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GOVERNMENT OF YUKON

Proposed FASD Prevention Services Delivery Model

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Background

Yukon Profile

Yukon is a federal territory located in the north west of Canada, with a current population of 35,862. Approximately three quarters of Yukon residents (24,150) live in the territorial capital, Whitehorse. The remainder of the population lives in small towns and communities, or rurally. There are 14 First Nation groups in Yukon, and approximately one quarter of the Territory's population has Aboriginal ancestry.

FASD Definition and Prevalence

Fetal alcohol spectrum disorder (FASD) is an umbrella term that refers to a group of disorders characterized by physical, mental, behavioural and learning disabilities that can endure a lifetime and that are associated with prenatal exposure to alcohol.[1] Four types of FASD have been described (Table 1). They are characterized by prenatal and postnatal growth retardation, a unique cluster of facial anomalies, and central nervous system impairments (neurological, cognitive, and behavioural).[2]

Table 1: Fetal alcohol spectrum disorder subtypes[3]

Subtypes	Description
Fetal alcohol syndrome (FAS)	Diagnostic classification for individuals who were prenatally exposed to alcohol and who present with growth deficiency, with height or weight below the 10th percentile, facial characteristics (e.g., small eyes, smooth philtrum, and thin upper lip), central nervous system damage (structural, neurological, and/or functional impairment)
Partial Fetal Alcohol Syndrome (pFAS)	Diagnostic classification for individuals who were prenatally exposed to alcohol and who present with some but not all of the physiological symptoms of full FAS
Alcohol-Related Neurodevelopmental Disorder (ARND)	Diagnostic classification for individuals who were prenatally exposed to alcohol, have symptoms of central nervous system damage associated with FAS but do not present the facial features typical of FAS
Alcohol-Related Birth Defects (ARBD)	Diagnostic classification for individuals who were prenatally exposed to alcohol and who have physical defects such as malformations of the heart, bone, kidney, vision, or hearing systems

[1] Sokol RJ, Delaney-Black V, Nordstrom B. Fetal alcohol spectrum disorder. *The Journal of the American Medical Association.* 2003;290:2996-9.

[2] Astley SJ, Clarren SK. Diagnosing the full spectrum of fetal alcohol-exposed individuals: introducing the 4-digit diagnostic code. *Alcohol & alcoholism.* 2000;35:400-10.

[3] Astley SJ, Clarren SK. Diagnosing the full spectrum of fetal alcohol-exposed individuals: introducing the 4-digit diagnostic code. *Alcohol & alcoholism.* 2000;35:400-10.

While no official data exists on the prevalence of fetal alcohol spectrum disorder (FASD) in Canada, this diagnosis is estimated to occur in nine per 1,000 live births and affects approximately 1% of the population.[4] In Canada, there is a greater prevalence of FASD in "rural communities, foster care systems, juvenile justice systems [9]and Aboriginal populations".[5] The rate of FASD within Aboriginal communities in northern Canada is estimated to be higher than the national average;[6] but researchers have been challenged to provide a generalizable prevalence estimate for this population as studies have drawn from a diverse range of research methodologies and have focused on different Aboriginal cultures that have different patterns of alcohol consumption.[7] Muckle et al. (2011) have estimated that 47 per 1,000 live births "may result in children at risk for alcohol effects" among Inuit living in Arctic Quebec.[8] Earlier literature reviewed by Chudley et al. (2005) revealed FASD rates (per 1,000 live births) of 25 (among native Canadian children in northern British Columbia), 46 (among nation Canadian children living in the Yukon), 190 (in an isolated Aboriginal community in British Columbia), and 55-101 (in a First Nations community in Manitoba).[9]

FASD is a national public health problem with serious education, social, and economic implications for society as those affected suffer a lifelong disability and may need lifelong support. Thanh et al. (2011) report that the annual cost of FASD in Canada is about CA$6.2 billion, using the commonly quoted incidence rate of nine cases per 1000 live births.[10] This translates to $25,000 per person with FASD per year, or a discounted incremental lifetime cost per person with FASD of $742,000(Cdn). While finding dollars to support FASD prevention may be problematic, the long term societal costs for not taking action will ultimately place considerable strain on available resources.

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[4] Health Canada. (2006). *It's your health: Fetal alcohol spectrum disorder*. Retrieved from: http://www.hc-sc.gc.ca/hl-vs/alt_formats/pacrb-dgapcr/pdf/iyh-vsv/diseases-maladies/fasd-etcaf-eng.pdf

[5] Jonsson, E., Dennett, L., & Littlejohn, G. (2009). Fetal alcohol spectrum disorder (FASD): Across the lifespan – Proceedings from an IHE consensus development conference, 2009. p.175.

[6] Health Canada. (2012). *It takes a community: Framework for the First Nations and Inuit fetal alcohol syndrome and fetal alcohol effects initiative. A resource manual for community-based prevention of fetal alcohol syndrome ad fetal alcohol effects.* Retrieved from: http://publications.gc.ca/collections/collection_2012/sc-hc/H34-84-1997-eng.pdf

[7] Muckle, G., Laflamme, D., Gagnon, J., Boucher, O., Jacobson, J., & Jacobson, S. (2011). Alcohol, smoking, and drug use among Inuit women of childbearing age during pregnancy and the risk to children. *Alcoholism: Clinical and Experimental Research, 35* (6), p.1081-91.

[8] Ibid. p.1089.

[9] Chudley, A., Conry, J., Cook, J., Loock, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal, 172* (5 suppl), S1-S21.

[10] Thanh NX, Jonsson E, Dennett L, Jacobs P. (2011). Costs of FASD. In: Riley EP, Clarren S, Weinberg J, Jonsson E, eds. (2011). Fetal alcohol spectrum disorder: management and policy perspectives. Toronto and Weinham: Wiley-Blackwell p. 45-70.

Yukon's Previous Work in FASD

Yukon has had a long-standing history of action in addressing FAS/FASD prevention. As early as 1997, in response to growing concern about the issue in the territory, the Yukon Government established a plan for the prevention of Fetal Alcohol Syndrome/Fetal Alcohol Effects (FAS/FAE).[11] This model was updated in 2000[12] and has, in part, guided action by Yukon Government Alcohol and Drug Services (ADS) over the last 16 years. Similarly, over the last two decades, many organizations, agencies and communities, including the Child Development Centre, Canadian Prenatal Nutrition Programs, Fetal Alcohol Syndrome Society Yukon (FASSY), and medical and health centres have engaged in various FASD prevention activities throughout Yukon.

This FASD Prevention Project

In 2013, the Yukon Department of Health and Social Services initiated an overview of current FASD prevention-related service delivery by government and non-government in Yukon, identification of FASD prevention-related service delivery gaps, and recommendations for addressing the gaps through a service delivery model based on best practice and evidence. This document and the associated Technical Report represent the products of this work.

The proposed Yukon FASD prevention service model contained in this document was informed by:

- Two literature reviews of effective FASD prevention strategies;[13,14]
- A jurisdictional scan of FASD prevention frameworks and models developed in nine leading jurisdictions or agencies in Canada and internationally;[15]
- An inventory of FASD prevention services in Yukon, including the perspectives of those engaged in FASD prevention activities;[16] and
- An analysis of the gaps and issues in relation to best available evidence and promising practice.[17]

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[11] Yukon Alcohol and Drug Services (1997). Proposed Planning Model for the Prevention of Alcohol Related Birth Defects. Yukon Government: Whitehorse.

[12] Yukon Alcohol and Drug Services (2000). Update on Planning Model for the Prevention of Alcohol Related Birth Defect. Yukon Government: Whitehorse.

[13] Ospina M. (2013). *Yukon FASD prevention gap analysis: Summary of the literature.* Produced for the Government of Yukon.

[14] Wodinski L. (2014). *Literature review: FASD prevention – a health determinants perspective.* Produced for the Government of Yukon

[15] Flynn S. (2013). *Yukon FASD prevention gap analysis: Summary of Jurisdictional review.* Produced for the Government of Yukon

[16] Alsbury B. (2014). *Yukon FASD prevention gap analysis: Summary of service inventory.* Produced for the Government of Yukon.

[17] Flynn S, Alsbury B, Wanke M. (2014). *Yukon FASD prevention gap analysis: Summary of gaps.* Prepared for the Government of Yukon

The following assumptions guided the development of this proposed FASD service delivery model:

- The proposed model builds upon the excellent relevant work previously undertaken in the northern territories, Canada and internationally – there was no need to reinvent wheels;
- This proposed FASD prevention service model represents a guide to inform future Health and Social Services planning for FASD prevention in Yukon. It attempts to outline a comprehensive array of potential services that collectively represent the mosaic of a comprehensive, multi-faceted approach to the complex issue of FASD prevention;
- This proposed FASD prevention service delivery model represents a high level strategic direction proposed for Yukon and does not include an operational plan for its implementation.

Service Delivery Model

Foundational elements of an FASD prevention service model are proposed to guide Health and Social Services and Yukon Government service delivery and strategic priorities: vision, contextual model, principles, strategic directions, and goals. We have selected and adapted from the rich base of models available in the literature and in other jurisdictions.

A Proposed Vision

The ultimate goal of a comprehensive FASD prevention service delivery model is *to effectively prevent FASD in Yukon.*

To this end, the vision is that:

> *Individuals, families/caregivers and communities across Yukon protect children from prenatal exposure to alcohol because they are supported and informed in a way that recognizes and reflects their health, social, economic, and ethno-cultural circumstances and needs.*
>
> *The people of Yukon have compassion and respect for women at risk of having a child with FASD and understand that this condition is preventable through effective and concerted action to address the underlying risk factors.*

Adapted from Public Health Agency of Canada (2003) [18]

[18] Public Health Agency of Canada. (2003). *Fetal Alcohol Spectrum Disorder (FASD): A Framework for Action.* Accessed March 12 2014 at http://www.phac-aspc.gc.ca/publicat/fasd-fw-etcaf-ca/index-eng.php

Understanding the Context

FASD is as much a social issue as it is a personal one and, therefore, must be understood in relation to the socio-demographic factors that influence alcohol consumption during pregnancy. The most influential individual characteristics appear to be age, experience, behaviours, health/conditions, and assets. Findings from our review of the literature suggested that women are more likely to drink if they are young or over the age of 35, if they use tobacco, if they have mental health issues, and if they are less educated.[19] In terms of a women's immediate external context (as defined by family and social supports), influencing factors include relationships, socio-economic status, culture and ethnicity, genetics, norms and expectations, and capacity and challenges. Being unmarried also appears to be a risk factor for drinking during pregnancy as is past experienced of physical or sexual abuse.[20] Socio-economic status has a demonstrated association with drinking during pregnancy, although the literature indicates that women of both higher and low socio-economic status are at increased risk.[21]

Beyond the socio-demographic factors that influence patterns of maternal alcohol consumption during pregnancy, it is also important to consider the social environment that enable or mitigate FASD outcomes. According to Nathoo et al. (2013), the literature "strongly suggests that the women most likely to have a child with FASD are those who will be least likely be able to respond to awareness messages about the potential harms of consuming alcohol during pregnancy because of the overwhelming social conditions within which they live".[22] Such socio-structural conditions include, but are not limited to, poverty, homelessness, cultural connectedness, violence, trauma, and a history of colonization. In the northern Canadian context specifically, FASD risk factors of age, income, education level, experience with violence and trauma are compounded by deeper issues related to the intergenerational effects of colonization, poverty, availability of health services in communities, racism, and stigma.[23] [24]

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[19] Wodinski L. (2014). *Literature review: FASD prevention – a health determinants perspective.* Produced for the Government of Yukon

[20] Ibid.

[21] Ibid.

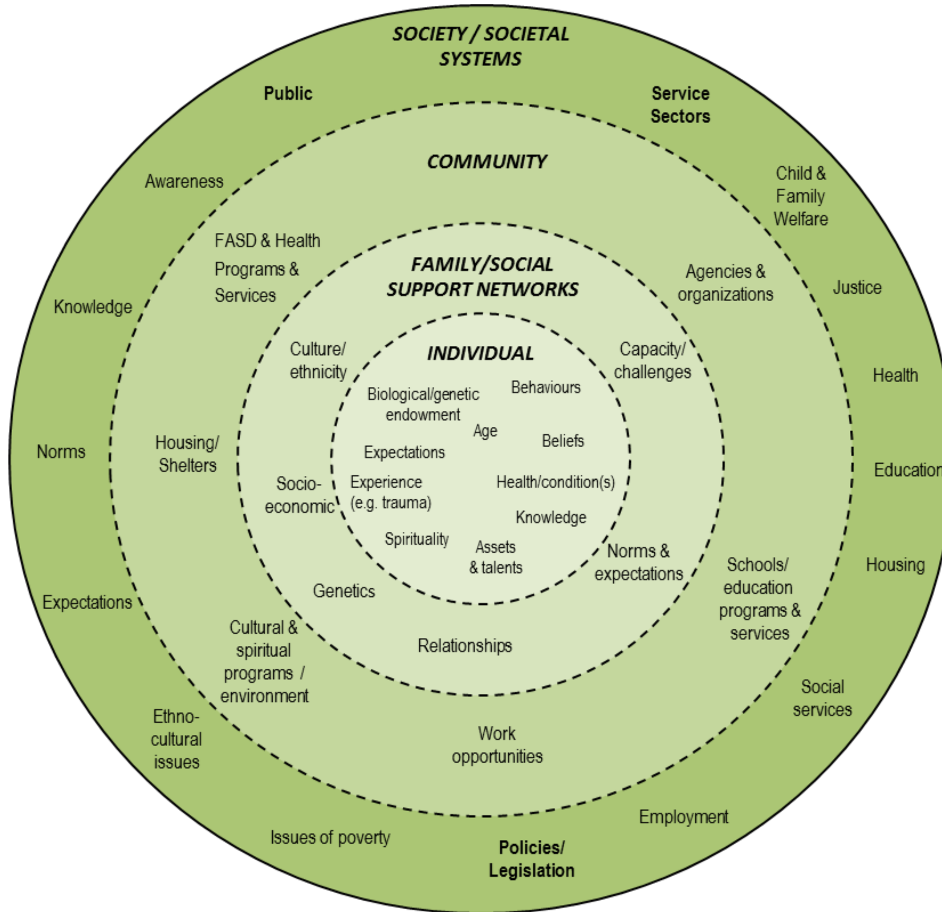
[22] Nathoo, T., Poole, N., Bryans, M., Dechief, L., Hardeman, S., Marcellus, L., Poag, E., & Taylor, M. (2013). Voices from the community: Developing effective community programs to support pregnant and early parenting women who use alcohol and other substances. *First Peoples Child & Family Review, 8* (1), 93-106.

[23] Badry, D. & Felske, A. (2013). An examination of the social determinants of health as factors related to health, healing and prevention of foetal alcohol spectrum disorder in a northern context – the brightening our home fires project, Northwest Territories, Canada. *International Journal of Circumpolar Health, 72,* 1-6.;

[24] Badry, D. & Felske, A. (2013). An examination of three key factors: Alcohol, trauma and child welfare: Fetal alcohol spectrum disorder and the Northwest Territories of Canada. *First Peoples Child & Family Review, 8* (1), 131-43.

Ultimately, it appears that a women's decision to use alcohol during pregnancy is influenced by a broad constellation of factors which exist at the individual level, in the immediate context of family and social supports, at the community level, within society as a whole, and at the system level. Figure 1, below, serves to illustrate the many factors that could potentially act upon an individual and influence the decision to use alcohol during pregnancy. Prevention activities may occur at each level.

Figure 1. Factors influencing alcohol use in pregnancy[25]



[25] Adapted from Charis Management Consulting (2008). *Enhancing Function for Meaningful Living: Phase II Report.* Prepared for Capital Health, Edmonton.

Principles

The contextual model implies the need for action at two fundamental levels:

- Principles to guide the frontline planning and delivery of FASD prevention programs and services; and
- Principles to guide FASD prevention activities across programs and services.

Principles to Guide FASD Prevention Programs and Services

It is hoped that, ultimately, all service providers will adopt these principles as a guide for their FASD prevention efforts. Yukon stakeholders have indicated that, at present, these principles are not necessarily recognized or consistently implemented among Yukon-based FASD prevention service providers.[26] These principles could serve as a basis for Health and Social Services action to build capacity among service providers involved in FASD prevention.

Collaborative	Service providers work in partnership with individuals at risk for FASD, their family and support system, communities, and with other service providers.
	Together, service providers strive to identify and address service gaps, and minimize duplication of effort.
Evidence-informed	Prevention approaches are informed by best available research evidence and promising practice.
	Prevention strategies and approaches consider both indigenous and western forms of evidence. Each is informed by unique assumptions about health and well-being as well as unique world views. Adapted from *Honouring our Strengths: a Renewed Framework (2011)*[27]
Family-centred	Women and their immediate and extended family are considered and incorporated in planning and providing FASD prevention services. Adapted from *It Takes a Community (2001)*[28]
Health Determinants Perspective	FASD prevention services will be: ▪ **Respectful** – conditions are created for women to discuss their experiences, identify coping strategies and healing processes; services will support the inclusion and full participation of women in their own health care and wellbeing. ▪ **Relational** – services acknowledge that the process of growth, change, healing and prevention does not happen in isolation, but moves forward through

[26] Yukon stakeholders. Personal communication at stakeholder meeting, February 18, 2014

[27] Author uknown. (2011). *Honouring our strengths: a renewed framework to address substance use issues among First Nations People in Canada.* Accessed at: http://nnadaprenewal.ca/?page_id=7

[28] FAS/FAE Technical Working Group National Steering Committee. (1997, 2001). *It Takes a Community: Framework for the First Nations and Inuit Fetal Alcohol Syndrome and Fetal Alcohol Effects Initiative.* Accessed at: http://www.turtleisland.org/healing/fasfae1.pdf

	interactions with others in long-term, supportive, trust-based relationships. ▪ **Self-determining** – recognizing that women have the right to both determine and lead their own paths of growth and change, service providers support women's autonomy, decision making, and control of resources, so as to facilitate self-determined care. ▪ **Women-centred** – prevention services involve women as informed participants in their own health care, and attend to women's overall health and safety. They also acknowledge women's right to control their own reproductive health, avoid unnecessary medicalization, and recognize women's patterns and preferences in obtaining health care. ▪ **Harm reduction oriented** – services demonstrate an understanding of substance use and addictions including the full range of patterns of alcohol and other substance use, influences on use, consequences of use, pathways to and from use, and readiness to change. Harm reduction strategies are used to minimize known harms associated with substance use and to enable connections and supports to develop between women who use substances and available healing services. ▪ **Trauma-informed** – prevention services take into account the influence of trauma and violence on women's health; service providers understand trauma-related symptoms as attempts to cope and integrate this knowledge into all aspects of service delivery, policy and service organization. ▪ **Health promoting** – service providers recognize that FASD prevention is not simply about alcohol; they understand that social health determinants such as poverty, experience of violence, stigma and racial discrimination, nutrition, access to prenatal care, physical environment, experiences of loss or stress, social context and isolation, and housing all converge to influence FASD risk factors and prevention. Accordingly, holistic, multidisciplinary, cross-sectoral, health promoting responses to these complex and interconnected needs are used. ▪ **Culturally safe** – service providers understand that women need to feel respected, safe and accepted for who they are with regard to their cultural identity and personal behaviours; they respect and take into account cultural location and women's values and preferences in all their service encounters. Such consideration extends to accommodating women's interests in culturally specific healing. ▪ **Supportive of mothering** – prevention services recognize the importance of supporting women's choices and roles as mothers, as well as possible short- and long-term influences that a loss of custody may have on a woman. Prevention approaches support a range of models for mothering, including part-time parenting, open adoption, kinship and elder support, shared parenting, inclusive fostering, and extended and created family. FASD prevention attends to the importance of pacing and support in transitions for women as they move between mothering roles. ▪ **Use of disability lens** – recognizing that women with substance use and mental health problems may also have disabilities, including FASD, prevention services take into account the current knowledge base regarding the spectrum of

	disabilities related to FASD. Extracted and adapted from *10 Fundamental Components of FASD Prevention from a Women's Health Determinants Perspective* (2010)[29]
Holistic	Prevention services consider and balance the full range of factors contributing to well-being over the lifespan: physical, spiritual, mental, cultural, emotional, and social. Service providers recognize that individual wellbeing is strongly connected to family and community wellness, and that a comprehensive, integrated continuum of care is necessary. Adapted from *Honouring our Strengths: A Renewed Framework (2011)*
Strengths based / resiliency focused	Prevention services recognize and support the natural strengths and resilience of individuals, families and communities. Service providers look for and honour these strengths as the foundation upon which they build their services, supports, and policies. Adapted from *Honouring our Strengths: A Renewed Framework* (2011)

Principles to Guide System Level Support of FASD Prevention Services

These principles are intended to guide to guide the Yukon government in overall planning and evaluation of FASD prevention programs and services. They are presented in alphabetical order; no prioritization is implied.

Accountability, Affordability and Sustainability	FASD prevention programs and services are planned and implemented in resourceful ways, maintaining sound management of finite human and financial resources.
	FASD prevention programs and services are planned and implemented according to addressing the greatest needs and service gaps according to where available resources will have the greatest impact, in accordance with best available evidence and promising practices. Service duplications or redundancies are avoided in favour of distributing available resources most fairly.
Capacity Development	Decision makers and planners consider evaluation and sustainability from the start. There is a focus on capacity building, identification and use of diverse resources, and evaluation of outcomes. Adapted from US (SAMHSA) *Strategic Prevention Framework* (2004)[30]
Community-based	Overall planning for FASD prevention takes into account (is related to) the needs, goals and aspirations of each community and proceeds at a pace determined by that community. Adapted from *It Takes a Community* (2001)

[29] Network Action Team on FASD Prevention from A Women's Health Determinants Perspective. (2013). *Consensus on 10 fundamental components of FASD prevention from a women's health determinants perspective.* Accessed at: http://www.canfasd.ca/wp-content/uploads/2013/02/ConsensusStatement.pdf

[30] SAMHSA's Centre for Substance Abuse Prevention. (2004). *The Strategic Prevention Framework*. Accessed at: http://captus.samhsa.gov/prevention-practice/strategic-prevention-framework

	Prevention services recognize and support the natural strengths and resilience of each individual community. Planners and decision makers honour these strengths as the basis for continuing to build community capacity. Self-determination, innovation and creativity are encouraged in the design and implementation of community-based FASD prevention programs and services. Adapted from *It Takes a Community* (2001)
Comprehensive	The system of available FASD prevention services incorporate the full range of effective strategies, including broad population-based approaches that complement services to women at risk for maternal alcohol consumption.
Culturally appropriate	FASD prevention services are planned and designed to be relevant and culturally appropriate, recognizing the unique context of each community as well as the cultural diversity that may exist within communities.
	Planners and decision makers promote cultural competence among program staff and, to the extent feasible, staff reflect the culture of the community they serve. Adapted from US (SAMHSA) *Strategic Prevention Framework* (2004) Cultural competence requires that all service providers are aware of their own worldviews and attitudes towards cultural differences, and that they are knowledgeable about and open to the cultural realities and environments of the clients they serve. Adapted from *Honouring our Strengths: A Renewed Framework* (2011)
Equitable access	To the extent feasible, policies and programs strive for equitable access to FASD prevention services across the territory.
Health determinants / public health approach	FASD prevention services adopt a health promotion perspective which recognizes that FASD and alcohol consumption during pregnancy is part of a complex interplay of biological, social, psychological, environmental, and economic factors. Decision makers and planners accept that the antecedents of FASD are not just a matter of personal responsibility and choice. Adapted from *Australia FASD Action Plan (2013-2016)*[31]
Integrated	FASD prevention programs and services are coordinated across agencies, communities and government departments with a view to avoid overlap and duplication, as well as to facilitate the sharing of expertise, information and resources. Adapted from *Honouring our Strengths: A Renewed Framework* (2011)
	Collaborative action is characterized by partnerships and leadership. Adapted from PHAC's *FASD: A Framework for Action* (2003)
	Recognizing that the broad range of health determinants which influence alcohol use do have an impact on FASD prevention efforts, linkages to other initiatives are made across the range of sectors: community services, education, employment, health,

[31] The Foundation for Alcohol Research and Education(FARE). (2012). *The Australia Fetal Alcohol Spectrum Disorders Action Plan 2013 – 2016.* Accessed at: http://www.fare.org.au/wp-content/uploads/2011/07/FARE-FASD-Plan.pdf

	housing, justice, and social services. Adapted from *Australia FASD Action Plan (2013-2016)*
Shared Responsibility	Decision makers and planners recognize that addressing the complexity and multi-faceted issues related to FASD prevention requires shared responsibility and collective action among individuals, families, communities, service providers, and governments. All have a shared responsibility to ensure services, supports and systems are effective and accessible, both now and for future generations. Adapted from *Honouring our Strengths: A Renewed Framework* (2011)

Strategic Action Areas and Associated Goals

A scan of the most relevant overarching frameworks for FASD prevention from nine jurisdictions (five Canadian; four international) found considerable similarity in terminology or areas of focus. Almost all frameworks incorporated action at multiple levels of prevention strategies, and considered action at the individual, family, community, and population levels.

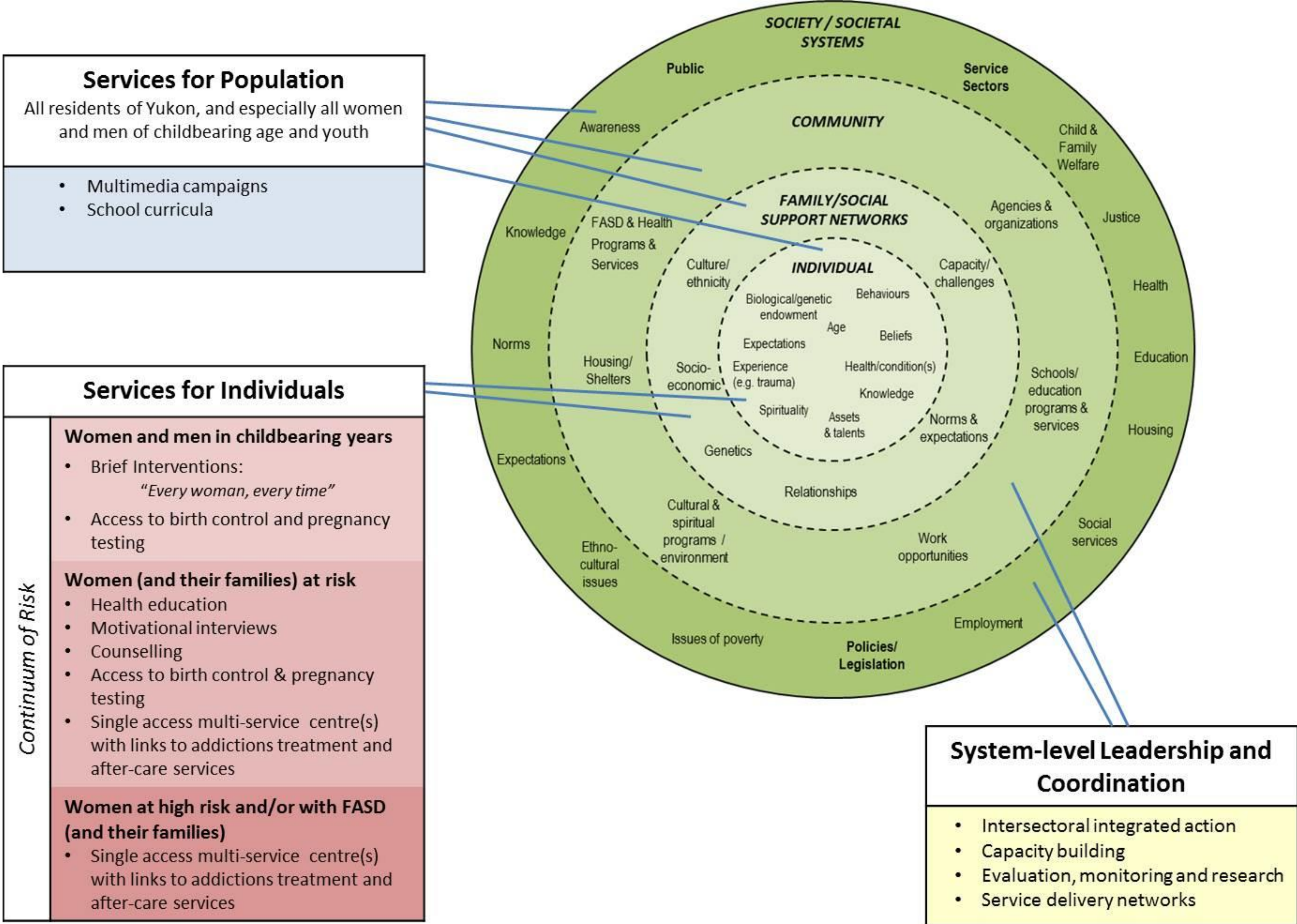
Three overarching levels of action emerge from the literature and from work undertaken in other jurisdictions:

1. System-level;
2. Population level, often referred to as *universal prevention*; and
3. Action at the individual level, sometimes linked to action at the family level.

In the FASD prevention literature, the third level of action is often subdivided into varying strategies based on level of risk, including women at risk for alcohol consumption during pregnancy (generally referred to as *selective* or *targeted* prevention) and women at high risk (generally referred to as *indicated* prevention). These terms are further defined below.

Revisiting our contextual model of the woman within the context of her family, community and society, specific strategies to address FASD prevention within this contextual framework are proposed based on best available evidence and practice (Figure 2).

Figure 2: Proposed FASD Prevention Strategies



Strategic Direction: Leadership and Coordination

Findings from Gap Analysis

Findings from the literature reviews, jurisdiction review, service inventory, and gap analysis are presented as key themes.

Inter-sectoral and Collaborative Action

- One of the most predominant themes arising from Yukon stakeholders was the lack of collaborative action and linkages across various service providers. They described diverse initiatives and services, each operating in silos with few coordinating mechanisms available.

- All jurisdictions included in the jurisdictional review identified intersectoral action as a necessary component of a coordinated approach to FASD and the harms of substance use. For example, the National Treatment Strategy Working Group's framework, entitled *A Systems Approach to Substance Use in Canada*, emphasizes the importance of intersectoral collaboration to address the social determinants of health in substance use treatment and prevention efforts.

- Strategies to promote and improve collaboration are found in the frameworks of the Public Health Agency of Canada, the Canada Northwest FASD Partnership, Alberta, British Columbia and SAMHSA. Strategies include establishing channels for communication, opportunities for networking, integrated resources and other mechanisms to support partnerships.

- Australia, Alberta and British Columbia have developed system level strategies to address FASD, each including a focus on prevention. Alberta has established a Cross-Ministry Committee (FASD-CMC) and supporting Councils to coordinate key supporting functions (for example, awareness and prevention, communications, networking through a community of practice, education and training, evaluation and research, evaluation, communication, training, networking). Additionally, Alberta and Australia promote the establishment of local "service networks" comprised of community agencies and organizations that provide coordinated assessment and diagnosis, targeted and indicated prevention, and support services for people affected by FASD and their caregivers.

- All jurisdictions included in the jurisdiction review recognized the association between socio-economic determinants of health and drinking during pregnancy. Determinants of health strategies proposed included service provider education in all relevant sectors, FASD and determinants of health research, prevention service planning through a determinants of health lens, multi-sectoral efforts, and broad social and economic interventions.

Evaluation and Research

- Identified gaps related to evaluation and research in Yukon included the lack of a network for information dissemination, a systematic approach to evaluation, and community-driven targets and outcomes for measuring the success of FASD prevention.
- Some Yukon stakeholders note the absence of FASD incidence and prevalence data, both territorially and nationally. This presents as a considerable challenge for monitoring changes in FASD rates over time as well as determining the effectiveness of a comprehensive FASD strategy.
- The Public Health Agency of Canada, Alberta, British Columbia, Australia, SAMHSA, and the World Health Organization incorporate research, monitoring and/or evaluation strategies in their FASD and substance use frameworks.

Capacity Building

- Feedback from Yukon stakeholders suggest that:
  - Knowledge of FASD and the harms of alcohol consumption during pregnancy vary amongst Yukon service providers (medical professionals in particular). As a result, Yukon residents are receiving inconsistent messages and information about FASD;
  - Stigma and prejudice around FASD still exist, especially in rural areas, and may prevent Yukon residents from accessing services;
  - Service providers require training on methods to engage female clients and discuss sensitive topics with them; and
  - Service providers lack awareness of their role in FASD prevention.
- Alberta, British Columbia, Canada's First Nations and Inuit, and Australia identify training and education of service providers as a strategy for preventing FASD and substance use harms. Educational strategies focus on the need for a single, consistent message; counselling for women at risk; general training for health professionals; and dissemination of research and best practice in multiple forums.
- The Government of Alberta has established a Fetal Alcohol Spectrum Disorder Education and Training Council to lead "coordinated and effective FASD education and training in Alberta". Alberta also has a formal Child and Family Services FASD Community of Practice, although its mandate does not cover FASD prevention. Australia has plans to develop a collaborative network of FASD experts to promote information exchange and evidence generation.

Proposed Leadership and Coordination Strategies, Actions and Objectives

Strategy	Focus	Recommended Action*	Objectives
Inter-sectoral integrated action	System level decision makers and planners in: ▪ Health & Social Services ▪ Education ▪ Justice ▪ Women's Directorate ▪ Community Services ▪ Yukon Housing Corporation	▪ Establish an inter-departmental FASD Committee to implement a comprehensive FASD strategy that includes prevention ▪ Establish mechanisms for guiding collaborative action on components of the strategy	▪ Increase awareness and knowledge among governmental decision makers regarding FASD effective prevention strategies ▪ Improve inter-governmental planning and programming toward integrated programs and services ▪ Presence of cohesive healthy public policies supporting FASD prevention
Capacity building	Service providers and FASD related program managers: ▪ Physicians ▪ Nurses ▪ Counsellors ▪ Teachers / early childhood educators ▪ Other front-line service providers	▪ Strengthen education of physicians, nurses and other frontline service providers ▪ Establish and maintain a Community of Practice Network to support service providers ▪ Establish an FASD webpage attached to the HSS website with information on FASD, programs & services, and links to resources and training opportunities	▪ Increase awareness and knowledge among service providers regarding FASD, and their role in supporting or delivering effective prevention services ▪ Increase knowledge and confidence in appropriately approaching clients regarding FASD ▪ Increase sharing of information in support of evidence informed practice
Evaluation, monitoring and research	Research networks and evaluators with	▪ Develop and implement an evaluation and research framework	▪ Increase availability and accessibility of current FASD and FASD-related knowledge base on best available evidence or promising practices
Service Networks	FASD and FASD-related programs and service providers Individuals and families affected by FASD	▪ Establish service networks as hubs for coordinated service delivery	▪ Increase coordination and availability of services as close to home as possible

* Not all suggested actions need be accomplished by the Department of Health and Social Services; some strategies may be assigned to specific organizations, agencies or networks.

Recommendations

It is recommended that:

1. *The Yukon government establish a Yukon wide cross-jurisdictional Committee or Council to direct action on FASD including FASD prevention programs and services.*

    1.1. *This inter-departmental Committee or Council be charged with developing a strategic plan for Inter-sectoral government action on FASD (and specifically on FASD prevention) to ensure a cohesive, comprehensive and efficient approach to the prevention of FASD.*

    1.2. *A limited number of committees be established to guide components of the overarching strategy, such as awareness and prevention, policy development, education and training, and evaluation and research. These committees would provide strategic direction to the leadership and coordination strategies as recommended below.*

    1.3. *FASD prevention strategies and actions in Yukon not occur in isolation but are integrated with:*

    - *Initiatives dealing with broader substance use issues;*
    - *Initiatives involving FASD and women's health issues more broadly defined than specifically FASD prevention; and*
    - *Complementary action to address underlying social economic determinants of health impacting the incidence and prevalence of FASD.*

2. *Develop and implement an outcomes evaluation and Yukon-based research framework to monitor and evaluate the effectiveness of FASD programs and services.*

3. *Enhance the capacity of providers of health and social services in Yukon to support FASD prevention.*

    3.1. *Establish and maintain an FASD community of practice (CoP), to support networking, information sharing and the provision of educational opportunities among service providers from all service sectors. The Yukon government may wish to assign this responsibility to an appropriate territory-wide non-governmental service provider agency.*

    3.2. *Work with medical and nursing leaders within Yukon to enhance their knowledge of FASD and best practice FASD approaches with families in their childbearing years, and specifically to women at risk for having a child with FASD.*

    3.3. *Establish a plan for education for front-line service providers in health and social services on FASD and FASD prevention strategies, including but not limited to program level principles (such as those presented earlier in this service delivery model), and best practice FASD approaches.*

3.4 Establish a webpage dedicated to FASD, attached to the HSS website. This webpage should provide an inventory of programs and services with contact information, links to resources and training opportunities, and a place to share information. It could serve as the platform for the CoP.

4. *Establish a limited number of service networks in Yukon to support FASD and FASD related services, including addictions services, through a less centralized model.*

4.1. These service networks could operate out of the largest centres, for example: Whitehorse, Dawson City and Watson Lake.

4.2. The service networks could serve as the hub for coordinated programs and services offered within the selected communities, with outreach services to the more remote communities.

Strategic Direction: Population Level (universal) Prevention

Findings from Gap Analysis

General

- Generally, the published and grey literature on FASD prevention frameworks describes *universal* prevention as strategies that are focused on the general population or for a sub-population, in this case, all women of childbearing age.
- Preconception health strategies are particularly important for optimal fetal health, as the critical period of fetal development (central nervous system, heart, arms, eyes, legs, teeth, palate, external genitalia and ear) occurs between precisely the time between the first missed period (at 5 to 6 weeks) and the average time that women enter into prenatal care (at 12 weeks).[32] This suggests the need for understanding of fetal risk during the first trimester among all individuals in child bearing years, whether or not pregnancies are planned. By the time many pregnant women see a prenatal care provider, a critical period of fetal development may already have occurred.

Multi-media Campaigns

- The best available evidence of effectiveness among universal prevention approaches is for multi-media and macro-level education on level of knowledge of FAS and on the effects of alcohol during pregnancy.

[32] March of Dimes (1991). Reported in Alberta Perinatal Health Program, *Preconception Health Framework*, April 2007

- The Public Health Agency of Canada, CanFASD, Canada's First Nations and Inuit, Alberta, British Columbia, Australia, the U.S. Institute of Medicine, and the World Health Organization prescribe the use of multiple media forms to inform the public about FASD.
- There is currently no coordinated population based multi-media campaign focused on FASD prevention in Yukon.
- Stakeholders believe there is a need to increase awareness of risks and reduce stigma. Middle class social and coping drinkers, rural and isolated communities, and youth are suggested as priority targets.

School Curricula

- The development of school curricula or educational models on FASD is proposed as a strategy in the frameworks of Canada's First Nations and Inuit.
- In Yukon, the Government of Yukon Department of Education and the Yukon Health Promotion Unit are currently collaborating to create the SHARE curriculum, a sexual health curriculum for grades 4-7 which will incorporate some aspects of FASD prevention.
- FASSY has developed and is currently providing presentations to grade 10 students across Yukon to address primary prevention and the preconception message. This organization is also collaborating with the Yukon College Student Council to make 2014/2015 college year a "FASSY-nating" year.
- Yukon stakeholders recommended that FASD prevention messages be integrated into positive school health and reproductive/sexual health curricula.

Policy

- The Yukon Liquor Corporation places warning labels on all alcoholic beverages, and two communities in Yukon have implemented community-wide alcohol bans, one considered a dry community and the other a damp community.
- Despite a few jurisdictions that recommend beverage warning levels (Australia, US Institute of Medicine) and community alcohol bans (World Health Organization suggestion of ban as possible strategy), studies from the literature on these policies are limited, of poor quality, and generally do not report significant impact.

Proposed Universal Prevention Strategies, Actions and Objectives

Strategy	Focus	Recommended Action*	Objectives
Multimedia education	▪ General public including all women and men of childbearing years	▪ Undertake a Yukon-wide multi-media strategy with a positive pre-conception message involving healthy pregnancy planning, with the key message: "no level of alcohol consumption is known to be safe"	▪ Increase awareness and knowledge of risks associated with alcohol consumption during pregnancy
School curricula	▪ All school and college students	▪ Ensure preconception health and healthy pregnancy messages are incorporated in junior and high school curricula ▪ Incorporate FASD prevention messages through college level health programs and services	▪ Increase awareness and knowledge of risks associated with alcohol consumption during pregnancy

* Not all suggested actions need be accomplished by the Department of Health and Social Services; some strategies may be assigned to specific organizations, agencies or networks.

Recommendations

It is recommended that the Yukon government:

1. *Conduct a territory-wide multi-media campaign, including the use of social media, to support knowledge of healthy pregnancy prevention practices.*

2. *Continue its efforts to incorporate FASD prevention messages into school health and sexual health curricula.*

Strategic Direction: Individual Level Action (Universal, Selective/Targeted, Indicated)

Findings from Gap Analysis

General

Three levels of FASD prevention activity are proposed in the literature and used by some of the jurisdictions with FASD strategies:

- **Universal** prevention is defined as strategies that are focused on the general population or for a sub-population. This definition may be applied to individuals when physicians or other service providers have the opportunity to serve women of childbearing age, regardless of their risk for alcohol consumption during pregnancy (on a one by one basis) .
- **Selective** or **targeted** prevention strategies are for *"at risk"* individuals, defined as women and girls in their childbearing years who drink, and all pregnant women; and
- **Indicated** prevention strategies are for women at *"high risk"*, defined as all women and girls in their childbearing years who are addicted to alcohol, women who drink while pregnant, and women in their childbearing years that have previously given birth to a baby with FASD.

While these three categories prove helpful in distinguishing particular strategies, in reality, women do not come packaged in three groups. Rather, these groups should be considered to reflect a continuum of risk.

Gaps identified by Yukon stakeholders include:

- Access to reproductive health services including birth control and pregnancy tests (specific issues include cost barriers and a lack of anonymity in accessing these services in small communities). Enhanced anonymous access to birth control and pregnancy testing could potentially be achieved through strategies such as subsidizing birth control and making pregnancy testing as readily available as condoms (for example, in drinking establishment washrooms).
- Access to, and availability of, prenatal and postnatal supports, including outreach services, healthy social supports, safe places (i.e., shelters), ongoing support through the postnatal period, supportive relationships, and case management.
- Insufficient attention to the role of men in receiving and engaging in FASD messaging, and in providing support. They suggest that programs and service providers should routinely incorporate males, family and support networks in their service offerings.
- Need for a more health determinants approach to service delivery.
- Need for adaptation of FASD prevention strategies and services for individuals with FASD and other cognitive impairments (adapted reproductive health resources, specialized treatment, intensive support and ongoing support services for women through their childbearing years).

Universal

- Given that many women report consuming alcohol before learning they are pregnant, one author[33] emphasizes a need to provide interventions to all women before and during pregnancy. She suggests supporting physicians to have an increased role in identifying and offering interventions to women who are at risk for alcohol-exposed pregnancy. A low cost option might involve yearly physician administrated prenatal alcohol-exposure clinical interviews or routine screening assessments for all women, rather than just those who are pregnant. In addition, Tough asserts that women should receive consistent messages about maternal alcohol consumption during pregnancy in a variety of contexts, such as when couples obtain a marriage licence, new home warranty and mortgage.

- The same author cautions against making assumptions that physicians have all they need to identify women at risk of an alcohol-exposed pregnancy. In a 2006 study, only 45% of family physicians were noted to frequently obtain a history of addictions, and about 25% routinely obtained a family history of alcohol misuse.[34] Given this, the author suggests the need to "support physicians asking *every woman, every time*".[35] Family physicians, public health nurses and dieticians who see the majority of pregnant women in Yukon during the prenatal period may be well positioned to provide universal messages on an individual, one-on-one basis. When applied to all women in their childbearing years, this would represent a substantive preconception health strategy.

Selective

- For women at risk, the literature provides evidence to support the use of a range of selective strategies, including assessment and brief interventions, health education, counselling, and motivational interview.

- These services are well represented by the many organizations and agencies providing services in Yukon; however, most services are located in Whitehorse and access within other communities is more limited, often offered through outreach or upon request. Stakeholders note difficulties in recruiting and attracting staff to work in Yukon, especially outside Whitehorse.

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[33] Tough, S. (2010). Dispelling myths and developing a framework for reducing the risk of alcohol-exposed pregnancies. *Forum on Public Policy*.

[34] Tough SC, Clarke M, Hicks M, & Cook J. (2006b). Pre-conception practices among family physicians and obstetricians - gynecologists: results from a national survey. *Journal of Obstetrics & Gynaecology Canada: JOGC* 28, 9:780 -788.

[35] Tough, S. (2010). Dispelling myths and developing a framework for reducing the risk of alcohol-exposed pregnancies. *Forum on Public Policy*. p. 6.

Indicated

- The scientific base supporting effectiveness of indicated prevention approaches is limited. Only one study of moderate quality involving a multi-faceted prevention strategy was identified, and it yielded inconclusive estimates of effectiveness.

- Despite limited evidence, FASD frameworks from other jurisdictions suggest the use of similar strategies as are proposed for selective prevention, and including a multi-service prevention approach, alcohol screening and outreach support programs. The US Institute of Medicine suggested a full range of indicated services: case identification, brief interventions, formal treatment, compliance with long term treatment, and after care.

- Eight examples of "one stop" or single access service delivery models were described in a recent literature review.[36] While the focus of the review was on street-involved pregnant and parenting women, the backgrounds and socioeconomic dispositions of this group are similar to those described for at-risk groups in the FASD literature. Socially marginalized women who may be pregnant and who are using substances are less likely to access health services due to structural barriers of stigma and negative public attitudes, feelings of shame or guilt, fear of losing their children, mental illness and low self-esteem, inability to access information, and mistrust of health providers. Community-based programs are challenged to connect this group to health supports that could positively impact maternal and infant health outcomes. While solid evidence of effectiveness of such single access model is limited, descriptive information suggests that the programs that appear to positively influence client knowledge, behaviour and lifestyle are those that:
  - Incorporate drop-in or mobile outreach services;
  - Offer centralized, integrated, comprehensive and multidisciplinary services;
  - Address women's immediate needs (i.e., food, shelter, clothing, transportation) and more complex needs (i.e., pregnancy, mental illness, addiction);
  - Provide primary health care, such as basic medical support, prenatal and postnatal care and health counselling;
  - Encourage client involvement in decisions about which services and supports would best help them to reach their goals;
  - Emphasize hopeful, non-judgemental, harm-reduction approaches;
  - Focus on both maternal and infant health outcomes; and,
  - Include an advocacy component to increase client access to resources, information, education and social supports.

[36] Brower, K. (2012). *Best Practices: Services and Supports for Street-Involved Pregnant and Parenting Women – A Review of the Literature.* Report prepared by Charis Management Consulting for the Alberta Centre for Child, Family and Community Research, Calgary, AB.

- More structured evaluations of two such programs suggested the possibility of improvements in perinatal health indicators such as birth weight and prematurity rates for Vancouver's Sheway program[37] and a conservative estimate of $8.42 in social return on investment for every dollar spent for Edmonton's Healthy Empowered Resilient Pregnancy Program.[38]

- A number of jurisdictions have prescribed addictions and withdrawal treatment as part of their FASD frameworks or strategies, including the Public Health Agency of Canada, British Columbia and the US Institute of Medicine. CanFASD recommends that multi-level model addictions treatment services, withdrawal management and stabilization services be considered as part of a holistic support package for pregnant women with alcohol problems.[39] Through ADS, Yukon offers a detox program in Whitehorse which offers priority access for pregnant women. The Treatment Unit also offers counselling and treatment services for youth in grades 5 – 12. In external communities, women, their partners and members of their support networks can access an ADS Community Development Worker and an Alcohol and Drug information line, but must travel to Whitehorse for more intensive services. The program emphasizes service provision for First Nations members and low income Yukoners.

- As identified by Yukon stakeholders, one group at highest risk is adult women with FASD or other developmental disabilities. These individuals are particularly challenged to access health services and require adapted strategies and intensive support throughout their childbearing years. Suggestions offered by stakeholders included adapted school curricula, integrated case management, repetition of messaging, and provider education regarding how to work with this group.

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[37] Marshall, S., Charles, G., Hare, J., Ponzetti, J., & Stokl, M. (2005). Sheways' services for substance using pregnant and parenting women: Evaluating the outcomes for infants. *Canadian Journal of Community Mental Health*, 24 (91), 19-33. P. 30.

[38] Wodinski, L., Wanke, M., & Khan, F. (2013). Impact Evaluation of the H.E.R. Pregnancy Program – Final Summary Report. Retrieved from the CanFASD Research Network:

[39] Network Action Team on FASD Prevention from A Women's Health Determinants Perspective. (2010). *Prevention of Fetal Alcohol Spectrum Disorder(FASD) A multi-level model.* Accessed at: http://fasd.alberta.ca/documents/CanFASD_4_levels_of_prevention_brief.pdf

Proposed Individual Prevention Strategies, Actions and Objectives

Strategy	Focus	Recommended Action*	Objectives
Brief interventions: ***"Every woman every time"*** (*universal*)	▪ Women and men seeking routine health services during childbearing years	▪ Educate physicians and other frontline service providers to initiate discussion regarding alcohol consumption during every encounter with individuals in their childbearing years	▪ Increase the percent of women whose health service providers initiate discussion ▪ Increase awareness and knowledge of the risks of drinking during pregnancy ▪ Increase rates of women reducing or abstaining from alcohol consumption during pregnancy and before pregnancy is known
Access to birth control & pregnancy testing *(universal* and *selective)*	▪ All women ▪ All women in childbearing years who drink	▪ Strive to ensure birth control and pregnancy tests are readily available at no or nominal cost in all Yukon health centres and drinking establishments	▪ Increase proportion of planned pregnancies and associated decrease in alcohol consumption before pregnancy is known ▪ Increase earlier pregnancy detection and associated decrease in alcohol consumption earlier in pregnancy
Health education **Motivational interviews** **Counselling** *(selective)*	▪ All women in childbearing years who drink ▪ Pregnant women who drink	▪ Increase access to selective FASD prevention strategies in rural areas through Yukon's health and social service delivery system	▪ Improve access to FASD prevention interventions to increase awareness and knowledge of risks of drinking during pregnancy ▪ Increase rates of women reducing or abstaining from alcohol consumption during pregnancy
Single access multi-service centre(s) with link to addictions treatment and after care services *(indicated; selective)*	▪ Women at highest risk, based on their addiction to alcohol, particularly those not regularly seeking health services ▪ Pregnant women who drink	▪ Pilot a community-based single access multi-service delivery site in Whitehorse ▪ Pilot service hubs in Dawson City, Haines Junction and Watson Lake, with outreach services to remote communities, to provide comprehensive integrated services for women at risk	▪ Increase connection and access to health and social support services, including addictions treatment services ▪ Improve access to health information, prenatal care, harm reduction and pregnancy products ▪ Increase number of women at high risk who reduce or abstain from alcohol consumption during pregnancy

Strategy	Focus	Recommended Action*	Objectives
Adapted strategies *(indicated)*	▪ Adult women with FASD or other developmental disabilities throughout their childbearing years	▪ Adapt curricula and FASD messaging ▪ Strengthen case identification and integrated care planning and management	▪ Increase access to FASD prevention messages ▪ Increase risk awareness and knowledge

* Not all suggested actions need be accomplished by the Department of Health and Social Services; some strategies may be assigned to specific organizations, agencies or networks

Recommendations

It is recommended that:

1. *Yukon Health and Social Services department take steps to educate physicians and other frontline service providers about the importance of initiating discussion about alcohol consumption with every woman (and their partners) in their childbearing years about their alcohol consumption – "every woman every time".*

   1.1 As part of this education, front-line service providers learn about the importance of partners in supporting pregnant women in reducing or eliminating alcohol consumption during their childbearing years.

2. *Yukon Health and Social Services investigate the potential to increase anonymous access to birth control and pregnancy testing, for example, through test kits made available for purchase in public restrooms.*

3. *Yukon Health and Social Services increase access to selective and indicated prevention services in areas outside Whitehorse.*

   3.1. Yukon Health and Social Services consider piloting service hubs in the largest centres outside of Whitehorse, possibly Dawson City, Haines Junction and Watson Lake, with a view to strengthening collaborative action in these communities, bringing services closer to these population centres, and possibly extending the frequency of outreach services to more remote communities.

4. *Yukon Health and Social Services fund a pilot implementation of a single access multi-service centre in Whitehorse, modeled after such services in other Canadian jurisdictions.*

   4.1. Because many women at highest risk are often reluctant to access traditional health services, this centre should be located in a readily accessible, community-based not-for-profit agency.

4.2. This centre should be closely linked with and supported by wrap-around services in the community, including shelters and more permanent housing supports, social support services such as income support, and additions treatment services.

4.3. This centre should be closely linked with the service hubs proposed in Recommendation 9, with a view to sharing information and expertise, and facilitating ready transfer for the highest needs women to Whitehorse, as appropriate.

5. *The Yukon Government, as part of implementing its FASD strategy, as proposed in Recommendation 1, consider the need to adapt all FASD prevention strategies for women with FASD and other developmental disabilities.*

5.1. Yukon Health and Social Services identify and implement mechanisms to identify women with FASD and other developmental disabilities who are in their childbearing years with a view to provide long term integrated care planning and support.