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Fetal Alcohol Spectrum Disorder (FASD)

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Healthy Canadians and communities in a healthier world

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Preface

As Minister of Health, I am pleased to introduce *Fetal Alcohol Spectrum Disorder (FASD): A Framework for Action*.

Many readers of this Framework will be familiar with FASD. You are frontline workers who see the impact of FASD on people with the disability and their families; police or corrections workers who see the social problems resulting from FASD; policy and program developers working to shape public policy and community services to meet the diverse needs of people with FASD; and health educators working to prevent FASD and help women and families eliminate alcohol use during pregnancy.

Other readers will be newcomers, ready to learn and join those committed to preventing FASD and improving outcomes for those with FASD. This Framework is designed to meet the needs of people with a range of knowledge and experience.

It has now been 30 years since Fetal Alcohol Syndrome became a medical diagnosis. During this time, much excellent work has been done across the country, in provinces and territories and in many communities. Still, it is estimated that approximately 9 in every 1,000 children in Canada are born with FASD.

FASD is a life-long disability without a cure — but it is preventable. It is time for renewed efforts and a comprehensive approach to preventing the disorder and supporting those with it.

I encourage you to discuss this Framework with others and consider how it can be used in your own community. It is not intended to be static in its approach, nor does it deliver a “one-size-fits-all” solution. Rather, it provides tools, information and ideas to guide and support communities and all levels of government on a wide range of activities.

Fetal Alcohol Spectrum Disorder (FASD): A Framework for Action reflects the contributions of hundreds of organizations and individuals from across the country. Contributors drew on their professional expertise, their knowledge of the gaps needing to be filled, as well as their personal experience as parents, foster parents and others affected by FASD.

Health Canada is pleased to have been involved in developing the Framework. I offer my congratulations to all partners on the work that has been done to date and look forward to continuing to work together in the coming years.

A. Anne McLellan
Minister of Health

Introduction



Use this Framework for Action ...

The Framework is for you if you are a frontline worker or a program or policy developer working at the local, provincial/territorial, national or federal level in one of the following fields:

- *Aboriginal issues*
- *Child and family welfare*
- *Community development*
- *Corrections*
- *Disability issues*
- *Education*
- *Employment*
- *Ethno-cultural issues*
- *Health education*
- *Homelessness*
- *Justice*
- *Medicine*
- *Policing*
- *Poverty*

Wherever you work or live, if you are interested in prevention of FASD and in improving the quality of life of people with FASD and their families, this Framework has been developed with you in mind.

Fetal Alcohol Spectrum Disorder (FASD) is a disability resulting from prenatal exposure to alcohol. With an estimated 9 in 1,000 babies born in Canada affected by the disability, FASD puts a heavy social and economic burden on those with FASD, their families, their communities and our society as a whole. FASD is a life-long disability. While there is no cure, the disorder is preventable. Those with FASD can, with the right supports, approaches and services, lead happy and productive lives.

This document, *FASD: A Framework for Action*, includes the basic building blocks required for concerted action within communities, provinces and territories as well as within the federal government. Initiated by the federal government, and shaped by the National Advisory Committee on FASD, the *Framework for Action* reflects the ideas and advice of many organizations and individuals. At the same time, it is designed to be used by groups across all sectors, in all regions of the country. Just as FASD affects many aspects of a person's life — health, education, social interaction and work life — many organizations need to be involved in preventing FASD and supporting and providing treatment for people with the disability.

Who this Framework is for

The *Framework for Action* is intended, quite simply, to encourage people to understand FASD better, to present the broad picture of where collaborative action could lead, to offer ideas and examples of what is needed to achieve that picture, and to inspire action at all levels, across all sectors.

The 2002/2003 consultations with organizations across the country clearly point out that “readiness” to take action varies from community to community, region to region and sector to sector. Ideally, the Framework provides a starting point for action, no matter at what stage a community may be. For some, it will offer food for thought — a discussion document to build support and consensus in the community. For others, it will be used to help develop action plans. Still others can use it to renew their commitment, see new ways of working, and approach different issues related to FASD.

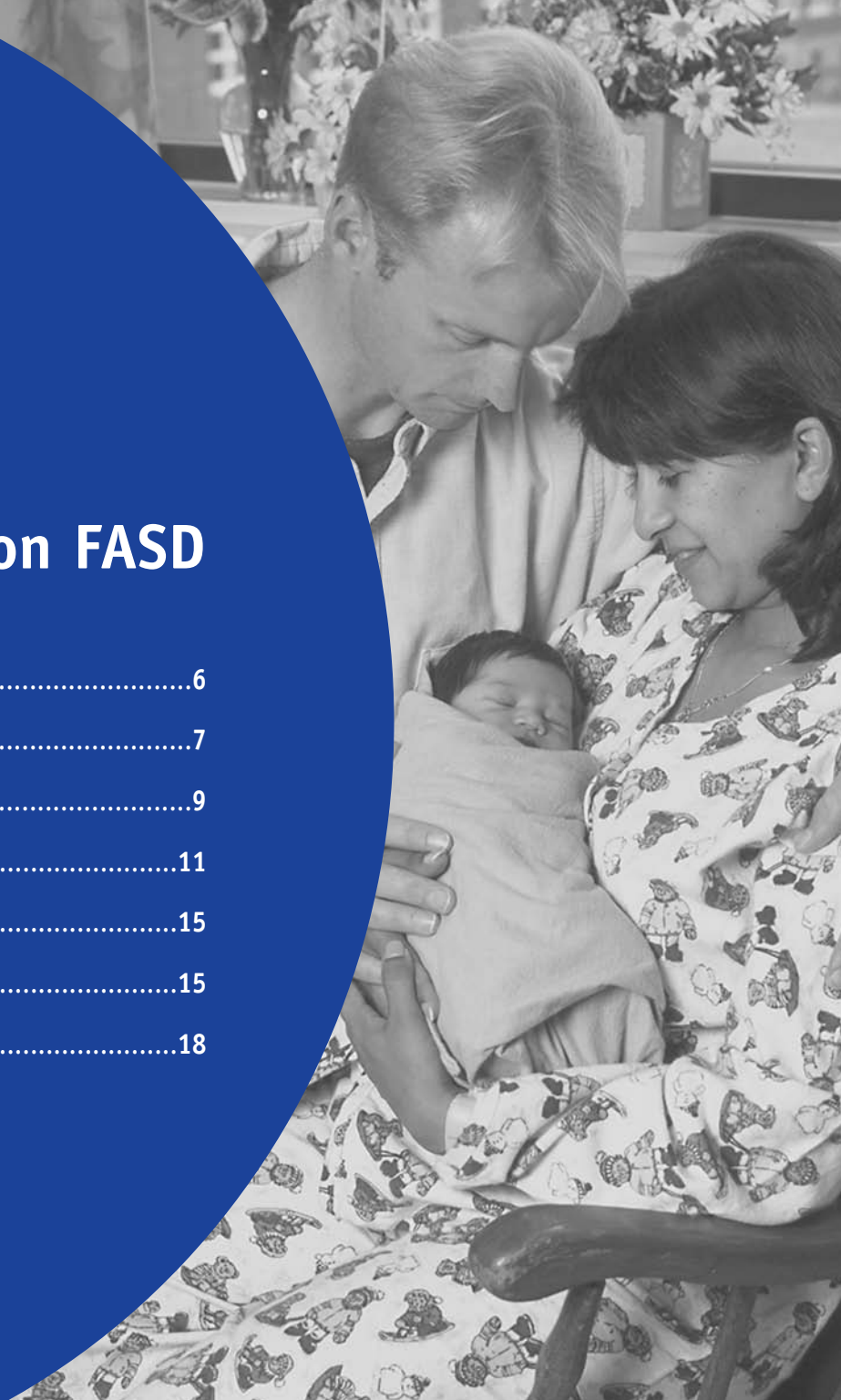
What *FASD: A Framework for Action* includes

The *Framework for Action* provides the structure and basic building blocks for comprehensive and consistent action on FASD prevention and support. By definition, it is broad, loose, non-directive and full of ideas. It is intended to be molded to the unique characteristics and opportunities of each community, allowing each “owner” to tailor the ideas to suit local needs. The building blocks include a vision for the future, five broad goals (a more precise definition of where progress is needed on a number of fronts), examples of strategies that should or could be used to reach the vision and achieve the goals, as well as a set of guiding principles that, ideally, will be adopted by every community, project, policy and program aimed at supporting FASD prevention and action.

The Framework also includes feedback from the consultations carried out across the country in early 2003. Highlights of ideas and comments on a Draft Framework (on which this *Framework for Action* is based) are included here to help readers understand some of the experiences, advice and ideas of those working in health, education, justice, policing, corrections and child and family welfare — advice that is reflected throughout this *Framework for Action* on FASD.

The Framework for Action on FASD

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A A Tool with Many Uses

The *Framework for Action* is a tool to guide future action on FASD in Canada. Intentionally broad in nature, the Framework is designed to inspire and guide the work of a wide range of organizations at the community, provincial/territorial and national levels — their work in planning, coordinating and implementing policies and programs. The ultimate goal of this collaborative work is to build and maintain a strong system of supports and services to prevent FASD and to meet the needs of people in Canada who are affected by this life-long disability.

Far from being restrictive or directive, the *Framework for Action* is designed to support efforts across the country — it includes a vision, a set of broad goals, as well as some principles to guide the work of organizations, families and communities. The result of extensive consultation, pooling of ideas, knowledge and expertise, the Framework offers a focus for collaborative action into the future.

The benefits of a Framework...

The broad and enabling nature of the Framework allows for:

- ④ Focused and **coordinated effort** to address the complexities of preventing FASD, the factors that create barriers to its prevention, treatment and support for those already affected
- ④ Collection and **sharing** of research findings, as well as to the knowledge and best practices across the sectors involved to effectively address FASD (including health, education, justice, law enforcement, corrections, child and family welfare)
- ④ **Flexibility** at the community and provincial/territorial level, while channeling efforts toward a number of national goals and objectives that will result in an improved understanding of how to prevent FASD and how to provide better supports and services to those affected by it.

The challenges...

Achieving the vision and goals set out here calls for commitment and action to coordinate efforts, learn from others, share expertise and resources. Working across jurisdictions, with a wide range of sectors and professionals is challenging. An important first step has already been achieved — widespread recognition of the need for commitment to prevent FASD and to support those affected by FASD. Challenges lie ahead, including:

- ⑥ **Widening the circle of interest in and commitment to preventing FASD and supporting those affected by it** — through ongoing education and discussion;
- ⑥ **Establishing measurable goals and objectives** for prevention, support and services;
- ⑥ **Forging and strengthening partnerships** within communities and across the country to share resources, expertise, experience and ideas across all sectors;
- ⑥ **Developing action plans** for prevention, support and services at the community, provincial/territorial and national/federal levels; and
- ⑥ **Identifying, securing and integrating funding** from a variety of sectors to support action to prevent FASD and improve the quality of the life of those with the disorder.

A call to action...

An immediate challenge is ensuring that the vision and broad goals of the Framework are clearly understood and embraced by governments, organizations, families and communities across Canada. While the Framework reflects the views of hundreds of individuals and organizations, captured during national consultation efforts in 1999 and again in 2002-2003, it is clear that communities across the country are at varying levels of understanding, commitment and capacity for action.

*Moving
forward calls
for commitment,
leadership and
collaboration.*

B About FASD

What it is...

Fetal Alcohol Syndrome (FAS) is the leading cause of developmental disability among Canadian children. FAS was first established as a medical diagnosis in 1973. Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term increasingly used to describe the spectrum of disabilities (and diagnoses) associated with prenatal exposure to alcohol. FASD is not itself a diagnostic term; rather the diagnoses under the FASD umbrella include:

- ⑥ Fetal Alcohol Syndrome (FAS)
- ⑥ partial FAS (pFAS)
- ⑥ Alcohol-Related Neuro-developmental Disorder (ARND)
- ⑥ Alcohol-Related Birth Defects (ARBD).

FASD — Quick Facts

It is estimated that:

- *9 babies in every 1,000 born in Canada have FASD*
- *FASD is the leading cause of developmental disability among Canadian children*
- *The costs of FASD to society are high — without taking into account the lost potential and opportunity, direct costs associated with FASD over a lifetime have been estimated at about \$1.5 million per person with FASD*

It is known that:

- *FASD is a life-long disability*
- *Many people with FASD have an IQ within the normal range but still face a range of social and economic challenges that require support, services and compassion*
- *FASD can be prevented with education, support and healing*
- *Early diagnosis, a supportive environment and a range of special supports and services are needed in order to give people with FASD, their families/caregivers and their communities the best prospects for improving outcomes and maximizing potential*

While preventable, FASD is a complex, multi-faceted, public health and social issue that affects Canadians in all walks of life, in all regions of the country. In some First Nations and Inuit communities, given the history of colonization and devaluation of culture, rates of FASD may be higher than the national average.

How it happens...

A mother's use of alcohol during pregnancy affects the developing fetus, causing a range of serious physical and mental defects. The impact of alcohol varies with the amount, timing and frequency of alcohol consumed, and depends on a number of other factors, including the genetics of the fetus and mother, and the overall state of health of the mother as well as other social, economic, physical and environmental factors.

Ideally, FASD-related diagnoses are made by a trained, interdisciplinary clinical team using established criteria.

What's been done...

Since the early 1980s, a patchwork of awareness campaigns and activities has grown to support women at risk of using alcohol during pregnancy, as well as to meet the needs of people and communities affected by FASD. Research, monitoring and evaluation of individual initiatives have also increased.

A starting point for more action...

At the same time, many people affected by FASD do not receive adequate and consistent support and services. The lack of an integrated national strategy, standardized diagnostic and screening tools and comprehensive epidemiological research, has meant that progress toward consistent and effective prevention and support has been slow. This *Framework for Action* is a starting point for coordinated, collaborative action.

C Vision for the Future

Imagine a world in which...

... individuals, families/caregivers and communities across Canada 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... a world in which FASD is effectively prevented in all communities across Canada.

Imagine a world in which people with FASD and their families are eligible for diagnosis, treatment, supports and services that are accessible — geographically, economically and ethno-culturally. These supports and services are appropriate for all stages of the lifespan and meet the needs of the individual, the family and the community.

Imagine that in this world, Canadians recognize FASD as a disability and demonstrate compassion and respect for those with FASD and address their needs where they live, learn, work and play so that they are able to participate in society to the best of their abilities. Frontline workers are aware of and understand FASD and are able to provide the necessary supports and services.

Imagine that, at the same time, Canadians have compassion and respect for women at risk of having a child with FASD and understand that this disability is preventable through effective and concerted action to address the underlying risk factors — through action by governments, organizations, communities, families/caregivers and individuals.

Within this vision the *Framework for Action* on FASD is aimed at:

- ⑥ **Preventing FASD** — through a range of social and economic supports that enable women who may use alcohol during pregnancy to make informed and positive decisions about their health and the health of their family, and by improving awareness of the dangers and impacts of alcohol consumption during pregnancy.
- ⑥ **Building a system of supports and resources** — developing an integrated system characterized by leadership, direction, partnership and collaboration at the national, provincial/territorial and community level, working together to prevent FASD and to meet the needs of people living with FASD and their families.
- ⑥ **Meeting the needs of individuals with FASD, their families and communities** — to improve their outcomes and enable them to develop to their full capacity, through the development and provision of screening tools and interventions that are appropriate in terms of both gender and culture.

Women at risk...)

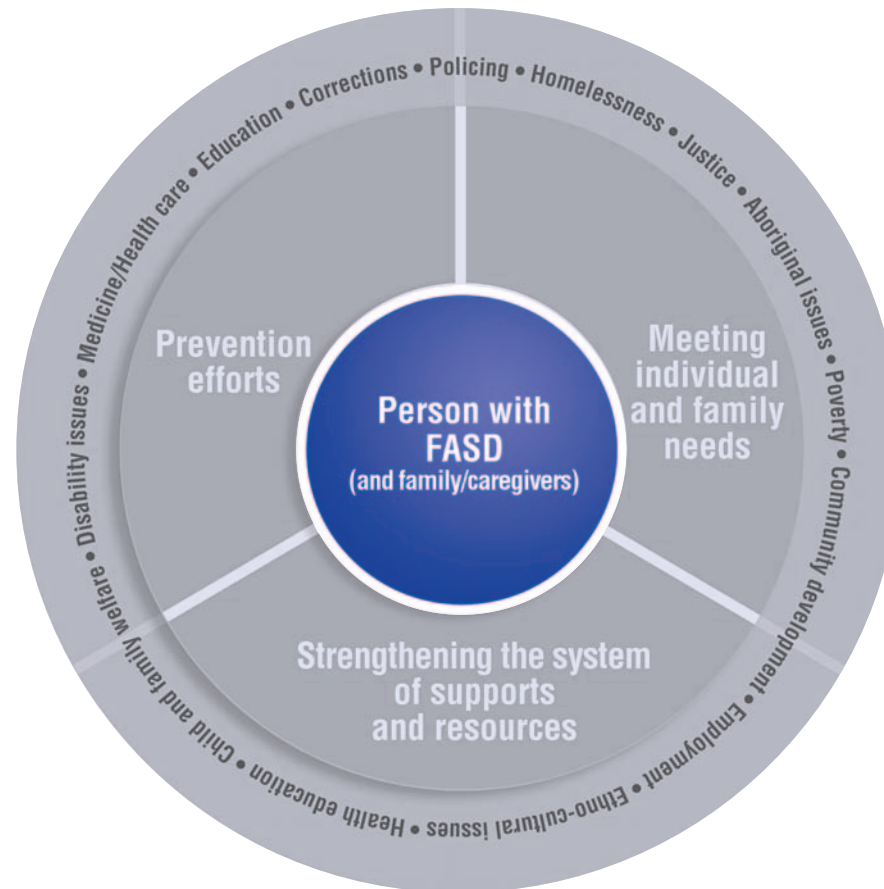
All women of child-bearing age who use alcohol are at risk of having a child with FASD unless and until they are:

- *Made aware of FASD and how it occurs*
- *Informed about the life-long, negative impact on the child born with FASD and the family and community*
- *Provided with the supports they need to reduce their risk and plan their pregnancies*

Setting the Stage for Future Action on FASD

“My daughter is getting the help she needs in school, my boss is letting me work from home some days, and now our whole family is functioning well again.”

Mother of a child with FASD



Individual and collaborative action is required in all sectors, at all levels — federal/national, provincial/territorial and community. Future effort needs to build on the excellent work done to date, focusing on prevention, meeting current needs of people with FASD, and strengthening and expanding the system of supports, services and resources.

D Five Broad Goals

Action is needed to support five broad goals, each with a distinct yet overlapping focus. The Framework provides “guideposts” for the development of more specific and measurable objectives and action plans by all jurisdictions and sectors. For each broad goal, examples of possible strategies are presented to help qualify and explain the goal.

1. Increase Public and Professional Awareness and Understanding of FASD and the Impact of Alcohol Use During Pregnancy

To build awareness and knowledge among women, families and the general population about FASD and its life-long impact on individuals, families and communities — key building blocks of prevention. Ensuring that up-to-date information is readily accessible — information that is gender appropriate and ethno-culturally sensitive, and that encompasses the complex factors that contribute to alcohol use during pregnancy — is vital to effective prevention. Equally important is improving the understanding among the myriad professionals in health, education, justice, law enforcement, corrections, child welfare and social services of how this multi-faceted disability affects individuals and families.

Possible strategies include...

- ④ Developing and disseminating clear, easy-to-understand information about the impact of FASD on individuals, families, communities and society for use by community organizations, individuals, families and caregivers
- ④ Developing and disseminating clear and current information about FASD for professionals in all sectors (including health, education, justice, law enforcement, corrections, child welfare and social services) positioned to help prevent FASD in a non-judgmental and ethno-culturally sensitive manner
- ④ Ensuring that information is presented in a way that is ethno-culturally appropriate (and/or adaptable) for the needs of a variety of ethno-cultural groups, including Aboriginal individuals, families and groups working with Aboriginal people
- ④ Promoting an understanding of and compassion for people affected by FASD and their families, improving awareness of their need for protection and support, as well as respect for their rights...

“Most women that drink [heavily during pregnancy] are abused women. They don’t drink to hurt their babies — they are victims.”

Participant from Yukon in the FASD Consultations, 2003



2. Develop and Increase Capacity

To increase capacity to identify and meet the needs of children, youth, adults and families affected by FASD, as well as women who may use alcohol during pregnancy. Increasing capacity includes drawing together the resources, skills and knowledge that already exist at all levels — in families, communities, regions, governments, private industry and

non-government organizations — and filling in gaps with additional training, sharing of best practices, knowledge and other resources.

Possible strategies include...

- Developing and increasing capacity for prevention, treatment and support across the sectors that work with people with FASD and their families — including health, education, justice, law enforcement, corrections, family and child welfare
- Improving evaluation, reporting and disseminating of best practices, lessons learned and experiences that will improve community capacity — these could include lessons learned in health, education, law enforcement and other sectors
- Building community capacity to meet the needs and rights of the individual affected by FASD, taking into account the broader community in which they live
- Increasing community capacity to access supports and services for women with alcohol use problems, with priority given to providing supports for pregnant women who may use alcohol during pregnancy...

3. Create Effective National Screening, Diagnostic and Data Reporting Tools and Approaches

To develop and disseminate national guidelines for screening and diagnosis of FAS and related disabilities that make up FASD. This work must go hand-in-hand with efforts to improve community capacity for screening and diagnosis of FASD. Guidelines and tools need to be appropriate for children, adolescents and adults, taking into account gender, diversity and community needs. An important aspect of this goal is the establishment of mechanisms for reporting the incidence and impacts of FASD.

“Community development is hugely important.”

Participant from NWT in the FASD Consultations, 2003

What shapes our health and well-being?

Physical and mental health is determined by a number of factors — including inherited characteristics and endowments, as well as those environments people grow up with and live in (the physical, social and economic environments). In 1994, federal and provincial ministers of health set out strategies that recognized the importance of 11 key factors, or determinants of health:

- Income and social status
- Employment and work environment
- Education
- Social environment
- Natural and built environments
- Personal health practices
- Individual capacity and coping skills
- Biology and genetic endowment
- Health and social services
- Culture
- Gender

These factors interact in various combinations, at various stages of life to affect our health and well-being.

Possible strategies include...

- ⑥ Developing and promoting a national, standardized system for monitoring and gathering data on the incidence and prevalence of FASD, along with tools for screening that are multi-disciplinary, age- and culture-appropriate in nature
- ⑥ Creating training materials and opportunities for key groups to support appropriate and correct use of screening and diagnostic tools (e.g., education, social service, child welfare, corrections, law enforcement)
- ⑥ Providing widespread access to guidelines and tools by community groups and organizations, as well as by federal, provincial and territorial governments and agencies
- ⑥ Improving access to diagnosis for rural and isolated remote communities...

4. Expand the Knowledge Base and Facilitate Information Exchange

To increase knowledge and understanding of the life conditions that influence health and well-being of those with FASD, of the root causes of alcohol use during pregnancy, of what works and does not work to support women to reduce or stop drinking, and of the permanent impact of prenatal exposure to alcohol on children. The body of research needs to include best practices, new research and monitoring and evaluation of progress towards achieving national FASD goals. As results are collected, mechanisms need to be developed to ensure their effective dissemination to and use by organizations and individuals in the field.

Possible strategies include...

- ⑥ Learning more about the impact of FASD on the individual and family, throughout the lifespan
- ⑥ Expanding the knowledge base to inform activities in prevention, treatment, support and protection of people with FASD

Behind FASD...

Call them root causes, life conditions and experiences or determinants of health ... they are the factors that set the stage for women's use of alcohol during pregnancy. Factors that contribute to women drinking during pregnancy include, among others:

- *Family violence* — physical, psychological or sexual abuse
- *Poverty, unemployment and homelessness*
- *Stress*, and lack of knowledge of strategies for coping with stress
- *Role of alcohol in society*
- *Social pressures* to drink alcohol and *poor role models* for some women
- *Low self-esteem* and social isolation faced by some women
- *Poor knowledge about the impact of alcohol* — many people don't know that even small amounts of alcohol consumed during pregnancy can affect the developing fetus.

Clearly, women have an important role in preventing FASD. What is equally important, and not as clear to many, is that family, community, governments and society have a vital role in understanding and dealing with the root causes of women's use of alcohol during pregnancy.

- Ⓛ Including people affected by FASD in research aimed at identifying action and best practices (i.e., participatory research)
- Ⓛ Establishing mechanisms for sharing research results and best practices that promote the use of current information in community-based prevention, treatment, support and related training...

5. Increase Commitment and Support for Action on FASD

To secure commitment from the full range of stakeholders to take action to prevent FASD and to support and treat people with FASD and their families and communities. This includes coordinating their efforts and contributions to shape a strong, comprehensive system of inter-related, complementary services and supports.

Possible strategies include...

- Ⓛ Identifying leaders and champions in all sectors and at all levels
- Ⓛ Establishing mechanisms for forging and supporting partnerships among existing service and support providers and funders
- Ⓛ Identifying gaps in support, service and funding and developing mechanisms for attracting new partners to fill gaps
- Ⓛ Developing approaches for monitoring and coordinating effort, activity and funding...

“There needs to be recognition of the huge loss of human potential and stress to families and communities.”

Participant from British Columbia in the FASD Consultations, 2003



E The Path Ahead — from Framework to Action

This *Framework for Action* brings together the advice, experience and expertise of a diverse array of organizations and individuals. Consultations in 2003 highlighted three key issues that provide stepping stones to the future:

- **There is widespread, whole-hearted commitment** in all sectors and all regions of the country that now is the time to make a concerted effort to prevent FASD and to support people affected by this disability. While much excellent work has been done in various communities and in many sectors, much more can be achieved with a common vision and goals in sight.
- **Community capacity, priorities and strengths vary** — calling for flexible approaches that provide the supports that the community needs and that can be provided and/or tailored to take action. Each community and sector needs to develop plans for action that build on local needs, strengths and networks, while drawing on a growing national body of tools and knowledge. Similarly, communities and organizations need to share their experience, expertise and other resources, making them accessible to all.
- **Planning and action at all levels, and in all sectors, need to be guided by common principles** that will ensure consistent approaches while maintaining the flexibility essential to successful outcomes. The guiding principles (see sidebar) established for the *Framework for Action* provide a checklist that all organizations and initiatives can follow to achieve the vision and goals of this Framework.

F Where to next? What to Expect, What to Do...

This *Framework for Action* is a dynamic tool — it provides a starting point for further discussion, for action and for change. The Framework draws together the essence of what has been done to date and what needs to be done in the future to affect change and achieve the vision and goals described here. The following are ideas, suggestions and options for taking action. Clearly, much work has been done in many jurisdictions — the Framework is intended to be used as a guide for those new to the issues, as well as by those already active.

Guiding Principles

All efforts to prevent FASD and to meet the needs of people living with FASD and their families/caregivers must be:

- **Collaborative** in nature, characterized by partnerships and leadership — always aimed at building and maintaining capacity;
- **Inclusive** – supporting and addressing the needs of women who may use alcohol during pregnancy, as well as birth, foster and adoptive parents, partners and extended families, people with FASD themselves and their partners and/or advocates;
- **Guided by understanding, compassion and respect** for women at risk, for people with FASD and their families, as well as for the need for safe and secure communities;
- **Culturally appropriate**, recognizing the importance and strength of cultural values and norms;
- **Evidence-based** and informed by research and communication among all partners; and
- **Sustainable and comprehensive.**



On the federal government front...

Much of the activity at the federal level will continue to focus on developing and strengthening the coordinating functions that ensure access to tools, expertise and resources across the country. In addition to forming the basis for action plans at the federal level, the Framework will be used to guide interdepartmental work to address gaps and issues not currently undertaken in other sectors, including:

- ⑥ **Development of national guidelines** for screening, and diagnosis of FASD, and the collection, analysis and reporting of incidence, prevalence and economic impact data through evidence-based research and consultations across sectors;
- ⑥ **Expanding scientific and social science knowledge** relevant to prevention of FASD and effective support for those affected across sectors, and providing tools and expertise for evaluating interventions and developing best practices information;
- ⑥ **Building the evidence base and establishing mechanisms for knowledge exchange** across sectors and communities — ensuring that research and evaluation results are available and accessible to inform future planning and action; and
- ⑥ **Increasing awareness of FASD among professionals** across the array of sectors that work with people, families and communities affected by FASD. Efforts will address the needs of professionals and frontline workers in health, justice, policing, corrections, education and child and family services.

At the provincial and territorial level...

Consultations demonstrate that there is strong interest across the provinces and territories in addressing FASD. Coalitions have been formed that bring together sectors and organizations that have not traditionally worked collaboratively on FASD issues — in some provinces and territories, developments have been focused on defining the problems and challenges and on sharing information, while in others, activity has been underway for some time, resources are committed and prevention and support services are thriving.

The *Framework for Action* provides common ground for all provincial and territorial jurisdictions, regardless of their current activities, as they commit to future action on FASD and, in many cases, build on the extensive planning and activity already undertaken. In particular, the 2003 consultations suggest several directions to be taken at the provincial/territorial level:

- ⑥ **Establishing and strengthening coalitions and networks** that span sectors and communities, and that bring together experience and resources;

- ⑥ **Reinforcing province-/territory-wide plans** that work toward the vision and goals of the Framework — while taking into account the stage of readiness for action unique to each jurisdiction; and
- ⑥ **Enabling provincial and territorial organizations to contribute to, and draw on, the growing body of knowledge, expertise and tools** to prevent FASD and support those affected by the disability.

In the community...

Work at the community level will depend on the unique needs of each community, its level of readiness for action, and on the existing knowledge, relationships between organizations and current work on the FASD front within the community.

The Framework provides common ground for all communities across the country. While the results of consultations show that communities are at various stages of consensus, collaboration and action; there is clear and widespread commitment to the vision and goals of the Framework. Each community or local coalition needs to identify its own next steps — some of the possibilities are set out below:

- ⑥ **Community-wide discussions on FASD, the *Framework for Action* and its use in the community** — this approach can widen the circle of people and organizations who understand the issues and are committed developing options. Gathering all points of view and reaching consensus can provide a strong foundation for future action. Each community needs to consider the guiding principles, the vision and goals — and how the community or network can adopt and act on them.
- ⑥ **Conducting a needs assessment** — many communities have not gone through the important exercise of assessing needs and priorities for action. Again, by bringing to the planning table a cross-section of organizations, each with strengths, capacity and ideas, communities can take into account the views, knowledge and experience of a range of interests and expertise — an important first step in planning effective action.
- ⑥ **Planning and taking action** — preparing action plans designed to meet communities needs — including needs for awareness building and training — through collaboration across sectors and with other communities. Using the Framework’s vision, goals and guiding principles, communities can prepare an action plans, with shorter-term goals and commitments.
- ⑥ **Sharing expertise, knowledge and results** — as mechanisms for collecting and disseminating knowledge, results of evaluation and best practices are put in place at the national level, communities need to ensure that their experience is readily accessible by others.

In all sectors, all regions of the country and at the organization and individual level, people must be committed to ever widening and strengthening the circle of those who can create change and influence others to prevent FASD and better serve those with this disability in their families, school, work and community.

G A Closing Word

The *Framework for Action on FASD* represents the contributions of a great number of people and organizations committed to preventing FASD and improving the lives of those with this disability. There is widespread understanding among those who participated in consultations that FASD is a very complex issue, one that calls for a flexible, broad and inter-sectoral approach.

Understanding and addressing the context of FASD, including factors that contribute to the role of alcohol in society, the use of alcohol during pregnancy and even perceptions about the value of women and children in society is crucial. These are important issues that are fundamental to achieving a world without FASD. At the same time, tangible steps can be taken to reduce the incidence of FASD, to improve awareness among professionals and the public, and to improve the quality of life of people living with FASD, their families/caregivers and communities. The *Framework for Action* provides a tool for this practical work.

Keeping the discussion going, integrating new ideas, approaches and results of work will keep the *Framework for Action* relevant into the future. The Public Health Agency of Canada will continue to gather feedback through its current and expanding networks.

Send your feedback, views and ideas to:

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A Wide Network of Interest and Expertise

Interest in and commitment to participating in a national FASD initiative have been widespread. Many sectors bring expertise and interest to efforts to prevent FASD and to support those affected by the disability. The importance of working across sectors is clear from looking at only a few examples of the contributions and interests of a number of sectors:

Child and Family Welfare — one focus of interest is on meeting the needs of women who may use alcohol during pregnancy, at the same time ensuring the safety of children...

Corrections — provide training and support to ensure the safety, appropriate care and rehabilitation of those affected by alcohol in institutional settings, and prevent the “revolving door” in and out of the prison system...


Employment — improve the prospects of finding and maintaining employment by people with FASD, and assist employers with their understanding of the issues surrounding FASD, of the special considerations needed for employees with this disability and of their worth as employees...

Education — educators can help to ensure that people with FASD participate to their full capacity in school by developing and sharing tools, adapting programs and training for educators as well as educating young people regarding the impact of alcohol use during pregnancy...

Health — health promoters bring, for example, skills in helping women and families understand the impact of alcohol use during pregnancy... medical professionals contribute to diagnosis and medical treatment... traditional healers are part of the partnership in effective health promotion...

Justice — not only is the justice system concerned with ensuring that the rights of those affected by FASD are respected, it is interested in increasing awareness of FASD among justice professionals so that justice is applied fairly in accordance with particular circumstances, that responses to wrong-doing are meaningful in light of special needs, and that community-based supports are used to help reintegrate people with FASD into the community...

Police Services — one area of interest and ongoing work is ensuring that officers are trained and knowledgeable in effectively responding to FASD-related



behaviours when working with people in the community, especially in investigative settings, and making appropriate referrals when working with people with suspected FASD who come into conflict with the law or who are at risk of such conflict — either as victims or as the accused...

While not “sectors”, both families/caregivers and grassroots organizations are essential partners in achieving the vision for FASD. **Families/caregivers** offer some of the best insights into the supports and services needed by people with FASD — at the same time, they feel the impact of FASD and themselves need supports. **Grassroots organizations** can be responsive to individual and family needs, can understand the culture of the community and can offer a high degree of accessibility — geographically, ethno-culturally and economically. These local organizations need support as well, including adequate funding and access to research, best practices, tools and up-to-date information.

**Appendix: Consultations on the Draft
Framework for Action**



A

About the Consultation Process

In late fall 2002 to early fall 2003, the Public Health Agency of Canada (PHAC) (then Health Canada) undertook consultations and discussions with organizations across the country to discuss a draft Framework for Action on FASD. The early draft, entitled “A National Framework for Action on FAS/FAE”, was prepared by PHAC and shaped by the National Advisory Committee on FASD, Regional staff and the Interdepartmental Working Group on FASD. The document took the form of a consultation workbook and was distributed both electronically and in paper version directly to over 15 national organizations with current or prospective interest in addressing FASD. Staff from PHAC’s Division of Childhood and Adolescence met with each group to present the draft framework and discuss initial reaction and suggestions for improving and strengthening it. For the most part, discussions of the draft framework were included as one component of a broader meeting.

The consultation process was developed collaboratively and participants were identified through the existing networks. In particular, PHAC Regional staff, in collaboration with members of the National Advisory Committee on FASD, drew on the diverse communities of organizations and individuals they work with across the provinces and territories, resulting in a rich and diverse cross-section of expertise, experience and knowledge. As well as professional expertise, the contributions of parents and foster parents were captured in many of the consultation discussions and are reflected in the Framework.

In addition, a number of organizations met with representatives of their own networks, often within a region of the country, or within a community of interest (e.g., Aboriginal representatives). Finally, the draft Framework for Action was disseminated electronically and feedback was provided by many who reviewed the document independently and offered suggestions and insight on behalf of their organization or themselves. In total, it is estimated that over 500 people met to discuss the Framework and the issues surrounding Fetal Alcohol Spectrum Disorder, representing a rich diversity of interests in FASD, a broad spectrum of organizations and individuals and a strong interest in making a difference in the lives of people living with FASD.

The following highlights capture key points made during the consultation discussions, as well as advice and ideas offered through written submissions — from the organizations consulted, and from interested individuals in those groups who took the time to review and submit feedback to PHAC. While highlights of feedback are presented here briefly, the substance of the advice offered is reflected in the revised *Framework for Action* – the preceding section of this report.

In general terms, there is widespread agreement on many issues — the consensus on the need for a Framework, the need for action at all levels and across all sectors is clearly evident. At the same time, consultation results show the importance of a *Framework for Action* that encourages and facilitates local flexibility in addressing the complexities of FASD.



B

Feedback and Advice on the Process

Stakeholders welcomed the Framework — based on specific comments and overall tone of many of the consultation sessions, participants were generally pleased to have an opportunity to shape the draft Framework into a document that will inspire and guide action in communities across the country.

At the same time, participants offered constructive feedback and advice on the consultation approach and process, and advice for future consultations on the issue of FASD. By far the most frequently offered advice is to ensure that the consultation process be more inclusive and community driven. In particular, many stakeholders suggested that Aboriginal groups and community-based groups be at the centre of future consultations, and that people with FASD and their families be active participants as well.

More specifically, comments suggest that:

The consultation process must include key groups...

- ⓑ Persons directly affected by FASD and their families/caregivers
- ⓑ Aboriginal organizations, communities, and governments
- ⓑ Women of child-bearing years, especially those with alcohol/drug dependencies
- ⓑ Community-based groups and service providers, including ethno-cultural groups

The consultation process needs to be community driven. In particular...

- ⓑ Recognize that this is a community problem for which everyone has to take ownership
- ⓑ Ensure that local/regional needs and priorities are taken into account
- ⓑ Encourage innovative approaches related to the assessment of needs and opportunities of different types of communities

Participants in future consultations should include...

- ⓑ First Nation, Inuit and Métis governments, other Aboriginal organizations, and community groups and leaders at the national, regional and local level
- ⓑ Community-based groups and service providers — NGOs, social service agencies/providers, frontline workers, health care workers, educators, police, etc.
- ⓑ People who are living with FASD and their families/caregivers
- ⓑ Key provincial/territorial government departments — education, health, justice, human resources, community development and family services, social services, corrections

Look at the determinants of health to see who should be included at the national, provincial, regional and local levels — education, social services, justice, finance, housing, health services and health professionals, gender groups, poverty coalitions, etc.

Connect with communities and families living these lives.

C

Feedback and Advice on the Draft Framework

The draft Framework included a variety of elements, including rationale for the Framework, an overview of activity to date, the consultation process, an overview of FASD, as well as four substantive components of a Framework – scope, guiding principles, vision and goals. Comments and suggestions were offered on all four of these substantive components, and many stakeholders made general comments that could apply to any or all of the scope, principles, vision and goals. To the extent possible, comments and ideas have been grouped into these four components, below.

Improve the scope...

Stakeholders expressed various views about the scope of the draft Framework — while many thought the initial scope was appropriate, others thought it was too broad (e.g., deals with too many target groups, too many issues), while some thought it was too narrow (e.g., it should deal more generally with alcohol use in our society, or it should include alcohol and drug use, or it should include alcohol use by breastfeeding mothers).

Perhaps the strongest and most consistent advice offered about the scope concerned the lack of separation of the core “needs” — namely, prevention of FASD, improving the quality of life of those with FASD (and their families), and addressing gaps and inadequacies in the systems for both prevention and support.

Other key points about the scope advise that the revised Framework:

- Be offered as a document to facilitate and help communities to take action, rather than direct their work
- Clearly support the needs of women, children and families — ensuring that women are not targeted as the “problem”
- Identify roles and responsibilities for various groups as action plans are developed (others cautioned against this, as such an approach would be too directive and not flexible enough to accommodate ethno-cultural needs and approaches)

Create a positive vision...

With respect to the vision, many suggested that the revised Framework include a vision that is more positive (showing where society could be, not focusing on how to get there), one that:

- Balances the need to prevent FASD with the need to support women who are at risk for having a child with FASD and the need to support those with FASD and their families
- Recognizes the need for system change (across all sectors with a potential role in preventing FASD and supporting people with the disability)
- Provides more specific references to and/or examples of the ideal is that is being sought after through the Framework and action

“FASD is not just a women’s issue or an Aboriginal issue — we are all invested in finding solutions.”

Participant from Alberta in the FASD Consultations, 2003

Streamline and clarify the goals ...

The consultation results show that, in general terms, the spirit and content of the initial eight goals are well supported. At the same time, suggestions were offered for expanding the content of the initial goals, while reducing unnecessary duplication. Collectively, the advice offered calls for fewer goals that are more comprehensive and that are supported by examples of how the goals could be achieved (with examples of strategies or action that can be measured). It was also suggested that some of the goals would more appropriately be included as guiding principles. Many of the comments suggested that the goals as presented in the draft Framework were too cryptic to be well understood by the diversity of groups that will need to share a common understanding of what needs to be done in prevention, support and system improvements.

Other comments and suggestions about the goals include:

- ⑥ Ensuring that women, children, families/caregivers and communities “see themselves” in the goals
- ⑥ Specific reference to adults with FASD, including that FASD is a life-long disability
- ⑥ Recognition that achieving the goals will require financial resources
- ⑥ Avoid using the term “surveillance” as it suggests “watching women to see if they are drinking”

Strengthen the guiding principles...

The guiding principles in the draft Framework were seen by many of those who commented on them as being more relevant to the consultation process than to the action that needs to take place. Stakeholders advised that the guidelines be revised to provide clear, broad principles that focus on inclusiveness, compassion and respect, and ethno-cultural appropriateness.

Draft framework as a whole...

Several called for inclusion of the need for dedicated funding and even more specific information particularly on supports and services needed in the vision, goals and throughout the Framework. Looking down the road to implementation of action plans, some also suggested that new organizations need to have the chance to receive funding. Other frequent comments that span the entire Framework and that stakeholders believe need to be reflected in the document include:

- ⑥ Sensitivity to those affected by FASD and their families
- ⑥ The need to address head-on the social stigma of drug and alcohol use
- ⑥ Appreciation and understanding of the underlying causes of FASD (root causes and “determinants of health”)

“We need to emphasize that with appropriate supports, people with FASD are working, going to school and living fulfilled lives. We need to give hope.”

Participant from Alberta in the FASD Consultations, 2003





- Ⓟ The importance of keeping in mind the best interests of those directly impacted by FASD
- Ⓟ Adoption and use of the term Fetal Alcohol Spectrum Disorder as the “umbrella term”, as such terms as FAE (incorrectly) imply less severe conditions
- Ⓟ Providing concrete ideas for each part of the framework – communities will need help exploring ways to use the Framework effectively as they develop local plans
- Ⓟ Even though it is a Framework (and not an action plan), keep it action-oriented (“going somewhere”) and clearly inclusive
- Ⓟ Recognition that a federal/provincial/territorial group must be created and effective — particularly to address the secondary disabilities dealt with (prevention, support and services) by provincial ministries (e.g., education, corrections, social services)
- Ⓟ Recognition of the need to develop a “business case” for FASD prevention — factual information that presents the social and economic costs of FASD