us identify what type of education and information is useful to include in subsequent training sessions.

STEP 4: IN-SERVICE TRAINING

The aim of in-service training is to provide practical knowledge, skills, and strategies to help create supportive environments for people who may require special assistance.

After the on-site visits and follow-up with staff, we create a training event that meets the unique needs of the organization. The training reflects what we learn together in the Inclusion System process and addresses any questions or concerns that staff members identify.

STEP 5: DEVELOP AN ACTION PLAN

Once we complete the on-site visits and the in-service training session, we meet with the organization to develop a written plan that addresses the recommendations resulting from these activities. This plan helps us to identify and document:

- short, medium, long term goals;
- actions to be taken;
- potential lead and partners for each objective;
- expected timeframe for completion; and
- successes and challenges experienced over time.

STEP 6: FOLLOW-UP & LEARNING EXCHANGE

The Action for Inclusion project continues to work with each organization to provide follow-up and support to implement recommendations for more FASD friendly environments. The highlights of local organizations and other BC communities that participated in the Inclusion System process are available on our website at www.cvfasd.org.

Action for Inclusion Year 2 Focus

The focus of Year 2 (April 1, 2004-March 31, 2005) of the Action for Inclusion Project was to teach other Canadian communities how to develop and implement the FASD Inclusion System model. The Action for Inclusion Project accomplished this by:

- Working closely with four other BC communities to transfer the model and its best practices;
- Presenting a workshop at a national FASD conference;
- Developing a project website to share information; and
- Developing a project network/list serve.

Our BC Community Partners

The Action for Inclusion Project has partnered with the following BC agencies and communities in transferring our FASD Inclusion System model:

- Vancouver Island Health Authority, Victoria, BC;
- Northern Family Health Services, Prince George, BC;

- Campbell River FAS Action Network, Campbell River, BC; and
- Coast Salish Employment and Training Society, representing 19 First Nations bands on southern Vancouver Island and the Sunshine Coast.

2.1. Transferring the FASD Inclusion System Model

The Action for Inclusion Project team worked closely with the **Vancouver Island Health Authority's (VIHA)** Mental Health and Addictions Prevention Services and the Victoria FAS Community Circle to present a full-day workshop on the FASD Inclusion System model in October 2004. This workshop was delivered to an audience of 60 participants from a range of backgrounds (e.g., social services, corrections, psychiatric services, special education, foster parents, caregivers, community support workers, and First Nations representatives), and included basic information on FASD, presented by adults living with FASD from Duncan and Victoria, and introduced the FASD Inclusion System and Walk About tool. Due to strong demand, a second full-day workshop was held in Victoria in December 2004, with 30 participants attending.

As an outcome of these two workshops, the Action for Inclusion Project team worked closely with VIHA's Mental Health and Addictions Prevention Services, to teach the FASD Inclusion System model to a group of individuals living with FASD in Victoria. The Action for Inclusion team provided ongoing training, mentorship, and support for four adults living with FASD who participated in the program in the Victoria area. The Action for Inclusion team provided on-site support for the Victoria group's first "FASD Walk About" in April 2005, undertaken at Camosun College in Victoria.



Figure 1 FASD Inclusion System Training with VIHA Victoria Group.

The Northern Family Health Society (NFHS) is located in Prince George, BC and provides outreach services to at-risk pregnant women and families. NFHS offers a variety of pre- and post-natal programs focusing on infant health and development, and parenting support.

We met with program staff via teleconference to explore a workable Inclusion System plan. It was determined that we would focus on assessing the Elizabeth Fry Society's Teen Mothers' Alternative Program, which provides child care to student mothers and offers courses for mothers in the same facility as the childcare centre, so that mothers can continue their education while providing care for their children. NFHS staff felt that it was likely that some of the student mothers may be living with FASD, and/or may have given birth to affected children.

The Action for Inclusion team traveled to Prince George, BC in November 2004 to work with the Northern Family Health Society (NFHS) to deliver training workshops for interested volunteers living with FASD and community practitioners. We trained six adults living with FASD in the Prince George area to conduct FASD inclusion Walk Abouts, and provided a full-day workshop for approximately 60 participants from a variety of backgrounds. We conducted practice Walk Abouts at the Elizabeth Fry Teen Alternative Program, and at the Prince George Public Library – Bob Harkins Branch, with adults living with FASD from both Duncan and Prince George.

To date, the FASD Inclusion System process has included the following:

- Discussion with key NFHS staff about the Inclusion System process;
- Distribution of Inclusion System and Walk About information;
- Pre-Walk About questionnaires;
- Agreement to move ahead and conduct the on-site visit (Walk About);
- One on-site Walk About visit (assessment of physical systems);
- Creation of action plan (list of recommendations resulting from the Walk About);
- Delivery of written report; and
- Distribution of follow-up questionnaire.

Since our joint November 2004 workshop, the Northern Family Health Society has been busy educating their community about the effects of FASD and implementing their own version of the FASD Inclusion System model. NFHS received funding to conduct this work, and is now providing training and employment to a team of adults living with FASD. Starting in February 2005, NFHS and a team of adults living with FASD have performed 12 Inclusion Walk Abouts. Their main focus has been on employment agencies, the Prince George Public Library, a local college, and the health unit.

The NFHS team has used the tools we have demonstrated to them, and has made modifications to meet the organization's needs, as well as those of individual participants. They have found that their team members prefer to record their findings using a tape recorder, rather than by making notes, and have also adjusted the data recording sheets.

Overall, their group has been very well received. The local businesses where they have performed their Inclusion Walk Abouts have greeted them with smiles and have given positive feedback. NFHS found that 60% of their inclusion Walk About participants asked their group to come back to give presentations to staff on the effects of FASD, and how they can contribute to

making their environments more FASD inclusive. They already have three presentations scheduled for April 2005.

NFHS had the opportunity to present at the Aboriginal Criminal Justice Conference with over 100 people in attendance. Once again, their group was very well received and has found that the Inclusion System tool has opened many new doors for them. The local community sees that they have an amazing group of young adults living with FASD who are willing to help. The group is currently in discussion about going into some of the local schools and giving presentations to youth on prevention of FASD.



Figure 2 Inclusion System Workshop at Prince George Civic Centre .

The Action for Inclusion project team traveled to Campbell River, BC in November 2004 to deliver a half-day training workshop for 30 community practitioners, in partnership with the **Campbell River FAS Network**. The workshop focused on “Getting to Know FASD”, and featured a panel of adults living with FASD from Duncan, Victoria, and Campbell River. It also introduced the FASD Inclusion System and Walk About tool. As a result of this community workshop, the Campbell River FAS Action Network has facilitated the transfer of this model to at least 4 of the organizations that participated in the November workshop. These four organizations have already begun performing Inclusion Walk Abouts at their own facilities. The Campbell River FAS Action Network team has been actively planning for their first walk about as well. They plan to follow up with the participants of the November 2004 workshop to identify those interested in participating in the FASD Inclusion System or presentation.

The Coast Salish Employment and Training Centre (CSETS) is based in Duncan, BC, and provides a range of employment support programs for members of 19 First Nation communities on southern Vancouver Island. CSETS is a funding agency committed to the support of individuals and First Nation communities to access opportunities to meet diverse employment needs, thereby enhancing self-sufficiency and self-reliance. We met with program staff and

determined that we would partner with CSETS in delivering an introduction workshop for the FASD Inclusion System to members of the 19 First Nations supported by CSETS.

The Action for Inclusion project presented “Getting to Know FASD” and the FASD Inclusion System Model at the 2005 Aboriginal Head Start Conference, organized by the Coast Salish Employment and Training Society (CSETS) held in Duncan, BC. We presented to about 15 participants from several BC First Nations communities. As an outcome of this workshop, the Action for Inclusion team was offered the opportunity to partner with CSETS to deliver an additional two full-day workshops on the FASD Inclusion System as part of CSETS’ Community Asset Mapping training in Saanich and Nanaimo. These workshops covered the basics of FASD, and introduced the FASD Inclusion System model, including the Walk About tool. We look forward to continuing partnerships with CSETS in the delivery of further training workshops, and in transferring the model to additional BC Aboriginal communities in Year 3 of the Action for Inclusion Project.

2.2. Mentoring and Training in Transferring the Model

The Action for Inclusion project team focused on a hands-on approach in providing mentoring and training to our community partners in adapting the FASD Inclusion System for use in their respective communities. We found that face-to-face meetings with volunteers living with FASD (those who would be conducting the Walk Abouts) combined with practice Walk Abouts at local community agencies was most effective in terms of creating understanding of the FASD Inclusion System process, and the Walk About tool, in particular. Team members living with FASD from the Action for Inclusion project were directly involved in designing and delivering the training, and they provided valuable insight and support for program staff and volunteer trainees.

In general, our approach consisted of the following:

- Face to face meetings and “getting to know” individuals living with FASD and support staff;
- Introduction of FASD Inclusion System model and Walk About tool;
- Detailed explanation of Walk About tool, including practice Walk About;
- Debrief of Walk About (e.g., what was learned, what was missed, impressions, feelings, and developing recommendations);
- Development of an action plan (e.g., how to organize recommendations into a plan); and
- Follow up support (e.g., touch back phone calls/emails; provision of further FASD Inclusion System materials; on-site assistance with Walk About if needed/if possible).

As a result of this mentoring and training, the Action for Inclusion project team has developed strong outreach ties with individuals living with FASD in the Victoria area. In Year 2, we have worked with six adults living with FASD who reside in the Victoria area, four of whom are frequent participants in delivering Action for Inclusion workshop presentations on Vancouver Island. This has been of great benefit to both the presenters and the workshop participants. Presenters have developed strong public speaking and presentation skills, increased self-esteem

and self-awareness, and have been recognized by community members as having valuable insights into the realities of living with FASD. Workshop participants get to experience first-hand the “spectrum” of individuals living with FASD and have the opportunity to learn from these adults’ lived experiences through question and answer components of the workshops.



Figure 3 CVFASD Action for Inclusion Team Assisting VIHA Victoria Group at Camosun College, April 2005.

Objective 2: Build FASD inclusion strategies within Cowichan Valley Regional District community organizations by involving at least eight of them in the FASD Inclusion System process.

3. CREATING AWARENESS ABOUT ACTION FOR INCLUSION: FASD INCLUSION SYSTEM

After nearly a year between funded community-based FASD projects at the start of Action for Inclusion in 2003, and because of the Cowichan Valley FAS Society’s (CVFASS) varied projects over the last nine years, it was necessary to create awareness about both the Action for Inclusion project objectives and the capacity of the Society to provide additional services.

In 2003, we found that many people in the community still believed that CVFASS provided an FASD peer support group (mentorship program), a parent support group, as well as advocacy for people living with FASD. (Our Society later received funding to run additional programs in some of these service areas). In the first six months of the project, we received many requests for all of these services in addition to education via the FASD Inclusion System, a trend that continued into Year 2. We experienced an increasing number of requests for information around diagnosis and support for crisis intervention for families, friends and persons with FASD.

In the second year of the project, we found that awareness of the project continued to grow. Many organizations in our own community and in other communities on Vancouver Island have

expressed interest in the project and/or have requested information about it. Some of the requests have arisen from workshop contacts, others from conferences and meetings, and others from FASD list serves.

And, as the project continues to move forward, we have increased our circle of community contacts and partners throughout BC and Canada. Our project formed new partnerships with the Ministry of Children and Family Development, Early Childhood Development Branch as well as the Child Welfare Advisory Committee of the Queen Alexandra Foundation for Children. In addition, we participated in the Aboriginal Early Childhood and Training Strategic Planning Session and as a result, were invited by the Early Childhood Development Branch of MCFD and Health Canada's Fetal Alcohol Spectrum Disorder Program to explore the potential applications of the Inclusion System tool.

3.1. Project Information, Presentations, and Media Releases

In Year 1, project information packages were developed and sent to community organizations representing education, health, school, law enforcement, social services, local government, employment and disability services, and others. Additional information meetings were undertaken in order to garner support for the project and to encourage participation in the FASD Inclusion System process and the development of a working committee to help guide the project activities.

Project presentations were given to: the FASD Community Capacity Building and Consultation conference held in Nanaimo in June 2003; Lake Cowichan, Duncan, and North Cowichan mayors and councils between May and August 2003; and the Vancouver Island FASD Consultation group in September 2003.

A description of the project was published in the 2003/2004 Directory for the Canadian Centre on Substance Abuse. As well, an abstract was submitted to the Canada Northwest Fetal Alcohol Spectrum Disorder Conference held in Winnipeg in November 2003. Our application, "Action for Inclusion: FASD Audits," was successful and we presented a workshop outlining the Inclusion System process to over eighty people.

Team members of the Action for Inclusion project participated in three educational videos. "Our Turn to Talk" was an educational video project being undertaken in partnership with the University of Victoria Social Work Program's Research Department. The project featured our team members living with FASD and provided insights into the challenges of adults with FASD and the potential to develop helpful strategies. In addition, our members were also interviewed for another University of Victoria video featuring FASD employment issues. Other media materials included several newspaper articles and television clips that highlighted the project and FASD issues.

In Year 2, we found that community awareness of the Action for Inclusion Program had grown significantly as a result of the initiatives undertaken in Year 1. The increased number of requests for community presentations demonstrated this success. Continued media coverage in the form

of newspaper articles in the local community paper, plus an interview on CBC proved to be highlights of the last half of Year 2. We anticipate continued interest in the Action for Inclusion Project as we develop further partnerships with communities outside British Columbia.

3.1.1 FASD Awareness Day

In building community awareness and recognition around FASD, the Cowichan Valley FAS Society wrote letters and delivered presentations to the mayors and councils of Duncan, North Cowichan, Lake Cowichan, and Ladysmith requesting the proclamation of International FASD Awareness Day. Both the City of Duncan and the Town of Ladysmith responded by proclaiming September 9 of each year as Fetal Alcohol Syndrome Awareness Day.

With the help of team members and volunteers, the Society undertook a variety of activities for FASD Awareness Day, including stamping a prevention message on liquor store bags, distributing “FASD bells” to local businesses, and hanging a banner in the City of Duncan and the Town of Lake Cowichan.

3.1.2 FASD National Conference

The Action for Inclusion Project team presented the “FASD Inclusion System” at the National Conference on FASD held in Victoria, BC in February 2005. The presentation was delivered to an audience of approximately 100 people. This conference involved experts in the legal, social services, medical, educational, psychiatric, and policy development fields, and provided a significant opportunity to raise the profile of the Action for Inclusion Project to professionals at a national level.

3.1.3 Web Site Development

An FASD friendly website, www.cvfasd.org was developed in consultation with team members affected by prenatal alcohol exposure as well as family members, and the Action for Inclusion working committee. The website contains sections including: CVFASS homepage with philosophy and values, accomplishments, goals and objectives; “What is FASD?”, which contains general information on FASD; “My Story”, which highlights people with FASD; publications; project information; links to other FASD-related websites; and “Ask People with FASD”, an interactive, monitored message board where people can submit questions about FASD and have them answered by people living with FASD. Much of the website content has been input by our team members living with FASD. In Year 2, we posted the FASD Inclusion System reports and action plans that resulted from our Inclusion Walk Abouts with the eight organizations involved in the process. In Year 3, we will be posting a training manual and additional information resulting from our work in transferring the Inclusion System model to Canadian communities outside British Columbia.

3.1.4 CVFASS Newsletter

The Cowichan Valley FAS Society began publishing its newsletter, “Inclusion News” in August 2004. It is distributed quarterly to over 100 organizations via email and list serve. Staff, team

members, and parents write articles that feature program highlights, upcoming events, and perspectives of caregivers and those living with FASD. Our newsletter has been warmly received, and we plan to continue publishing it throughout Year 3.

3.2 Building FASD Inclusion Strategies: Completing the Individualized FASD Inclusion System Plans

Our aim in building FASD inclusion strategies is to reduce community exclusion for people with FASD by promoting change within community organizations to better accommodate people with FASD. The first two years of the project have focused on:

- creating awareness about the Action for Inclusion project;
- supporting partners to participate in the project;
- developing an FASD Inclusion System process framework with relevant organizations;
- gathering information about FASD knowledge (meetings and questionnaires);
- analyzing this information to develop responsive training sessions for each of the audited organizations; and
- delivering training sessions and responding to requests to provide additional educational workshops and presentations that arise.

In Year 1, the Action for Inclusion team worked with seven community organizations to initiate the FASD Inclusion System process. In Year 2, we completed the process with those seven organizations with further training workshops, written reports, and action plan development. We completed the FASD Inclusion System process with one more community organization to meet our project target of building inclusion strategies with eight organizations working in the Cowichan Valley Regional District.

The Action for Inclusion team worked with the following organizations:

- Association for Community Living
- Cowichan Family Life
- Growing Together Child Care Centre
- Ladysmith Resource Centre
- Malaspina University-College
- RCMP – Duncan/North Cowichan Detachment
- Somenos Transition House
- Whitecrow Village Society

To date, the FASD Inclusion System process has included the following:

- Initial meeting to identify lead staff and agree upon which areas, programs or services would participate in the FASD Inclusion System
- Pre-Walk About questionnaire distributed to staff
- In-service training workshop covering identified needs
- On-site FASD Walk About visits

- Summary of Walk About findings and creation of Action Plan
- Development of project report and inclusion strategies
- Presentation of project report and Action Plan
- Follow-up on Action Plan

3.3 Results from FASD Inclusion System Process

Results of the on-site visits (Inclusion WalkABOUTs) undertaken with community organizations have continued to produce a wide range of educational and learning opportunities. As of the end of Year 2, 11 Inclusion System workshops have been completed in response to the educational and environmental needs identified during the Inclusion WalkABOUT process. Written reports have been completed for 11 organizations with a range of recommendations for inclusion strategies including reducing clutter, noise and distractions, adding or improving signs, establishing quiet areas for focused work, and providing additional education, supports, and programming for staff and clients. **Appendix A** contains details on the completion of the FASD Inclusion System process for each organization.

As part of the completion of the FASD Inclusion System process, we developed a brief follow up questionnaire that was mailed to the eight organizations listed above. (A sample follow up questionnaire is included in Appendix C). To date, we have received 5 of 8 questionnaires back, and the results are summarized as follows:

- All 5 organizations identified the audit process (FASD Inclusion System and WalkABOUT) as either “very useful” or “somewhat useful”
- 4 of the 5 indicated that they had already made changes as a result of the process
- 4 of the 5 organizations had indicated they had made changes to their communication and physical environments
- Examples of changes included:
 - Adding more visual cues to office
 - Improving/simplifying signage
 - Reducing clutter on walls and bulletin boards
 - Installing lighting that does not hum
 - Closing cabinets when not in use
 - Using name tags for key staff
 - Painting in muted colours
 - Adopting a scent-free policy for staff and volunteers
- Of the 5 responses, when asked what additional supports they would need in implementing the inclusion strategies, 2 of the 5 identified financial supports, 1 identified time and someone to take the lead on implementing the changes, and 1 requested another on-site visit from the Action for Inclusion team

- 3 of the organizations identified that they would be renovating or moving in the near future, and would be considering the recommendations from the Inclusion System process in their new spaces
- Suggestions for improving the experience included:
 - Shortening the written report
 - Shortening the time between the on-site visit and the written report/recommendations
 - Additional on-site follow up visits by Action for Inclusion team members
 - More time with team members living with FASD

All of the organizations we worked with during the FASD Inclusion System process were very positive in their responses, and the majority made changes to their environments and communication processes as a result of participating in the Inclusion System. Changes made by these organizations showed an increased level of staff awareness concerning the affects of living with FASD and a genuine commitment in making their environments more FASD friendly and accessible. We recognize that change takes time and a supported effort. In Year 3, we will conduct another round of follow up and on-site visits with these organizations to assist them in further implementing the recommendations and inclusion strategies identified through the Inclusion WalkABOUTs.

In Year 3, we look forward to working with Global Vocational Services, an employment services agency in Duncan, to conduct an FASD Inclusion Walk About of their employment resource centre. We have already begun the Walk About process with this organization, and will provide further on-site training and follow up support in implementing inclusion strategies.

<p>Objective 3: Promote more positive attitudes about, and employment for, people with FASD, by involving them in project activities that educate the community about FASD inclusion strategies.</p>

4. Involving People with FASD

Our aim within this objective has been to provide adults living with FASD employment opportunities that place them in the forefront of community education focused on practical solutions around FASD. By personally educating the public about their daily challenges, people living with FASD promote deeper understanding and compassion about the issues, which in turn, motivates the community to make changes to accommodate people with invisible disabilities.

Face-to-face connection with people with FASD provided the most vital piece in our community education process and assisted with creating a strong message that motivated people to make responsive changes. A total of 19 people living with FASD have been integral team members on the Action for Inclusion project: 5 people in Year 1, and 14 people in Year 2. (The increase in numbers in Year 2 was a result of our outreach work in the communities of Prince George and Victoria, BC). Their roles included participation in presentations and workshops, office support,

and assistance with the development of educational and training materials. Other members who support the project include an office assistant, an FASD support person, an external evaluator, parents of people with FASD, volunteer community members, the project director, and the project assistant.

When people with FASD are given the chance to share their unique life experience and to offer suggestions about potential strategies, it can avoid or transform negative stereotypes and fear that others may associate with FASD. Recognizing the value of lived experience also provides people with FASD an opportunity to gain valuable employment and transferable work skills such as arriving at work on time, keeping appointments, completing assigned tasks, and working as part of a team. The following section describes how the Action for Inclusion project has involved people with FASD.

4.1 Team Members' Contributions

Fourteen people living with FASD were involved in the project in Year 2. Roles and responsibilities of members varied depending upon their strengths and interests. Team members provided input and feedback about the project's activities and materials. For example, team members with FASD helped to create both the format and content of the Cowichan Valley FASD website at www.cvfasd.org, which they deemed to be FASD friendly. Our team members' contributions to project planning activities, meetings, and presentations helped to strengthen community understanding, and in turn, helped the Cowichan Valley FAS Society to serve as an example of a positive, integrated workplace for other Canadian organizations.

As a result of this project, team members developed other transferable employment skills, such as:

- providing support, training and mentorship to others with FASD;
- public speaking;
- entering data, using the Internet, filing;
- answering phones and taking messages;
- mailing out and faxing information;
- liaising with community organizations;
- completing tasks;
- practicing time management skills;
- planning and attending meetings;
- assisting with planning project presentations; and
- working closely with project staff as part of a team.

4.1.2 Cross-Program Participation

In addition to providing valuable support in the Action for Inclusion project, team members and volunteers living with FASD played vital roles in other programs run by the Cowichan Valley FAS Society. The Youth Inclusion Program involved youth living with FASD in developing and presenting a unique drama piece featuring an educational message about the prevention and

impacts of FASD. This presentation was delivered at two local high schools, and received positive coverage in the local community newspaper.

Team members also provided ongoing mentoring and support for participants in the Society's weekly adult drop-in group starting in July 2004. This drop-in group was part of the Community Inclusion Program, whose main objective was to address barriers to participation in the local community. Team members helped out with problem solving, skill building activities, creating strategies for stress management, and developing a FASD friendly community resource guide.

4.1.2.1 Whitecrow Village Family Inclusion Camp

In Year 2, the Cowichan Valley FAS Society worked with the Whitecrow Village Society in bringing its inclusive-style camp for families with children who have FASD to the Cowichan Valley. The Action for Inclusion team used the Inclusion System model in assessing the camp facilities to help prepare the site. Two FASD WalkABOUTs were conducted: one before camp started, and one during camp, with recommendations made for improving the FASD friendliness of the site and buildings, and for adjusting some of the camp activities to better suit participants. In addition, adults living with FASD gave presentations to volunteers and camp staff on the challenges and strengths of living with FASD before the start of camp which provided an opportunity to increase FASD knowledge and discuss inclusion strategies specific to camp life.

In our first collaborative initiative, both organizations provided funding, volunteers, staff, and campers for the Whitecrow Family Inclusion Camp held from June 27 to July 3, 2004 at Riverbottom Camp just outside Duncan, BC, on the Cowichan River.

Whitecrow Village Family Camps provide the opportunity for a positive experience for families and individuals living with FASD. The program is designed around the characteristics associated with prenatal exposure to alcohol. A formal diagnosis is not required to attend the camp. Over 60 people attended Whitecrow at Riverbottom Family Inclusion Camp, including children, youth, families, staff, team and community members, and volunteers. Families that attended were from a wide range of socio-economic and ethnic backgrounds, which proved insightful, as well as educational, and in turn enriched the Camp's environment.

The immediate goal of the Family Inclusion Camp was for children, youth, and families to have fun, and to participate in traditional camp activities such as hiking, boating, nature lore, and crafts. The camp program also strives to incorporate the development of social and self-care skills, and provide training, guest speakers, consultation, and support for parents, family members, and caregivers.

As one parent stated, *"No longer were the kids being judged for what they could not do but instead their successes were being celebrated."*

Camp staff working with the children and youth had experience with and understanding of the disabilities, behaviours, and strengths that often accompany FASD. Whitecrow Village Camps practice and teach positive communication skills to ensure each camper has daily success.

All camps provide formal training on the following topics:

- Everyday structure and strategies at home;
- Why structure and strategies are necessary;
- Looking at environments: what works, what doesn't, and why;
- Everyday structure and strategies at school;
- Teambuilding at home, in school, in the workplace, and in the community; and
- How to support individuals and families: what's needed, what does not help, and what positive outcomes can look like in our communities.

Depending on the needs of the families at camp, morning workshops for parents could also include:

- Practical solutions for success with FASD;
- Healthy sexuality for children, adolescents, and adults with disabilities;
- Awareness of work issues for people living with FASD;
- Non-violent crisis intervention;
- Legal system issues;
- Care for caregivers;
- Systemic advocacy; and
- Life skills.



Figure 4 Staff and Volunteers of the Whitecrow Camp, June 2004.

4.3 Educating the Community About FASD Inclusion Strategies

Because our presentations were intended to reach a wide variety of audiences from caregivers and foster and adoptive parents to professionals in social services and education, we adopted a flexible yet structured approach in our delivery, combining interactive portions with more traditional delivery methods. We also involved individuals living with FASD as presenters, as they are the experts of their own experience and can provide much needed perspective on the

impacts of living with FASD. The focus of our workshops was twofold: to provide basic information on FASD, and to provide an approach in reducing the impacts of secondary disabilities as a result of living with FASD. Our workshop outline is as follows:

Part 1

- Icebreaker – interactive exercise (“Bremmel” or distraction activity)
- Getting to Know FASD – presented by adults living with FASD
- How it happens
- Primary disabilities – physical, behavioural, cognitive signs
- What it’s like to live with FASD
- Introducing secondary disabilities
- Question and answer

Part 2

- FASD Inclusion System: Reducing Secondary Disabilities By Improving Accessibility – presented by adults living with FASD
- FASD Inclusion Walk About
- Practice Walk About
- Question and answer
- Debrief and check out

We continued to work on presentation development throughout Year 2, having made improvements and adjustments based on audience feedback and suggestions. One area that has been challenging is in the introduction of the FASD Inclusion System itself, and making a clear link for audiences between secondary disabilities associated with FASD, and the need for improved accessibility to reduce secondary disabilities. This is where the life experiences of the presenters living with FASD becomes key in illustrating these linkages, and in providing concrete examples for audiences of the struggles and strategies of these individuals. This participation is also essential in promoting more positive attitudes about people living with FASD, and dispelling some of the misperceptions that persist around FASD.

From our audience feedback, we have seen that this integrated approach works. Participants very much appreciated hearing directly from people living with FASD; the sharing by these individuals of their personal experiences has been a consistent highlight for workshop participants. We also noted the importance of hands-on practice with the FASD Walk About tool, and therefore incorporated a “practice Walk About” into the majority of our presentations.

4.3.1 Community Education Workshops

The Action for Inclusion Project team delivered a total of 23 community education workshops during Year 2 to nearly 500 individuals. Of these workshops, 13 were training sessions associated with the FASD Inclusion System process, and 10 were “stand-alone” community education workshops delivered at the request of service providers and agencies in the Cowichan Valley and elsewhere on Vancouver Island. A special highlight from Year 2 was a presentation given at the National FASD Conference held in Victoria in February 2005.

Table 1 Summary of Workshop Statistics from Year 2 Action for Inclusion, April 1, 2004 to March 31, 2005.

Total workshops	23
Total participants	~489
Average number of participants	18
Number of organizations involved	15
Number of communities involved (includes 4 First Nations communities)	7
Involvement of team members living with FASD per workshop	2-3

FASD Training Workshops (as part of FASD Inclusion WalkABOUTs):

- Association For Community Living, Duncan, BC
- Cowichan Family Life: Alexander Resource Centre, Duncan, BC
- Parksville Mental Health Centre, Parksville, BC
- Malaspina University-College, Duncan, BC
- Somenos Transition House, Duncan, BC
- Cowichan Valley Childcare Resource and Referral Centre, Duncan, BC
- Campbell River FAS Action Network/Sunrise Resource Centre, Campbell River, BC
- CSETS Community Asset Mapping I – Saanich, BC
- CSETS Community Asset Mapping II – Nanaimo, BC
- VIHA at Juan de Fuca Recreation Centre, Victoria, BC
- VIHA and Victoria FAS Community Circle at Erik Martin Pavilion, Victoria, BC
- Northern Family Health Society, Prince George, BC

Community Education Presentations:

- Chemainus First Nation Alcohol and Drug Awareness Week
- Kuper Island Community Forum
- MCFD Health and Prevention Forum, Vancouver, BC
- Cowichan Intercultural and Immigration Society, Duncan, BC
- Cowichan Alternate School, Duncan, BC
- Social Worker Training Workshop – PEERS, Victoria, BC
- Aboriginal Head Start Conference, Duncan, BC
- Foster Parents Association, Duncan, BC
- FASD National Conference, Victoria, BC

The Action for Inclusion Project continues to receive strong interest and support from community organizations, both locally and around Vancouver Island. In Year 3, we have been invited to present at a Health Canada Prevention Forum, School District 79-Cowichan Valley, and Kwumut Lelum Child and Family Services. The Foster Parents Support Program of Port Hardy has also indicated an interest in having Action for Inclusion deliver a workshop and training session in that community in Year 3. Beyond BC, we have received interest from the Northwest Regional FAS Society in High Level, AB to participate in training for the Inclusion System.

4.4 Measuring Success: Summary of Workshop Participants' Feedback

Audience response to our community education workshops over the past two years has been overwhelmingly positive. We have received more requests for presentations than we are currently able to accommodate, and we anticipate that this trend will continue into Year 3. Feedback from the workshops clearly demonstrates that the Action for Inclusion Project achieved its objective of promoting more positive attitudes and understanding of people living with FASD, and educating communities and organization about the FASD Inclusion System model and FASD inclusion strategies.

The following section describes the highlights from the participant feedback forms from training workshops held on Vancouver Island, and mainland BC throughout the first two years of the project. These presentations involved both basic information on FASD (“Getting to Know FASD” or FASD 101) and the introduction of the FASD Inclusion System model. A sample feedback form is included in **Appendix C**. Responses were gathered from 275 participants.

4.4.1 Knowledge of FASD Accessibility Issues Before Training Workshop

When asked to describe their knowledge of FASD and accessibility issues, the majority of participants identified that they were “somewhat or fairly knowledgeable” before the workshop, while 36% identified that they felt “knowledgeable” or “very knowledgeable” prior to attending. A similar number however said they felt they had “very little” or “no previous knowledge”. **Figure 5** below shows the breakdown of responses.

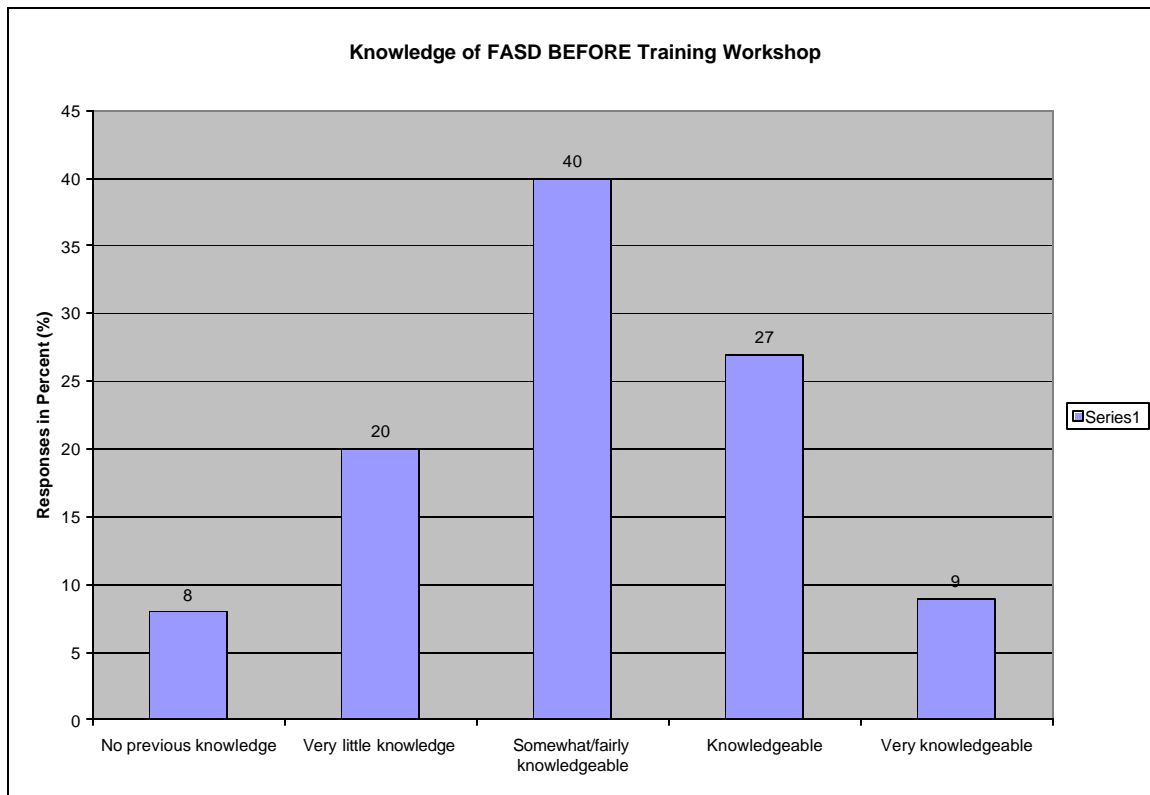


Figure 5 Knowledge of FASD Before Training Workshop

4.4.2 Knowledge of FASD Accessibility Issues After Workshop

When asked to describe their knowledge of FASD accessibility issues after attending the workshop, a majority indicated they felt their knowledge had increased. 51% said they felt “more knowledgeable” and 36% felt they were “much more knowledgeable”. **Figure 6** shows the breakdown of responses.

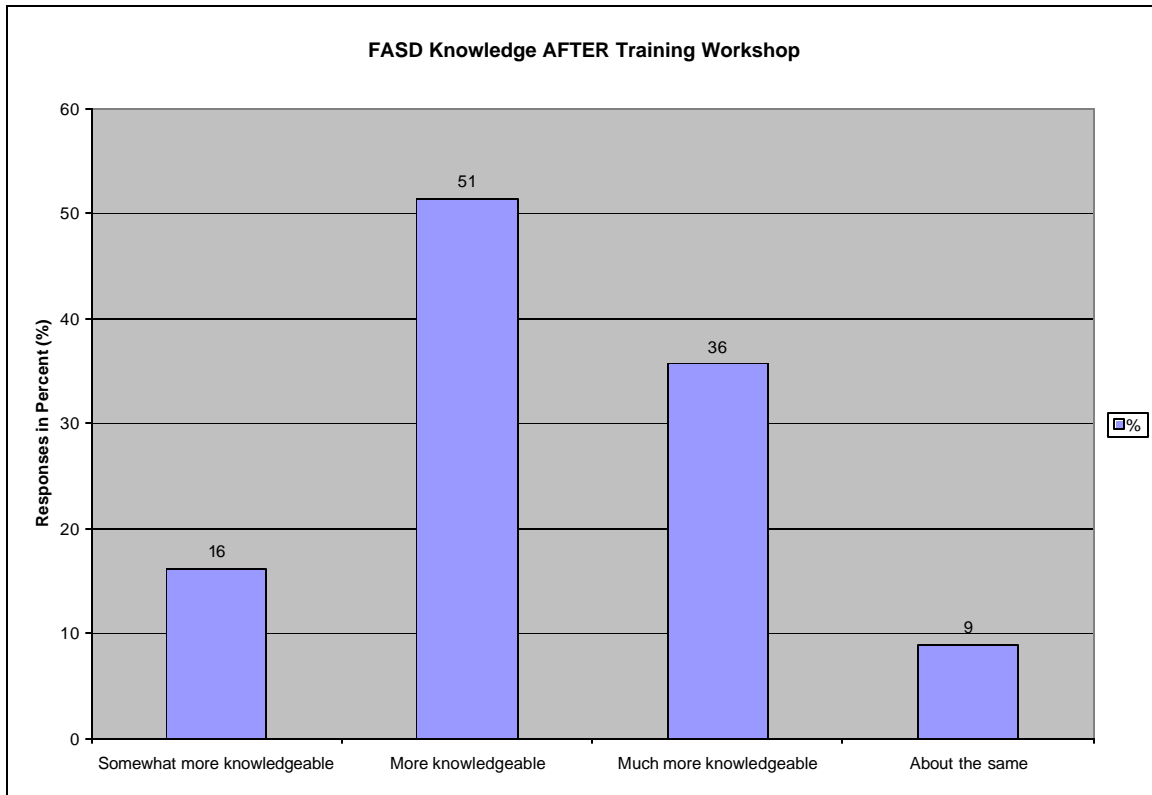


Figure 6 Knowledge of FASD Accessibility Issues After the Training Workshop

When asked if the information presented at the workshop would help participants in addressing the challenges faced by those with neurological disabilities, an overwhelming majority (98%) said “yes”.

4.4.3 Top Learning Outcomes from the Training

Participants were asked to describe the top three things they learned at the training. We received four common responses to this question, as shown in **Figure 7** below. These were: “challenges faced by a person with FASD”(36%) (accessibility issues); “how to make changes and support someone with FASD”(35%); “increased understanding of FASD” (20%); and “new strategies”(9%) for working with people with FASD. This demonstrates that the workshops were effective in increasing awareness and understanding of FASD within the communities and organizations where the Action for Inclusion project conducted its community education and training.

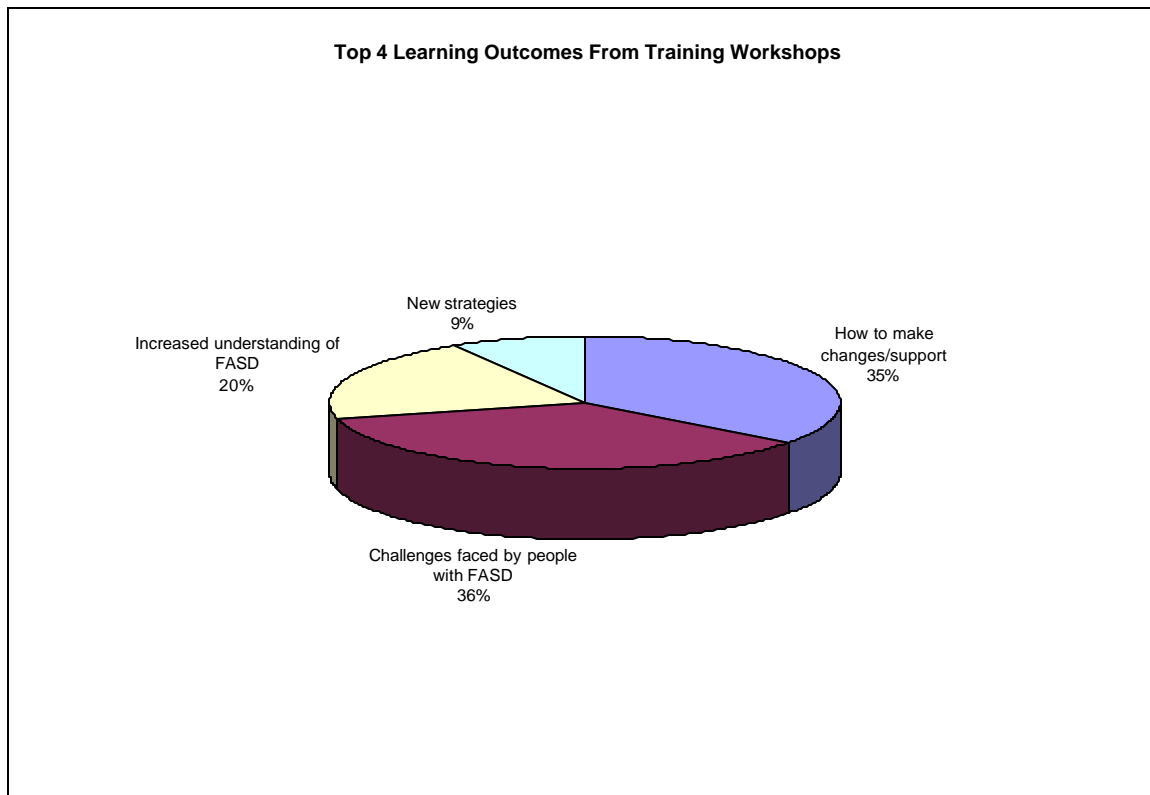


Figure 7 Top Learning Outcomes as a Result of Training Workshop.

4.4.4 Using the Workshop Information

Participants were asked to describe how they would use the information or skills gained from the FASD training workshop. **Figure 8** shows the breakdown of the responses. 41% indicated they would make changes in the home or the workplace to improve the environment and accessibility for people living with FASD. 22% said that they were more aware of issues concerning FASD and would educate others, while 19% stated they would be “more inclusive” and 18% would be “more supportive” of individuals living with FASD.

4.4.5 Workshop Ratings and Audience Make Up

When asked to rate the format of the workshops, over half of the participants (53%) indicated they felt the format was “excellent”, while 46% rated the format as “good”. A majority of respondents gave the workshop information content, skill development, and presentation style an overall rating of “excellent”. Our audiences were made up of a wide variety of individuals working in organizations with FASD clients, as well as parents or caregivers of people with FASD. **Figure 9** shows the audience make up in percentages.

The following audience comments highlight the value of the Action for Inclusion workshops for the participants, and illustrate the increased awareness of FASD inclusion strategies as part of the FASD Inclusion System model:

- *“It seems to me that altering environmental, social, and procedural issues would benefit most people, even those without FASD.”* – Comment from workshop participant (CSETS, Saanich)
- *“I’m much more enlightened – more aware of my surroundings – more empathy and understanding [for people living with FASD]”*
- *“[I am] increasingly aware of the ‘special’ issues of this population and lack of services to meet the need”*
- *“The interactive exercises were excellent, as were the “inclusion audits” – they gave me a much better idea of what my children are dealing with”*
- *“The panel discussion with young adults was exceptionally interesting and helpful. Listening to what these young adults are faced with on a daily basis and how they adjust and cope is extremely helpful. Their ideas and recommendations will be very useful in my own job...”*

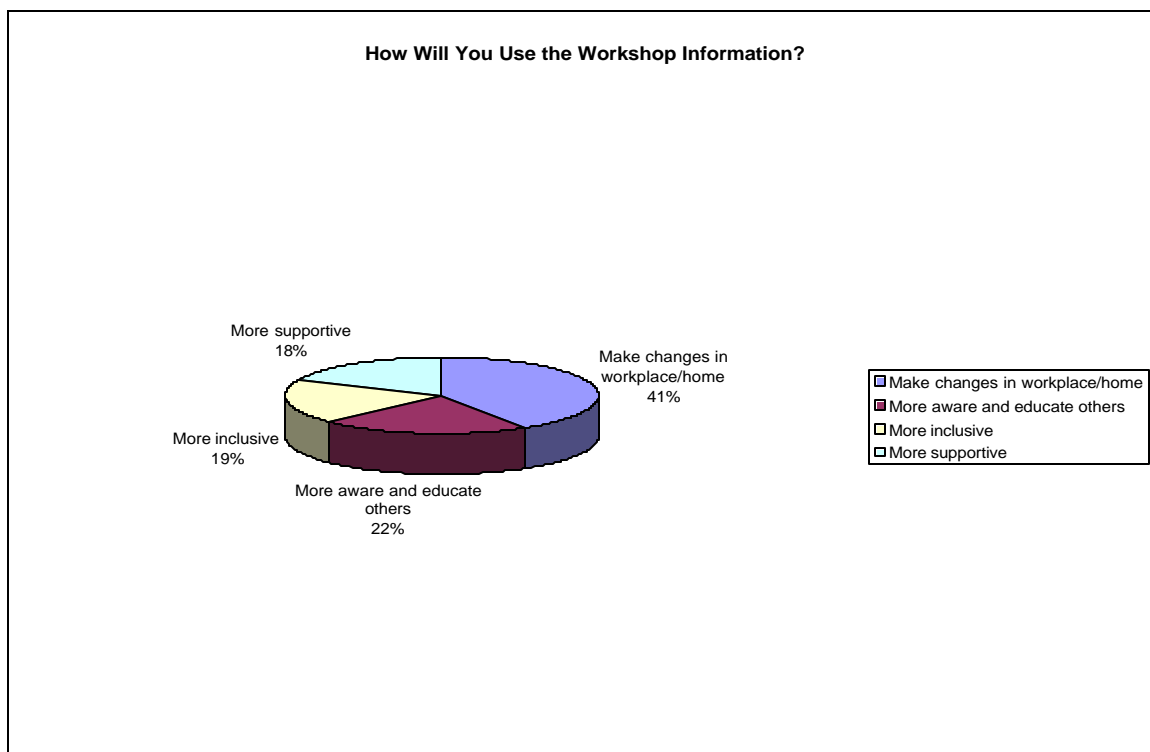


Figure 8 Using the Information/Skills Gained from the Workshop.

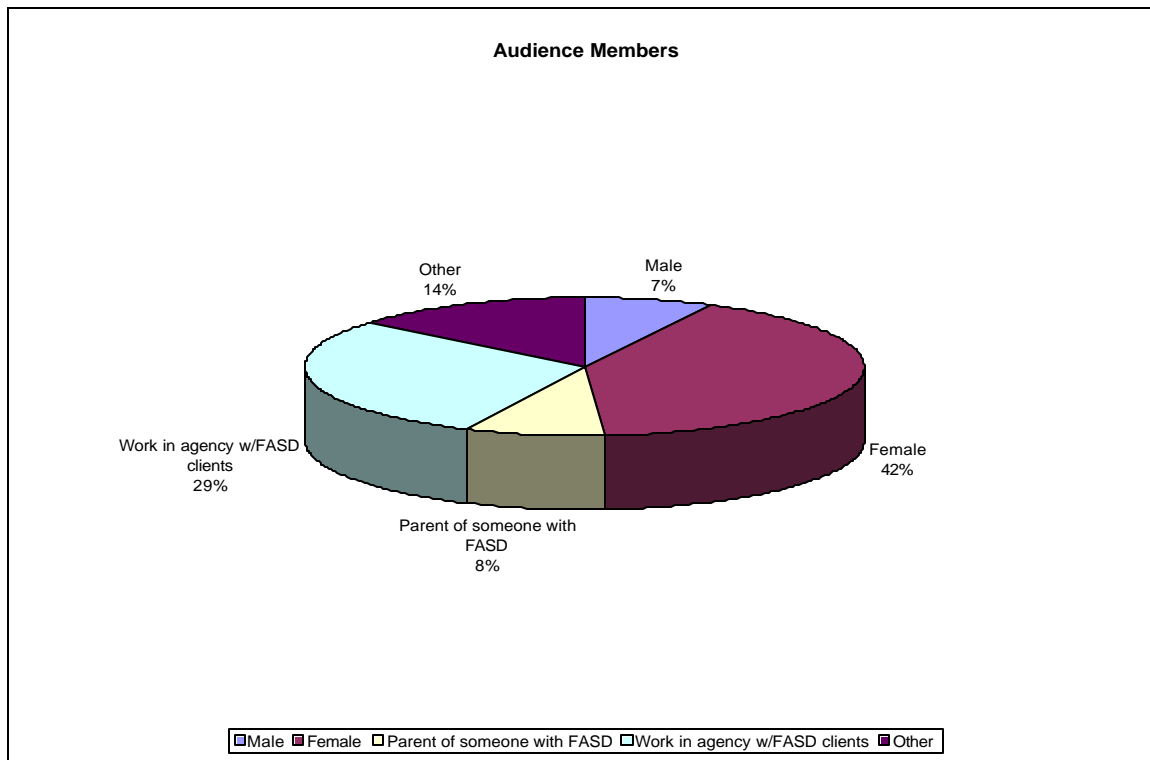


Figure 9 Audience Make Up.

5. PROJECT EVALUATION

In Year 1, we held an evaluation planning session to develop a plan based on the logic model. An independent evaluator, familiar with FASD and the recent activities undertaken by the CVFASS was contracted for the Action for Inclusion project. The external evaluator agreed to facilitate this meeting in order to better familiarize project team and board members with the expectations of the evaluation process for this project.

In early October 2003, the evaluator terminated the contract with the Action for Inclusion project due to unexpected personal circumstances that prevented her from completing the work. We later identified a highly experienced evaluator who was interested in taking on the project, and he has been working with Action for Inclusion since 2004.

Project staff in collaboration with the new project evaluator have collected and documented evaluation data over the first two years of the project. These data include numbers and types of contacts, information for a regional survey and pre-audit questionnaire, workshop participant numbers, agency names and locations, and comments from participant feedback forms. Our evaluator has attended several of our FASD training workshops to get a first hand look at what is involved in our community education work, and has spent time talking with staff and team members to gather their perspectives on the successes and challenges of this project. As well, there has been follow up with workshop participants and organizers to gather more information on their views of the Inclusion System process, and how they were able to implement the

inclusion strategies presented in the workshops. Details of the evaluation findings are available in a separate evaluation report.

6. PROJECT CHALLENGES

Overall, the second year of the project went very smoothly and the Action for Inclusion team met its Year 2 objectives, and is on schedule for meeting the objectives for Year 3 of the project. In Year 1, minor challenges included some delays in developing Inclusion System plans over the summer months because of high numbers of community organizations' staff holidays. This however, provided project team members with time to work on the website, educational brochures and surveys, and opportunities to build FASD awareness through planning for FAS Day activities. In Year 2, we focused our energy on transferring the model to four other BC communities, and completing the inclusion process with all eight organizations. Both of these processes involved extensive collaboration, via phone, email, and in-person meetings with key contacts. As a result, in our second year, we experienced some challenges with regard to the competing demands of report writing, action plan development, organizational follow up and support, and increasing community interest in having the Action for Inclusion team deliver presentations.

Other challenges are mentioned in the evaluation report and reflect the comprehensive and evolving nature of the Inclusion System process. Building relationships with community organizations and encouraging them to actively participate and collaborate in the process took more time than conducting on-site assessments and giving written reports and training. The benefits however, were that organizations gained a deeper understanding of the issues and were more receptive to new ideas. For example, after our extensive audit of the Ladysmith Resource Centre, training was provided for staff and the larger community. As part of the community workshop planning process, our team collaborated with the resource centre and a nursing practicum student. In addition to community members, nursing students from Malaspina University also received the FASD training. The next step planned with this organization is a prevention initiative for high-risk youth in the area. As a result, we created the Youth Inclusion program, which brings young people together to learn about FASD and to develop prevention message for other youth.

In another example of the reciprocal relationships we are building, during the inclusion process, Malaspina University formed an FASD advisory committee comprised of community representatives, including members of the Action for Inclusion project and the Society Board. In addition to addressing the recommendations of the inclusion process, this committee also spearheaded a proposal for the development of a new FASD credit course. The course, titled the "FASD Community Practitioner Certificate Program" was started in January 2005 and runs until June 2005.

Over the course of Year 3, the Action for Inclusion project will need to work hard to ensure that we maintain a balanced approach as we partner with two new Canadian communities in transferring the FASD Inclusion System model, and work on the development of a Canadian FASD inclusion strategy. We will also maintain follow-up and support to local organizations to

implement the recommendations made in the first two years of the project. As we move into our third year, we look forward to continuing to educate communities and organizations about the FASD Inclusion System and sharing what we have learned during the process.

7. CONCLUSION AND NEXT STEPS

In conclusion, in its first two years of work, the Action for Inclusion project has demonstrated success in meeting its goal of developing practical, site specific strategies that prevent community exclusion experienced by people living with FASD. The project has undertaken and completed a variety of activities to enlighten community service providers about the daily challenges of people with FASD and to provide them with education and skills that promote inclusion. Specifically, the Action for Inclusion project has increased capacity within the Cowichan Valley Regional District to be more inclusive of people living with FASD by involving eight community organizations in the FASD Inclusion System process. It has helped to change attitudes about people living with FASD by including them in the development and implementation of project activities and community education about FASD inclusion strategies. Lastly, the Action for Inclusion project has successfully transferred the Inclusion System model to four other BC communities, successfully meeting one of the project's key objectives for Year 2.

In looking ahead to Year 3, the ultimate goal of the Action for Inclusion project will be to build on the activities of the previous two years and work toward the development of a Canadian FASD inclusion strategy. The specific project objectives for Year 3 are to:

- 1) Transfer the FASD Inclusion System model to two Canadian communities beyond British Columbia;
- 2) Continue to provide follow up and support to implement FASD inclusion strategies with the four BC communities and the eight Cowichan Valley organizations engaged in the Inclusion System process; and
- 3) Develop an educational film about the FASD Inclusion System process as a companion to the Action for Inclusion manual.

APPENDIX A: COMPLETING THE INCLUSION SYSTEM PROCESS

Malaspina University College is located on the banks of the Cowichan River, in downtown Duncan, and comprises classrooms, computer labs, library, cafeteria, bookstore, health care lab, science lab, student services and administrative offices. The reading and writing centre is located in downtown Duncan. The Cowichan Campus offers college preparation, the first two years of university studies, career and applied certificate and diploma programs, as well as continuing education courses and customized contract training for business and industry. The campus serves students from the Cowichan communities of Youbou, Lake Cowichan, Saltair, Chemainus, Crofton, Maple Bay, Cowichan Bay, Cobble Hill, Mill Bay, Shawnigan Lake, and the Malahat. Currently, the Cowichan campus has approximately 80 faculty and staff members, 1000 full-time equivalent students, and 5000 evening and weekend students.

After attending the regional planning session, Malaspina University College expressed interest in participating in the FASD Inclusion System process. Meetings were held with the coordinator for Continued Education programs and the campus principal, in order to explore options about how to develop a workable approach for the Walk About. It was decided that members of the Action for Inclusion team would present to the Campus Development Management Committee in order to garner support from faculty and support staff. As a result of the presentation, a working committee comprised of project team members and college representatives was developed to help steer Malaspina's FASD Inclusion System process.

Some of the highlights of Malaspina's Inclusion Plan include:

- Recommendation to define parameters of the Walk About to include the library system, the front line areas, continuing education programs, the reading and writing center, and the cafeteria;
- Request that the Action for Inclusion project deliver a workshop on March 5th, 2003 as part of the Malaspina's continuing education program;
- Recommendation that findings of the Walk About serve to develop new staff orientation criteria (for example, that all staff are trained/understand a minimum number of FASD inclusion strategies);
- Request that project team members sit on the newly formed FASD program development advisory committee; and
- Request to assist with the development of a proposal to secure funding for an FASD credit program at Malaspina College, Cowichan Campus.

The FASD Inclusion System process included the following:

- Completion of pre-Walk About questionnaires by staff and volunteers;
- 3 on-site visits involving persons with FASD to examine the physical environment, the food security programs and general practices;
- Assessment of front line services--physical and social/communication systems;
- Analysis of pre-Walk About questionnaires;
- Presentation of 2 FASD training workshops in February 2004;

- Completion of a written report outlining findings and recommendations;
- Development of an Action Plan for implementation of inclusion strategies identified;
- Follow up questionnaire on implementation of inclusion strategies.

The RCMP—Duncan/North Cowichan detachment provides police and highway patrol services to the Cowichan Valley through approximately 88 personnel in five detachments: Duncan, North Cowichan, Shawnigan Lake, Cowichan Lake and Ladysmith. In the Duncan/North Cowichan detachment there are currently 51 members, 4 public service staff, 5 NC municipal staff and 4 guards that service an area population of approximately 31,830. The Duncan/North Cowichan RCMP detachment services electoral areas C, D, E, the City of Duncan, the District of North Cowichan and the eastern portion of electoral area I. The RCMP Aboriginal Policing Unit also services First Nations reserves contained within these geographical areas (see Appendix C).

Our team met with the Duncan/North Cowichan detachment community policing liaison coordinator, police inspector and three officers to determine the best way to proceed with the FASD Inclusion System process. It was determined that we would work with one watch for the Walk About, with the goal of transferring what is learned to the rest of the detachment through follow-up training.

It was also determined that our team would have a main contact person who would provide guidance and information about the RCMP during the FASD Inclusion System process. To facilitate better understanding between the main contact person and our team, it was decided that the RCMP contact person would attend a two-day FASD training workshop held in Victoria in October 2003.

The FASD Inclusion System process included the following:

- Completion of pre-Walk About questionnaires by staff;
- 2 “ride alongs” involving persons with FASD to examine police practices;
- Assessment of front line services--physical and social/communication systems;
- Assessment of cell blocks to examine physical and communication systems;
- Analysis of pre-Walk About questionnaires;
- Presentation of 2 FASD training workshops in December 2003;
- Completion of a written report outlining findings and recommendations;
- Development of an Action Plan for implementation of inclusion strategies identified; and
- Follow up questionnaire on implementation of inclusion strategies.

Growing Together Child and Parent Society began in 1993 in response to a local community need. In the Cowichan Valley in 1991 and in 1992, there had been 41 and 42 births respectively to teen-aged mothers between the ages of 12 and 19 years; these comprised 7 – 8% of the total births. Continuing their education was most difficult for these young parents, as few spaces offering high quality infant care for babies under three years of age were available in the vicinity of schools which the parents might attend.

The vision of GTCPS is to provide high quality childcare for children up to 3 years, enabling their young parents to complete their education at the Cowichan Valley Open Learning Co-op., an alternate high school located in an adjacent building. In this way, parents may easily come and go to see their children. Approximately 20 student/parents have children less than 3 years of age enrolled in the childcare program. A voluntary Board of Directors, backed by a community Advisory Committee, runs the operation, employing a Coordinator and six Child Caregivers specifically trained in early childhood education for children under 3 years.

Our team met with child centre coordinator and the principal and educational staff of the alternate school. It was felt that it could be very beneficial for the alternate school to jointly participate in the FASD Inclusion System, both because of its connection to parents at the child centre and because of the noted learning and behavioral differences among many of the students attending the alternate program.

Our team had a follow-up meeting with the staff and volunteers at the Growing Together child centre, at which time the centre agreed to participate in the Inclusion System process and staff filled completed pre-audit questionnaires. A plan was developed around the Walk About process in conjunction with staff and the coordinator and included consideration of the following:

- Ways to do an on-site assessment (Walk About) with minimal disruption to children's routines (sleep times, etc.);
- Developing a component of the Walk About process that included the parents' interactions/experience with the centre; and
- Involving parents and alternate school students in FASD education and training.

The FASD Inclusion System process included the following:

- Completion of pre-Walk About questionnaires by staff;
- 2 on-site visits involving persons with FASD to examine environment and practices;
- Assessment of front line services--physical and social/communication systems;
- Analysis of pre-Walk About questionnaires;
- An FASD training workshop and Walk About findings in December 2003;
- Completion of a written report outlining findings and recommendations;
- Development of an Action Plan for implementation of inclusion strategies identified; and
- Follow up questionnaire on implementation of inclusion strategies.

The Ladysmith Resources Centre Association is a multi-functional, non-profit agency that provides access to needed services, support, networking, and training to the Ladysmith and surrounding area, located in the northern section of the Cowichan Valley Regional District between the cities of Duncan and Nanaimo.

The Association operates the Ladysmith Food Bank, Emergency Food/Clothing/Bedding, several parenting programs, Youth Literacy, and the Volunteer Centre. In addition to those programs listed above, there is a Youth-at-Risk worker, a Youth Drug and Alcohol worker, Community Advocate, and an in-house psychologist. The Centre provides referrals to other agencies

covering a wide range of topics and needs and offers computer and Internet access to the public. A full time Executive Director, four staff and additional employees responsible for specific programs, as well as a large base of volunteers, manage the day-to-day operations.

After a comprehensive tour of the facilities and introduction to the many programs, our team met with the Executive Director, key staff, volunteers, and a nursing practicum student to discuss the FASD Inclusion System process. Some initial ideas for the Inclusion System process discussed at this meeting are as follows:

- It was felt that many of the programs operating out of the centre may come into contact with people with invisible disabilities and would benefit from new knowledge and specific skills;
- The physical environment of the centre could greatly benefit from an on site assessment;
- In-service training could be offered to the staff and volunteers of many of the programs that utilize the centre;
- An additional educational session could be offered to the clients using the programs; and
- It was suggested that the nursing practicum student incorporate FASD prevention and education material in her pregnancy outreach study.

The FASD Inclusion System process included the following:

- Completion of pre-Walk About questionnaires by staff and volunteers;
- 4 on-site visits involving persons with FASD to examine the physical environment, the food security programs and general practices;
- Assessment of front line services--physical and social/communication systems;
- Analysis of pre-Walk About questionnaires;
- Presentation of 2 community FASD training workshops by team members in March 2004;
- Completion of a written report outlining findings and recommendations;
- Development of an Action Plan for implementation of inclusion strategies identified;
- Follow up questionnaire on implementation of inclusion strategies.

The Cowichan Family Life Association is a non-profit agency that provides family, marriage, couple and individual counseling, as well as support groups, special services to children referred by the Ministry of Children and Families, and family violence intervention programs.

This organization has been an especially helpful member of our working committee by providing excellent feedback about project materials such as brochures and the survey. The executive director has advised staff of the audit process and they agreed to participate in the process. At this time, follow-up meetings are needed to determine the best ways to approach the development of an audit plan.

The FASD Inclusion System process included the following:

- Discussion with key staff about the audit process

- Distribution of audit information
- Pre-audit questionnaires
- 2 on-site visits at CFL staff and administration
- Assessment of front line services--physical and social/communication systems;
- Analysis of pre-Walk About questionnaires;
- Presentation of an FASD training workshop and Walk About findings in October 2004;
- Development of an Action Plan for implementation of inclusion strategies identified; and
- Follow up questionnaire on implementation of inclusion strategies.

The Cowichan Valley Association for Community Living is a multi-service agency incorporated in 1957 for children and adults with developmental disabilities. It provides a range of programs and services including employment, recreation and leisure, semi-independent living, infant and child development, and child care resource and referral.

We met with the administration and staff of this organization to explore a workable FASD Inclusion System plan. It was decided that we would focus on the agency's employment programs—specifically, the Lunch On Clements Program. Lunch on Clements is a pre-vocational training program that offers a friendly lunch cafeteria, open to the public Monday through Friday, from 11:30 a.m. to 2:30 p.m. The Association for Community Living agency felt that there are likely people with FASD participating in the training program as well as coming to the cafeteria for lunch.

The FASD Inclusion System process included the following:

- Completion of pre-Walk About questionnaires by staff and volunteers;
- 2 on-site visits involving persons with FASD to examine the physical environment, the employment/lunch program and general practices;
- Assessment of front line services--physical and social/communication systems
- Analysis of pre-Walk About questionnaires;
- Presentation of 2 FASD training workshops by team members in April 2004 and November 2004;
- Completion of a written report outlining findings and recommendations;
- Development of an Action Plan for implementation of inclusion strategies identified; and
- Follow up questionnaire on implementation of inclusion strategies.

Somenos Transition House is part of Cowichan Women Against Violence Society, a non-profit organization that serves women and their children in the Cowichan Valley. Somenos House means “safe resting place” in the Coast Salish language. Somenos House provides free and confidential emergency shelter and emotional support, primarily for battered women and their children. It is a comfortable and supportive place where women and their children can stay when they need safety from violence and abuse. Staff members at Somenos House provide emotional support, information about other resources, and help for women to explore options that promote their well being. Women from all walks of life who are at risk of violence or abuse from their

male or female partner, other family member/s or other person/s are welcome at the transition house.

With such a broad range of women and children coming into the transition house each year, education and training around FASD inclusion strategies have been welcomed by staff and administration. Our project provided information about the FASD Inclusion System process and then worked with key transition house staff to develop a Walk About plan that included an assessment of:

- The physical building and grounds
- The intake process for women and their children coming into the transition house; and
- A special look at programs and services for boys at the transition house, carried out by our male team members.

The request to assess the transition house from a male perspective was critical. As staff reported, boys (especially the older ones) tended to isolate more than girls when at the transition house. Staff requested that our team members assess the teen room and other aspects of the house to help understand how they might make the space more accessible to boys, especially those living with invisible disabilities.

The FASD Inclusion System process included the following:

- Development of Walk About plan with key staff;
- Completion of pre-Walk About questionnaires by staff;
- 2 on-site visits involving persons with FASD to examine the physical environment and the intake process in May 2004;
- Consultation of team members living with FASD to assist with renovations to Somenos House so that new carpets, flooring, appliances would be FASD friendly;
- Analysis of pre-Walk About questionnaires;
- Presentation of 2 FASD training workshops by team members in April 2004 and November 2004;
- Completion of a written report outlining findings and recommendations;
- Development of an Action Plan for implementation of inclusion strategies identified; and
- Follow up questionnaire on implementation of inclusion strategies.

The Whitecrow Village Society is located in Burns Lake, BC. Kee Warner, the Society's Executive Director, has been working with children and youth living with FASD since 1996. Ms. Warner has hosted family inclusion camps throughout British Columbia, tailored to the specific needs of children and youth living with FASD. The family inclusion camps are an opportunity for parents and children to engage in traditional camp activities, while building skills and experiencing success in a supportive, fun camp setting. The Whitecrow Village Society partnered with Cowichan Valley FAS Society to host a weeklong summer camp at the end of June 2004, at a location in the Cowichan Valley. This camp involved over 60 people, including children and youth living with FASD, their families, camp staff and volunteers.

With such a broad range of children, youth and adults attending the camp, education and training around FASD inclusion strategies were welcomed by camp staff and volunteers. Our project provided information about the FASD Inclusion System process and then worked with key Whitecrow staff to develop a Walk About plan that included an assessment of:

- The physical buildings and grounds where the camp was to be located from a safety perspective;
- Camp facilities, including cabins, washrooms, kitchen, dining hall, and river access; and
- An assessment of camp programs, such as crafts and games.

The Action for Inclusion team conducted two inclusion Walk Abouts: one before camp started, and one while camp was in session. Recommendations from the Walk Abouts included improving signage, establishing clear boundaries for the camp area, identifying safe river access for swimming, setting up a shade tent, and some suggestions for managing noise and improving the flow of activities.

The FASD Inclusion System process has included the following:

- Discussion with key Whitecrow Village Society staff about the Inclusion System process;
- Distribution of Inclusion System and Walk About information;
- Completion of pre-Walk About questionnaires;
- 2 on-site visits (pre-camp and during camp);
- Analysis of pre-Walk About questionnaires;
- Completion of a written report outlining findings and recommendations;
- Development of an Action Plan for implementation of inclusion strategies identified; and
- Follow up questionnaire on implementation of inclusion strategies.

APPENDIX B: PARTICIPANT FEEDBACK FORMS

Workshop Participant Feedback Survey

Your thoughts about this presentation are important to us. Please take a few minutes to give us feedback in the space provided below.

<p>What was your knowledge of FASD accessibility issues <u>before</u> attending today's session? <i>Please use the space below to provide additional relevant detail.</i></p>	<p><input type="radio"/> No previous knowledge</p> <p><input type="radio"/> Very little knowledge</p> <p><input type="radio"/> Somewhat knowledgeable</p> <p><input type="radio"/> Fairly knowledgeable</p> <p><input type="radio"/> Very knowledgeable</p>																									
<p>What is your knowledge of FASD accessibility issues <u>after</u> attending today's session? <i>Comments?</i></p>	<p><input type="radio"/> About the same</p> <p><input type="radio"/> Somewhat more knowledgeable</p> <p><input type="radio"/> More knowledgeable</p> <p><input type="radio"/> Much more knowledgeable</p>																									
<p>Can you please describe three main things that you learned at this workshop?</p>																										
<p>Was the workshop different in format or content than you had anticipated it would be? How?</p>																										
<p>How will you be able to use the information or skills you learned today?</p>																										
<p>Please rate the following features of the workshop:</p> <table border="1"> <thead> <tr> <th>Information content:</th> <th>Presentations:</th> <th>Walk about:</th> <th>Planning Scenario:</th> <th>Venue / location:</th> </tr> </thead> <tbody> <tr> <td><input type="radio"/> Excellent</td> <td><input type="radio"/> Excellent</td> <td><input type="radio"/> Excellent</td> <td><input type="radio"/> Excellent</td> <td><input type="radio"/> Excellent</td> </tr> <tr> <td><input type="radio"/> Good</td> <td><input type="radio"/> Good</td> <td><input type="radio"/> Good</td> <td><input type="radio"/> Good</td> <td><input type="radio"/> Good</td> </tr> <tr> <td><input type="radio"/> Fair</td> <td><input type="radio"/> Fair</td> <td><input type="radio"/> Fair</td> <td><input type="radio"/> Fair</td> <td><input type="radio"/> Fair</td> </tr> <tr> <td><input type="radio"/> Poor</td> <td><input type="radio"/> Poor</td> <td><input type="radio"/> Poor</td> <td><input type="radio"/> Poor</td> <td><input type="radio"/> Poor</td> </tr> </tbody> </table>		Information content:	Presentations:	Walk about:	Planning Scenario:	Venue / location:	<input type="radio"/> Excellent	<input type="radio"/> Excellent	<input type="radio"/> Excellent	<input type="radio"/> Excellent	<input type="radio"/> Excellent	<input type="radio"/> Good	<input type="radio"/> Good	<input type="radio"/> Good	<input type="radio"/> Good	<input type="radio"/> Good	<input type="radio"/> Fair	<input type="radio"/> Fair	<input type="radio"/> Fair	<input type="radio"/> Fair	<input type="radio"/> Fair	<input type="radio"/> Poor	<input type="radio"/> Poor	<input type="radio"/> Poor	<input type="radio"/> Poor	<input type="radio"/> Poor
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<p>What worked particularly well?</p>	<p>What could have been done differently?</p>																									
<p><i>About you:</i></p> <p><input type="radio"/> Parent of someone with FASD</p> <p><input type="radio"/> Work in an organization with FAS clients</p> <p><input type="radio"/> Other _____</p> <p><input type="radio"/> Male <input type="radio"/> Female</p>	<p>Is this your first experience with the FAS audit process?</p> <p><input type="radio"/> Yes <input type="radio"/> No</p>																									
<p>Do you have any other comments or suggestions?</p>																										

APPENDIX C: FOLLOW UP QUESTIONNAIRE



Inclusion Audit Follow Up Questionnaire

Thank you for participating in the Action for Inclusion FASD Audit process. To help with our program development, we have some follow up questions listed below.

1. How useful was the inclusion audit process for your organization?

- Very useful
- Somewhat useful
- Not useful
- Don't know

3. Has your organization made any changes as a result of the audit? YES / NO

3.a) Please list changes made in SERVICE DELIVERY methods:

3.b) Please list changes made to COMMUNICATION (client approach):

3.c) Please list changes made to the PHYSICAL ENVIRONMENT:

4. What additional supports does your organization need to move forward in implementing the audit recommendations?

5. Do you have any suggestions for improving the inclusion audit experience?

APPENDIX D: EVALUATION REPORT

FASD Action For Inclusion Project

Interim Evaluation Report

May 2005

Submitted to:

Jennifer Kyffin
Cowichan Valley FAS Action Society

Prepared by:

Jerry Hinbest
Hinbest & Associates Consulting

Action For Inclusion Project: Interim Evaluation Report

The Action For Inclusion: FAS Audits Project is a three-year educational and training pilot project designed to increase the capacity of organizations in B.C. communities to effectively accommodate people living with Fetal Alcohol Syndrome. It has grown out of and builds upon community needs identified in the Finding Alternative Solutions Project. The project team works with community organizations in the Cowichan Valley Regional District and other parts of Vancouver Island and British Columbia to build capacity about Fetal Alcohol Syndrome / Effects (FAS/E), (also referred to as Fetal Alcohol Spectrum Disorder - FASD) and how to accommodate people living with it.

The project's stated initial objectives are:

1. Build FASD inclusion strategies within Cowichan Valley Regional District community organizations by involving them in the FASD Audit process, which will include:
 - assessments of physical and social environments;
 - in-service training workshops that respond to needs identified and;
 - follow-up and support for strategy implementation and best practice exchange
2. Help promote more positive attitudes about people with FASD by involving them in project activities that educate the community about FASD inclusion strategies
3. Provide employment to people living with FASD
4. Educate other communities about the model through the development of the Action for Inclusion network, holding a provincial workshop, presenting at a national conference, developing a project web site, and creating educational resources and tools.
5. Work with four other Canadian communities to transfer the model.

The project was designed with a two-phase intended implementation process, corresponding to the two years of the implementation. Phase one involved developing the audit process, and identifying, connecting with and undertaking the comprehensive on-site audits with the community organizations. Phase two involves sharing the process with other communities. In practice, some planning for phase two activities was done in phase one, as well as a variety of presentations to community organizations and the national conference. Similarly, the longer-term follow up with community organizations involved in the action for inclusion process has extended into phase two.

A full evaluation report will be prepared for the conclusion of the project. This report represents a status report on the first two years of the project, and a discussion of emerging issues identified through interviews and data collected to March 2005.

SUMMARY OF PROJECT ACTIVITY STATUS:

Key activities undertaken to date:

- The comprehensive on-site audit process was developed with input and active participation of people living with FASD.
- Eight organizations have engaged in the audit and 'walkabout' process; all had attended the meeting and completed the community survey.
- Physical audits have been conducted with eight local organizations. These audits involved multiple visits to organizations, by teams that included a minimum of one (and usually two or three) people living with FASD, plus support people.
- Audit reports have been developed for each organization, and are the basis for planning sessions on follow up and implementation.
- Workshops and audits have been completed with additional organizations beyond the initial eight – sometimes with a less formal approach reflecting different organizational needs and priorities.
- Information sessions were held with each of the audited organizations. These provided in service training related to the findings of the audit, and information about the process.
- Follow up has begun with all of the organizations, completed with some, and is ongoing with most. This involves coordinating with working committees, presenting detailed findings and information, planning implementation of audit findings, and identifying support requirements.
- Additional workshops and staff training sessions have been designed and delivered based on the needs of organizations undergoing audits.
- Work with four other communities has taken place, with a variety of workshops designed and delivered in these communities. The communities are engaged efforts to make the approach locally sustainable.

To date, eight local partners include:

1. RCMP, Duncan
2. Ladysmith Resource Centre
3. Cowichan Valley Association for Community Living, Duncan
4. Malaspina University College - Cowichan Campus
5. Somenos Transition House, Duncan BC
6. Growing Together Child and Parent Society, Duncan
7. White Crow Village Society, Burns Lake
8. Cowichan Family Life - Alexander Resource Centre, Duncan

Other local organizations for which workshops and audits / walkabouts have been conducted include:

1. Cowichan Valley Childcare Resource Centre, Duncan

2. Mental Health Unit, Parksville
3. Global Vocations Services Inc., Duncan (in process)

The four British Columbia communities with which the model is being shared through workshops, audits / walkabouts and follow up are:

1. Campbell River - via Sunrise Resource Centre (SRC) (2 workshops)
2. Victoria - via Vancouver Island Health Authority (VIHA) (2 workshops)
3. Prince George - via Northern Family Health Society (NFHS)
4. 19 Vancouver Island First Nations Communities - via Coast Salish Employment and Training Society (CSETS) (2 workshops)

A variety of local community education presentations have been done for:

1. Chemainus First Nation Alcohol and Drug Awareness Week
2. Kuper Island Community Forum
3. MCFD Health and Prevention Forum
4. Cowichan Intercultural and Immigration Society, Duncan, BC
5. Cowichan Alternate School, Duncan, BC (2 presentations)
6. Social Worker Training Workshop – Hosted by PEERS, Victoria, BC
7. Aboriginal Head Start Conference – Coordinated by CSETS, Duncan, BC

In addition, team members made presentations at the Canada Northwest FASD Conference in Winnipeg (November 2003) and the FASD National Conference in Victoria (February 2005).

Over the first two years of the Action for Inclusion project, team members made formal presentations of workshops and audits / walkabouts on approximately forty occasions, with twice as many workshops and presentations made in year two than in year one. The typical number of participants in these workshops was fifteen to twenty individuals, with a few sessions having half that number, and a handful significantly more. The latter were primarily workshops in which the model was being shared with other communities. For example, the largest workshop group was in Prince George, with sixty-four individuals representing over twenty organizations and other interest groups attending. In total, close to 500 individuals have participated in workshops, information sessions, and audits / walkabouts in the second year of the project, and over 700 in total over the first two years.

Action for Inclusion has employed people living with FASD as integral team members. Typically two or three, and up to six individuals with FASD have been involved in conducting and presenting each of the workshops and audit demonstrations. A total of approximately ten individuals living with FASD have taken part in this process over the past two years.

Actual audits / walkabouts conducted for community organizations always are intended to involve at least two individuals living with FASD, and a support person. This appears to be actual practice in most cases. For audits / walkabouts with large workshops, several individuals take part, each leading and

working with teams of between five and ten individuals, which usually (but not always) includes one support person.

EVALUATION STATUS:

The project began with a community survey, and the many presentations to community and organization groups have been followed up with feedback surveys as well. Staff participating within organizations have completed information surveys, and have been asked to do follow up surveys as well, some of which have been completed.

Interviews with project team members have begun. Individual interviews have been conducted with representatives of seven of the local community organizations participating in the audit / walkabout process, and with individuals from three of the four communities to which the approach is being transferred. Over the coming months additional individual and group interviews and will focus on understanding the process of participating in the audits, how to improve the process, what remains problematic, and what has worked.

Initial findings have been based on survey results and individual in-person and telephone interviews. Additional information used for the report includes participation and observation at several workshops in which the audit / walkabout process was explained, demonstrated and undertaken, and casual discussions of the process and reflections on it by participants at the workshops.

INITIAL EVALUATION FINDINGS:

The Audit / Walkabout Process with Local Organizations

The audit process for the Action for Inclusion project was initially conceived as involving a process of 1) organization surveys, 2) physical audit(s), 3) data analysis, 4) report preparation, 5) presentation of findings back to the organization, and 6) follow up support. In practice, this has been a much more iterative and interactive process than anticipated, lasting a longer duration than initially planned. This has had benefits for organizations and the action team, but also some impacts that challenge the effectiveness of the process.

Working committees established in each organization actively participated in decisions about how to conduct audits, identifying which programs or physical areas to emphasize, how to inform staff that the process was going on, scheduling the audits / walkabouts and follow-up presentations, and other logistical and practical concerns. The audits were conducted over a period of time, and this usually involved multiple visits, reflecting the need to coordinate schedules of people on the project team as well as individuals within each organization. Initial results were compiled in an audit report, and shared with the organization. One of the challenges resulting from the iterative process has been that the audit reports have not typically been shared with the agencies immediately following the walkabout sessions. In part it reflects the challenge of compiling information that may be obtained at several points in time, and by a

variety of individuals. In part this reflects the desire for this process to be interactive, and to invite comments and review of draft reports. For example, for several interviews with lead agency contacts, the individuals pointed to a draft report sitting in their in-basket, awaiting time to review it and send it back for comments.

The final audit / walkabout reports to agencies have grown over the course of the two years. Recent reports have reached a substantial fifteen to twenty pages in length, with one comprehensive report reaching fifty pages. While the first several pages of the audit have tended to include basic information about FASD, the walkabout process, and the project's goals and objectives – often repeated from report to report as a form of template – the main report includes detail in the form of tables and specific findings for individual agencies and organizations.

Suggestion: *For rapid feedback from agencies, try to immediately (within two days?) share with them a brief one or two page summary of findings, rather than taking time to craft a longer draft report. This could be done after each site visit, with a request to give feedback (perhaps in the form of quick tick boxes and comment options), within a week. The benefits would be faster turnaround for the comments, more accurate comments relating to the current situation, and opportunities for organizations to obtain some closure on efforts rather than having them spread out for an extended period of time.*

In most cases, organizations requested more than one 'presentation' of audit findings and information. Follow up involved planning presentations, developing action plans, working with committees to plan changes in the organization, and an ongoing monitoring of implementation of changes. The audit follow up involved evolving relationships with the organizations, and the pace and extent of follow up has been diverse. For most organizations, this iterative process has not been considered problematic, and indeed, the perception is that CV-FAS has been accommodating the organization's needs and timetable. However, extending the process in such a manner has also contributed to some confusion about the status of the process, and questions about 'who's turn it is' to take the next steps.

Leadership within Local Organizations

The lead participants in most organizations had either personal or professional interest in FASD prior to participation, and championed the issue of FASD and the audit process within their organization. The level of awareness about FASD among staff of organizations prior to participating in the audit process was quite mixed. Some had a few staff with special or personal knowledge; most had few staff who were very knowledgeable, but most staff had at least a basic level of knowledge about FASD.

It appears likely that having a key contact who has had prior experience and knowledge of FASD, and who can champion the issue within the agency will be more highly associated with successful organizational change, and long term implementation of action plans and organizational commitment to supporting

people living with FASD. The current process of having agencies and contacts within them go through a self-selection process would appear to be an effective approach.

Reflections on the Audit / Walkabout Process

Reflections on the audit process have been overwhelmingly positive. Respondents repeatedly noted the non-intrusive and respectful process used – those doing the audits (now usually called ‘walkabouts’) were noted to have asked permission, ensured confidentiality, and accommodated the needs and priorities of staff in the organizations. The iterative approach employed – making repeated visits to complete the audit – was considered effective and respectful. It allowed more staff within small organizations to see and be part of the process, particularly when staff worked on a rotating basis. It ensured that the process reflected the diverse nature of the environments in small organizations.

For the most part the organizations have described tackling the task of becoming more FASD friendly by addressing signage, reducing clutter, clarifying processes and tidying public spaces, although most stated that they were not yet as far along as they would have liked. All organizations have made at least some changes, expect to make more, and expressed satisfaction with the immediate results.

Reflections on the Workshops

Comments expressed in the post-workshop surveys have been quite positive. Respondents have indicated that they have become more knowledgeable about FASD after the presentations than they were before attending. The most commonly identified learning at the workshops has been 1) understanding the different challenges faced by someone living with FASD, 2) how to make changes or support those with FASD, and 3) understanding the nature of FASD. Over 80% of respondents (n= 256) indicated that the information in the workshop would help them address challenges faced by someone with FASD in their work or home situation.

A central aspect of the Action For Inclusion presentations and community education focuses on FASD as not just a primary, but also a secondary form of disability. This is a powerful element of the total message, as it addresses some of the perceived inevitability of impacts and outcomes for those living with FASD. This discussion can be challenging, in that it often walks a fine line between contrasting the permanent nature of the physical disability and the brain damage that has occurred with FASD, with the possibly even more devastating impacts of how the primary disability has contributed to problematic interactions in families, schools and workplaces. Thus one emphasis is on the futility of expecting significant change on the part of those with FASD as they navigate their daily life challenges, and yet the discussion about secondary disabilities speaks to the ways in which the life experiences of those with FASD are shaped by the reactions, supports and expectations of those among whom they live and interact. This contrast of inevitability alongside potential empowerment and change is strikingly portrayed in the stories and descriptions of life experiences of

the people living with FASD who are making the presentations. It also reflects some of the ambiguity and tension in the message, in that the individuals are talking about past and current experiences of disability, conflict, discrimination, and daily challenges in living. Yet the same individuals, who face such trials in many aspects of their lives, when given the opportunity, are capable of speaking effectively, forcefully, and powerfully in front of a room of strangers, expressing clear knowledge and an important message. This is a very powerful statement, and it is received as such. While the physical impacts of FASD are both permanent and significant, the secondary impacts of the disabilities are exposed to be in many ways more damaging, but also somewhat recoverable and potentially avoidable.

Suggestion: *The current PowerPoint presentation used in the FASD 101 section of the workshops emphasizes secondary disabilities, but not until over half way through the material. This is a key message for CV-FAS, and one that demands priority placement in the presentation. It should be given more prominence, earlier in the workshop, and include a more comprehensive discussion of the implications.*

Another aspect of this inherent contradiction in the message of Action For Inclusion concerns the stigma associated with FASD. It is difficult to market a message to parents and people working in agencies that self-advocacy concerning one's rights and needs related to FASD is worthwhile, when the same individuals are describing stories in which they acknowledge that admitting they have FASD in job interviews or when first meeting people invites stereotyping behaviour and potential discrimination. This can be a hard sell to parents and guardians in particular, who know that with the label comes a stigma, but not necessarily a great deal of understanding about FASD or substantive supports. In this sense the audiences are somewhat torn – they want to help, and want to be part of an approach that acknowledges need for support and advocacy, but on a realistic basis when dealing with individuals, they must balance the individual's need with the benefits of openness about the disability. Self-identifying as someone with FASD at an institution such as Malaspina University-College may bring few practical benefits, but potentially some stigma and stereotyping; self identifying as having a 'learning disability' will open the doors on a host of support options with less stigma. The same is true for many institutions and government organizations.

Transferring the Model to Other Communities

Workshops and presentations have been conducted as part of sharing the model with four other communities – Campbell River, Victoria, Prince George, and with First Nations communities on Vancouver Island through the Coast Salish Employment and Training Society (CSETS). All of these communities took part in workshops and sample audit / walkabout training in the second year of the project.

Status: Campbell River. The Sunrise Resource Centre (SRC) has been the lead agency in bringing the Action For Inclusion model to Campbell River. Two

workshops were held in the community, in May and November of 2004. There has been little follow up to the two workshops by the local FASD committee to date. The committee will be meeting again on May 25th, at which point they hope that an action plan can be developed. Several of the agencies that took part in the workshop have established internal processes to review and adapt their workplaces based on the walkabout model. Nothing formal has been set up by the committee to share the approach further within the community, mainly because at this point there is no one with the time and resources able to take the lead on the issue, or play a coordinating role. It is being done “off the sides of peoples’ desks” or not at all. All those involved already have their regular jobs, and this activity is added to their load on a voluntary basis.

The other barrier noted to date is that there are not many individuals coming forward who might serve as the adults living with FASD, who could conduct audits / walkabouts, or participate actively on the committee. The committee has found it to be a challenge to find these individuals, and invite their participation. This has nothing to do with the number of people who are living with FASD in the community. While the audit process has been viewed very positively within the community and by the committee and workshop participants, collectively they have not yet determined a way to find the resources needed to make it happen in an effective way.

To date, the community has had some telephone follow-up with members of the CV-FAS team, but they have received no follow-up report on the audit / walkabout, although it has been six months since the second presentation.

Status: Victoria. The Vancouver Island Health Authority (VIHA) has been the lead agency in bringing the Action For Inclusion model to the capital region. The lead contact in the Health Authority has been able to adapt his work responsibilities to encompass the project. Although there is a local FASD Community Circle (FCC) committee, it has not been directly involved in establishing the audit / walkabout process since the workshops were held in October and December of 2004. The FCC has no staff, resources or capacity to take on such a task, although there is interest among committee members.

The Victoria group has begun doing audits / walkabouts, and to date has conducted three with local organizations, including Camosun College. Some of the people living with FASD who have been participating in these workshops also have participated with the CV-FAS workshops in other communities, and learned about the model in that way. The VIHA does not have a specific budget to pay participants, but the group has obtained a small grant to purchase gift certificates for Wal-Mart, Thrifty Foods, and other locations, which are shared with individuals who do the workshops. This funding will not last long, and they are searching for additional resources to help support the process.

A key challenge faced in keeping the project moving ahead is the lack of basic supports for people living with FASD. These were described as consisting of three elements – appropriate housing (not independent living), social supports, and meaningful roles in the community. The projects can help build the third

element, but the others are not easily facilitated by the current support system for people with FASD. Thus in order to ensure that individuals who are living with FASD are available to take part in the workshops and audits / walkabouts, other team members must expend a high level of effort in contributing social supports to individuals who in many cases still maintain unhealthy lifestyles and severe challenges to living. While the process of expanding the model to the Victoria region was described as “still happening, moving ahead, and going ok”, it is clear that to date it is somewhat precarious, and will depend in the future on obtaining some additional funding and a longer term mandate. Without the support and involvement of a broader coalition of individuals, the effort is subject to the impacts of decisions within one organization, and at the moment, one individual.

The Victoria group has received copies of sample audit reports based on the workshops at two locations in the region last year. The reports included recommendations about the locations. The group has been supported by phone and e-mail throughout the process, received training and support for their FASD consultants, assistance in developing their own reports for their audits / walkabouts, staff in-service training, and support in developing processes and activities as they build their own approach.

Status: Prince George. The Northern Family Health Society (NFHS) has been the lead agency in bringing the Action For Inclusion model to Prince George. The organization brought together 64 individuals representing over 20 agencies for one intensive session in November of 2004.

Prince George has been active in introducing an audit / walkabout process to the community since the workshop. Three months of initial funding was obtained through an HRDC employment program, which was used to hire several young people living with FASD. The funding has been extended for an additional three months. To date, over a dozen audits / walkabouts have been conducted, and reaction has been very favourable. The audit reports and process used in Prince George have been adapted, and tend to be shorter and less comprehensive than those in Duncan, but appear to be well received.

The focus of the NFHS has been on following up on the audits and implementing the process, rather than working to establish the broad base of the initiative across the community, although some community education is being done. The audits themselves are being used to spread the word among local agencies, and the expressed hope is that this will lead to enough people gaining an understanding of the nature of FASD so that a broader coalition can take a more long-term approach to addressing it in the community.

The lead community contacts received the follow-up and audit / walkabout reports in April of 2005. They expressed concern during the interviews (in March) about not receiving them yet, and wondering where they were. They felt that the reports could help them to apply the model and framework more quickly and effectively in the community.

Reviewing the ways in which other communities have tried to implement the Action For Inclusion model has clearly identified an important barriers to setting up workable audit processes – the level of prior organization required. In Duncan, the audit process has grown out of several years' worth of advocacy, grassroots organization and development, and a variety of programs that have served to develop an 'infrastructure' of individuals living with FASD who are knowledgeable about themselves and the processes, and able meaningfully to take part, as well as a level of knowledge in the community about what to expect. The Cowichan program has also been complemented by concurrent programming that gives supports to people living with FASD.

A common comment from those attending the workshops has been surprise and admiration for the professional approach of the people living with FASD who are presenting the information. They are articulate, passionate, and knowledgeable. They have usually honed these skills over a period of time, and in a supported environment that is not easy to replicate.

Other communities working to implement the model also face barriers of funding, the lack of a history of organization and infrastructure, and the need to have some local agency or organization take the lead in carrying through with the work. Clearly the model cannot just be handed to other communities, even given the well-received advice, guidance and enthusiasm that the Duncan team has demonstrated to date.

Suggestion: *The lack of significant progress after the workshops represents a challenge for the Duncan team working to share the model in other communities. The project team need to reflect on the ways they can provide support to communities given its resources available over the coming year. This may involve such activities as 1) completing and sharing useful follow-up reports immediately after workshops, 2) working to share ideas and strategies for obtaining short-term or seed funding for coordinators and / or project teams who will conduct audits / walkabouts, and 3) providing an ongoing presence in the communities that can help bring together interested parties and cement longer term coalitions of local agencies.*