

Out of the Basement

Moving Forward with FASD Services and Supports

Report arising from the multi-stakeholder conference

**Fetal Alcohol Spectrum Disorder (FASD) Supports and Services:
The Need for Collaborative Action in Newfoundland and Labrador**
St. John's, October 23-24, 2008

Convened by St. John's Housing & Homelessness Network and the FASD Committee of St. John's and Surrounding Area

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1.0 Introduction

The first multi-stakeholder conference on Fetal Alcohol Spectrum Disorder (FASD) to be convened in Newfoundland was held in St. John's on October 23 and 24, 2008. "Fetal Alcohol Spectrum Disorder (FASD) Supports and Services: The Need for Collaborative Action in Newfoundland and Labrador" was presented by the St. John's Housing & Homelessness Network and The FASD Committee of St. John's and Surrounding Area. Over 90 participants representing justice, health care, education, housing, foster and adoptive families, community-based organizations, and FASD specialists came together in the basement of St. James United Church to share information, increase their understanding and collaborate.¹ Participants were united in their determination to heighten awareness of FASD and increase support services for people with FASD, their guardians, and young women who are at risk of using alcohol during pregnancy. Municipal, provincial and federal government departments were represented, including two individuals who had previously worked on FASD issues in Labrador.

FASD

The term fetal alcohol spectrum disorder (FASD) describes a range of birth defects that occur as a result of the mother consuming alcohol during pregnancy.

2.0 Courageous Voices

Conference participants were educated and inspired and moved deeply by four individual speakers, each sharing a different face of FASD.

Denise

For Denise, a young woman affected by FASD, the face of FASD means that she:

- Did not feel emotionally connected with others as a young child
- Has difficulty understanding concepts (needs concrete examples expressed in plain language)
- Misreads social norms, non-verbal cues
- Can't say how she feels
- Can't express her own opinion
- Prefers solitude because she doesn't have to try to understand others
- Frequently has to ask for help; people become impatient
- "Every day is a struggle"

Denise is proof that success is possible when key supports are put in place, starting at a young age.

The Honorable Claudette Bradshaw, former Minister of Labour and Minister of Homelessness, said that FASD "is the biggest social problem facing us today", and emphasized that people with FASD need secure, supportive housing and they need to be given appropriate work opportunities so they can realize their potential.

¹ See List of Panel Participants – page 14

Sherry, a 14-year-old junior high school student who is affected by FASD and an award-winning speaker, delivered an impassioned speech that made the point that FASD is invisible and preventable, and shared some of her struggles such as poor social judgment and difficulty understanding the concept of time.

Mary, a mother who gave birth to a baby with FASD, explained her life as a victim of domestic violence and the one refuge she had—alcohol. She had little education, was isolated in a rural community, was not aware of the effects of alcohol on the fetus, and had no community supports. Mary also described the times when she needed others to support her and to care for her son when she could not, both the difficulty and success she had locating supports, and, finally, her pride in her son's achievement in completing his education and entering the workforce.

3.0 Positive System Responses

While there is no coordinated provincial FASD effort, participants at the conference identified efforts and initiative that have showed promise.

3.1 Justice System

- Mental Health Court is a model that can be applied to people with FASD, to keep them out of the criminal justice system.
- Correctional Service of Canada has been proactive in developing multidisciplinary teams to assist people with FASD. They provide transitional reintegration and counseling, and partner with community-based organizations (e.g., Stella Burry Community Services, Turnings) to locate appropriate housing upon release.
- Training for corrections staff is currently underway (Royal Newfoundland Constabulary Recruits. Some staff at the Clarenville Correctional Centre for Women have received training. Discussions for provision of training for provincial corrections officers, and the Sheriff's Office are currently underway. Correctional Service of Canada is developing a screening tool to identify people with FASD.

3.2 Health Care

- A representative of one of the health authorities credited a champion within the department for significant improvements in service.
- Following a letter-writing and media-awareness campaign, the Department of Health provided \$1.5 million in funding over three years to support the newly formed Labrador Fetal Alcohol Support Management Committee, and a full-time coordinator. This is a model that can be followed in Newfoundland.

3.3 Community Programs and Services

- The Department of Education provided funding for three years for teacher in-service training at schools across Newfoundland. The training, which is not specific to people with FASD (in the absence of sufficient diagnoses), helps children with memory issues and impulse-control issues.
- The Department of Education is in the process of building capacity at the district level (rather than sending one person around the province, as was done previously).

- Genesis House in British Columbia is a model of a community-based residential facility for people with FASD.
- Stella Burry Community Services Community Support Program reduces the number of days a person with FASD spends in the hospital and in jail.

3.4 Parent Support

- The Brighter Futures play group and the Healthy Baby Club are examples of parental supports that help mothers build self-esteem and engagement with others.
- When the mother is incapable of raising the child due to aggressive behaviours, Child Protection becomes an ally and puts needed supports in place.
- Foster and adoptive care provide key supports for babies and young children with FASD.

The presentations and discussions throughout the conference highlighted both strengths and weaknesses in terms of the capacity to assist and support people with FASD on the island portion of the province.

4.0 Gaps and Barriers

Significant gaps and barriers exist. The lack of coordination of efforts and services is hampering the ability of government and service providers to adequately serve those with FASD and their families. At one end of the spectrum are women who need to know of the risk related to alcohol consumption during pregnancy. Clearly public awareness is important. Those women who struggle with alcohol use need a different kind of support and different messaging if we are to give them the best possible chance of giving birth to healthy babies. Along the continuum of care are diagnosis and supports for young children who are FASD affected, their families, and for youth and adults. The gaps and barriers identified during the conference include the following:

4.1 General

- There is insufficient training and a lack of multidisciplinary support, coordination, and integration of services. Without multidisciplinary case management, the individual does not receive adequate service from the various government departments and community-based agencies.
- The individuals and families who are affected would best be served by “one-stop shopping” in a facility where all of the services are co-located.
- Individuals affected by FASD could be served by existing programs and services such as CLASS and the ABA autism program. However these opportunities are not available to them because the criteria excludes them (e.g., IQ must be below 70, and most people with FASD have an IQ above 70).
- FASD currently has a low priority in government (it’s one of many files and it appears this issue is addressed “off the side of somebody’s desk”).
- What is needed is a provincial body that represents the interests of people with FASD and those who provide services to them.
- Non-judgmental and supportive services in all areas, available in a way that maximizes the chances that they will be utilized, need to be available to women who struggle with alcohol use while pregnant.

4.2 Gender Lens on FASD

We must consider the realities of women's lives, as they relate to FASD. To consider how gender and FASD are intricately related it is imperative that we examine Health and social issues, substance use patterns and women's experience in relation to substance use, treatment programs and the structural barriers in our systems and society.

Life conditions and their experiences of the determinants of health set the stage for women's use of alcohol during pregnancy. Girls and women often use substances to self-medicate for mental health concerns and victimization. Factors such as poverty, poor nutrition, mental health and women's experience of trauma; social and geographic isolation, family violence and abuse all profoundly affect women's lives and increase the risk they will give birth to babies affected by FASD. Yet little effort is made to understand women's substance use in pregnancy and to develop the interventions they need to prevent use and / or mitigate harms associated with it.

Evidence-based literature tells us that programs for women work best when there is flexible philosophy, friendly staff, few rules, individual counselling, women-only space, home visiting and child care available. Research clearly identifies the addictions treatment approaches that work best for women – they follow theories of women's psychological development and recognize the role that relationships and connection to others play in women's sense of self, they recognize the importance of using counselling methods that empower and strengthen women and they recognize women's experience of trauma.

This awareness is critical when we consider how to address FASD. It will impact the:

- Priorities we use to direct action
- Literature we choose to inform and educate
- Primary prevention message we use
- Long-term strategies
- Ownership and responsibility we take as a society for addressing the needs of those affected by FASD

The three levels of prevention required are:

1. Increasing public awareness of FASD
2. Helping service providers are comfortable and non-judgmental when discussing alcohol and other drug use with women.
3. Specialized, multi-faced support for women at highest risk.

4.3 Justice

- The justice system cannot adequately serve people with FASD if they have not been diagnosed, and diagnosis for adults is almost non-existent in the island portion of this province.
- Currently, a judge may sentence a person with FASD to more jail time because of the lack of support services that are available to him / her.
- Prisons have become housing options of choice because people with FASD sometimes do better with the structure prison offers and because services and supports are unavailable in the community.

4.4 Health Care

- FASD diagnostic capacity is woefully inadequate. The face of diagnostics in Newfoundland, Dr. Ted Rosales, operates an office out of the basement of his home. The service is offered because of his commitment and is not a formally funded office by the Department of Health.
- People 18 years and older currently have a long wait for a diagnosis (with only one diagnostician in the province, babies and younger children are the priority).
- People who are misdiagnosed receive the wrong medication and housing that is not appropriate for them.
- Health professionals (including doctors) and the public need to be educated. There is also a need for more physicians to screen for alcohol use in pregnancy.
- Young pregnant women, who are in the highest risk group, need to have priority access to addictions treatment services.

4.5 Education

- Alternative education opportunities for youth with FASD who are not able to function in the classroom setting are grossly inadequate.
- More teacher training is needed, including follow-up contact.
- Workers should be able to accompany a youth with FASD in the classroom to assist him/her. Alternatively, student support workers who are currently offering this service need to be trained.

4.6 Housing

- Appropriate housing is scarce. We know that the most appropriate housing for young and older adults who are affected by FASD is self-contained housing such as a bachelor apartment, or a room in a house with a family.
- All too often individuals are housed in substandard housing where the individual is exposed to and influenced by people who are not making positive life choices, and where landlords may take advantage of them (e.g., by not returning their damage deposit).
- Young adults with FASD have difficulty maintaining housing due to lack of money management skills, and vulnerability to peers who force them out of their home.
- Housing alternatives are a necessity for those who cannot be supported in the home because of violence.

5.0 A Shared Dream

Quite simply, the Dream is that FASD has moved out of the basement, literally and figuratively. The Dream covers all aspects of FASD prevention, education, training, support and services, multidisciplinary collaboration and provincial co-ordination.

Public awareness and health promotion include early intervention efforts and three levels of prevention. They achieve goals such as a common understanding that FASD is a brain-based disorder not a mental illness. Consequently expectations are realistic and people with FASD have more success.

Women are no longer blamed but instead they are supported in meeting their needs and in their efforts to give birth to healthy babies. Public support is mobilized and compassionate responses to parents and individuals affected by FASD are the norm.

A provincial FASD Diagnostic Team provides travelling clinics throughout the entire province. The team includes a physician, coordinator, and a psychologist.

A provincial FASD initiative exists, with a provincial committee that is interdisciplinary, and supported by a provincial coordinator and regional coordinators. There is also a network of service providers who share resources and ideas, and collaborate together. Consequently there is greater likelihood of universality of programs that are available.

Professionals in all public service areas (e.g. education, health, justice) are well trained, knowledgeable and appropriately responsive to those who are FASD affected. In addition, FASD awareness is incorporated into the K-12 school system.

One stop shopping is available for those affected by FASD and their families. Holistic wrap-around case management services are available to those affected by FASD. Collateral services such as appropriate housing, employment supports, etc. are also readily available.

6.0 Action Plans

Unlike the Labrador part of the province, the Island lacks a concerted and collaborative focus and effort. This lack of connectedness and focus affects those who are FASD affected, their families, and the work of many provincial departments and community based initiatives. It is time to take action, move FASD out of the basement and meet needs effectively and efficiently.

Short-Term Actions

1. Form a provincial committee, comprised of those who self-identified at the conference, and any others who might be identified.
2. Meet with government representatives, both political and bureaucratic, and ask for support in taking action and moving FASD out of the basement.
3. Begin to build a network of interested people who can share resources.
4. Harness the fantastic resources available and find ways to fund awareness and education initiatives that allow individuals affected to tell their story.

Intermediate Actions

1. The province has a provincial FASD organization with a provincial coordinator who can be the conduit for information sharing, collaborative action and building an FASD network and strategy.
2. The province has an FASD Diagnostic Team that travels throughout the province.
3. Education and training initiatives are put in place to a) raise public awareness in young people and the public in general about the cause of FASD and how it can be prevented, and b) educate and train service providers who work with people with FASD, as well as students who are preparing to work in the field.

7.0 Summary

Currently, individuals affected by FASD are inadequately served and services and supports are uneven throughout the province. The consequences of this are substantial costs—both social and economic. Improving the supports and services to those affected by FASD must therefore become a high priority. Conference participants, comprising representatives who work in the federal, provincial, and municipal governments, as well as diverse community-based service providers and family members of FASD-affected children and youth, believe action is imperative.

There is a strong collective will to “move out of the basement” to improve supports and services for people with FASD in the island portion of this province. The determination to elevate the level of care for this population has never been stronger, which indicates that there has never been a better time to move from words to action.

Furthermore, as The Honorable Claudette Bradshaw said, improving supports and services for people with FASD is not only a social issue; it’s an economic development issue. “In the future, you will need every Newfoundlander in the workforce,” she said in her keynote address. A commitment of funding and resources is required in order to embark on Taking Action: Moving FASD Out of the Basement.

Appendix

The following Dreams and Next Steps were identified by the various working groups:

Justice

Dreams

Participants working in the justice system envision a world where people with FASD would be identified and treated appropriately by staff who are well trained and who work collaboratively with the other professionals who are providing services to these individuals.

- FASD would not be treated as a mental disorder.
- People with FASD would get concrete, physical reminders (pictures) of appointments and what needs to be done.
- There would be a “wellness court” and specially trained police officers for people with FASD.
- Assessment and screening would be in place so people with FASD coming into the system would be identified as such.
- Because information would be shared, people with FASD would not have to keep repeating their story
- Holistic wrap-around case management services
- Everyone who interacts with the person with FASD would be educated, from police officers to correctional staff. People would listen well and have no biases. Improved service would reduce involvement in the justice system.
- Enough resources.
- Champions in every workplace.
- Responses from staff would not stigmatize and ostracize.

Next Steps

- Training and education to raise awareness about FASD.
- Conduct a consultation to find out what’s already being done and what the existing capacity is.
- Form a provincial organization.
- Apply best practices
- Build capacity in each community

Education

Dreams

Participants who work in education envision both professionals and the public being educated about FASD, and having more community-based education opportunities for youth with FASD who need an alternative to school.

- An education campaign would yield the result that blaming and judging the mother would no longer get in the way of delivering services to her.
- The message about FASD would be communicated to the public by people with and affected by FASD, like Denise and Mary.

- There would be more community-based education opportunities for youth who cannot function in school. Programs like Choices For Youth's Youth At Promise program would be available in other communities besides St. John's.
- Educate the medical profession and increase the capacity for diagnosis.
- FASD would be included in K-12 curriculum.
- Mentoring programs for youth who are FASD-affected.

Next Steps

- Create a provincial FASD committee which will hire a staff person, coordinate the diagnostic team, share information, conduct a media campaign, support families and children, and lobby government for additional supports.
- Get FAS on the radar of government and the public.

Housing and Supports

Dreams

Participants whose work centres on housing and support services envision universality of services for individuals with complex needs, sufficient housing that is appropriate for people with FASD, and integrated services focused on mothers.

- There would be services for adults, youth, and children with complex needs that are not fragmented by criteria. Universality would remove barriers to services.
- Sufficient housing, both communally-based with supports and located at scattered sites with services going to them.
- Intensive case management would be applied to rural areas.
- Integrated services would be available for mothers, such as supportive housing and counseling and treatment for substance use

Next Steps

- Establish universality of programs for people with complex needs; remove barriers (includes expanding the CLASS program for people with FASD)
- Create community-owned supportive housing that's affordable
- Develop lobby group; send coordinated message to the provincial government
- Educate young people by getting FASD into the sex education curriculum and piggybacking on the DARE program
- Distribute pregnancy tests and condoms in schools
- Establish a treatment centre for youth including youth with FASD which would provide an option for sentencing in the province.
- Provide assisted living with life skills training (showering, laundering clothing, etc.)

Health Care

Dreams

Participants who work in the health care field envision well-trained students and professionals, early intervention with at-risk young women, available resources being accessible to everyone, and the delivery of services in a single location.

- Province-wide access to services using the “one-stop shop” model
- A list of available resources and contacts would be accessible to everyone
- Early intervention to assist young women with coping skills and prevent alcohol use during pregnancy
- Newfoundland would be as advanced as Labrador in working with people with FASD
- Students as well as practitioners would be trained across the province
- Understanding FASD is a brain-based disorder, people’s expectations would be realistic, and people with FASD would have more success.
- The discrepancy between chronological and developmental age would be taken into consideration when the age of consent (for sexual intercourse) is determined
- Funding would be committed to support a team including a physician, coordinator, and possibly a psychologist to travel throughout the province to make diagnoses.

Next Steps

- Each region has the responsibility to educate professionals and individuals at professional schools regarding FASD. The PowerPoint education package developed in St. John’s will be shared with the regions, or the regions will receive help in developing their own package.
- A list of resources that are available and contacts in different parts of the province will be compiled and shared.
- A public awareness media campaign (including television) will be launched to put a face to FASD. This will help the public gain a better understanding of FASD, its effects, and its impacts on families. People like Denise, Sherry, and Mary would help put a face to the issue, and their voices would be heard.
- People working in the field will write to the Premier’s office explaining what supports and services are needed. Both an e-mail campaign in which a consistent message is expressed, and a petition were both recommended.

Supportive Family Members

Dreams

Parents and supportive family members envision a place where young people can go to dance and enjoy themselves without alcohol and drugs, “one-stop shopping” for services,

- Have facilities where children can dance and socialize without alcohol or drugs
- Child protection would be painted in a more positive light, and would have a 24-hour facility open to children and young adults
- Professional Development day for youth to come together so we can see what their needs are.
- Have one big facility for people with FASD
- Youth whose parents are too ashamed to come forward need to have a voice

- Leaders in both provincial and federal governments would help our youth.
- Put scholarships in place for academic achievement.

Next Steps

- Have a place where youth can go for fun, without drugs and alcohol.
- Professional development workshops at schools for youth, teachers, and professionals.
- Have youth and parents who are FASD-affected speak on issue across the province.
- Have a single contact point where people can get information.
- Ensure parents know what services are available.
- Launch a large media campaign to dispel myths and educate the public that FASD is everyone's responsibility.

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