History of FASD in Manitoba: 1970's – 2014

Table of Contents

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Introduction

Throughout the last several decades, Manitoba has actively responded to the needs of people impacted by Fetal Alcohol Spectrum Disorder (FASD). Manitoba become one of the many leaders in spreading awareness of FASD, advancing research, and creating prevention and intervention supports for people who are impacted by FASD. This has led to people from all over the world seeking to gain an understanding of Manitoba’s FASD strategy. After undertaking the challenge of explaining our inspiring history to many, and because many early leaders in the FASD field have recently retired, it became evident that it was important to compile and document all relevant historical information. We want to make sure the next generation knows that community advocacy and action have truly driven and shaped the FASD programs and policies we have in Manitoba today.

This report will discuss the evolution of FASD initiatives in Manitoba informed by in-depth interviews with various stakeholders and experts who played a pivotal role in creating the programs and policies in Manitoba.

Methodology

The data for this report was collected in 2017 and 2018 through structured interviews, policy and program documents, and government reports. A total of 22 structured interviews were conducted with people who currently or had previously worked in the field of FASD in Manitoba. Interviewees each held one or more of the following positions at some point in their careers: medical doctor, university professor, researcher, government official, school teacher, community worker, program manager, parent, and/or employee of a not-for-profit organization.

The interviews were conducted in person and on the phone in cases where geography restricted an in-person meeting. The interview questions were designed to trace the history of FASD in Manitoba as described and understood by the interviewees. Interviewees were also asked their perspective on prevention and Manitoba's best practices in FASD programming. The interview results were manually transcribed and used as basis for further investigation. Some respondents provided documents and reports as supplement to the interview.

What is Fetal Alcohol Spectrum Disorder?

Fetal Alcohol Spectrum Disorder (FASD) is the diagnostic term used to describe the impacts of prenatal exposure to alcohol on a person's brain and body. Often, there are no physical features to show that the person has FASD, even though the brain is impacted; for that reason, FASD is sometimes referred to as a hidden disability. All individuals with FASD are unique; people with FASD may experience challenges in their daily living and may need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and/or social skills (Flannigan, Unsworth & Harding, 2018). Understanding the unique abilities and challenges of a person with FASD is key to supporting the individual's success.

Canadian FASD diagnostic guidelines, updated in 2016, established "Fetal Alcohol Spectrum Disorder" as the exclusive diagnostic term used to describe the constellation of effects that result from prenatal alcohol exposure. The presence or absence of 'sentinel facial features' may also be identified as a part of an individual's FASD diagnosis (Cook et al, 2016). Prior to this, other terms such as 'fetal alcohol syndrome' (FAS), 'fetal alcohol effects' (FAE), 'partial fetal alcohol syndrome' (pFAS), and 'alcohol related neurodevelopmental disorder (ARND)' were used as diagnostic terms to indicate prenatal alcohol exposure. Throughout this report you may see the use of these older terms, however please note that these terms are now referred to as FASD.

FASD is the most common developmental disability in Canada, impacting approximately four per cent of Canadians (Flannigan, Unsworth & Harding, 2018). Determining the prevalence of FASD is difficult due to two major barriers. First, families where a child has been prenatally exposed to alcohol do not always seek a diagnosis. There may be a variety of reasons for this such as a lack of knowledge, fear of shame and blame, or a lack of readiness. Second, the diagnostic process is complex, requiring multiple assessments. Although Manitoba's diagnostic capacity, including access in rural and northern Manitoba, has grown over the past decades, wait lists, access, and readiness for the diagnostic process can still pose challenges.

There is no known safe amount of alcohol use at any stage of pregnancy. There are many reasons why a person may drink alcohol during pregnancy, including being unaware they are pregnant, experiencing addiction, experiencing abuse or trauma, and not knowing the impact alcohol can have on pregnancy. It is essential to approach alcohol use in pregnancy with understanding and compassion.

1970’s – 1980’s: Early Discussions of FASD in Manitoba

The first of many scientific articles on FASD were published in the late 1960’s, indicating a link between prenatal alcohol exposure, and adverse infant outcomes (Lemoine, P. Harousseau, J. P. Borteyru, & J. C. Menuet, 1968). By the early 1970’s, communities in Manitoba recognized a need to address the newly coined term “Fetal Alcohol Syndrome” (FAS) (Jones & Smith, 1973). The seminal articles that were published had caught the attention of the medical community in Manitoba. Medical professionals from Manitoba and Washington came together to discuss FASD and their clinical findings. By the early 1980’s, there was growing concern for children’s health issues both in Winnipeg and in First Nations communities.

The Manitoba medical community was inundated with requests for diagnostic assessments for FASD. Manitoba was still in the early stages of understanding the disability. Parents (including birth, adoptive, and foster parents) of children with FASD had a hard time coping with the realities of their children’s needs. There was a lack of knowledge, lack of supports and services, prejudice, and bias in trying to cope with the realities of parenting a child with an “unknown” disability. These challenges generated considerable frustration, anger, and physical and mental exhaustion for all parents.

First Nations families faced compounded challenges caring for children with disabilities due to ambiguity about which level of government was responsible for providing support services. For First Nations communities, services came from two different jurisdictions: Federal and Provincial. Most of the First Nation communities received services from the Medical Services branch of Health and Welfare Canada who had not developed programs for First Nations people with disabilities (Patenaude, 1993). This lack of support often led to challenges caring for children with physical and developmental needs; some children were placed in foster homes or with extended family, even though they may have also not had the resources needed to meet the child’s needs.

The health authorities in First Nations communities realized that the health challenges among First Nations’ children needed to be addressed. Despite the problems of inadequate diagnosis, unknown incidence, lack of resources, and heavy caseloads among nurses, these communities were determined to improve the health issues and programs.

Winnipeg medical doctors and clinicians were puzzled by children presenting with multiple symptoms. With growing concern for children’s health issues both in Winnipeg and the First Nations communities, the Winnipeg Children’s Hospital Department of Pediatrics held a National Symposium on Fetal Alcohol Syndrome in 1983. The conference was attended by medical doctors, nurses, and First Nations community leaders. The symposium suggested an increase in number of females using alcohol in general and this included using alcohol while pregnant. It was discussed that the increased use of alcohol in women may be due to their changing roles in society and the pressure and conflicts brought on by these new roles. There was also discussion of increased alcohol use in First Nations communities as an impact of colonization (Government of Canada, 1992).

FASD was not talked about outside of the medical and First Nations communities. Most of the population including parents, service providers, and the general public were still unaware of FASD. Parents and foster families identified that they had children who had complex needs and started to put increased pressure on the medical and education systems to respond. A foster parent shared the following: “(FASD) wasn’t well known in Manitoba. We learned from our foster kids that were with us about the disability without knowing what it was. We just tried different ways of managing behaviour without a diagnosis.”

Despite the leadership from the medical community and the advocacy from First Nations communities, there was still a huge gap in terms of information and awareness for the general public. Medical professionals continued to see babies born to people who used alcohol during pregnancy. There was also an increased rate of children with disabilities coming into the care of Child and Family Services. In the school system, children were being expelled or were asked to leave their schools due to the lack of supports available for them. Furthermore, there was a significant increase in the number of young people who were involved with the justice system. These incidences occurred simultaneously, attributing speculations of additional causes other than FASD such as attention deficit hyperactivity disorder (ADHD), autism, and behavioural / mental health concerns.

The financial costs of placement breakdowns for children in care, service provisions for children with disabilities within the school system, as well as the increased rate of young people in the justice system started to gain the attention of the provincial government but there was not enough momentum around the issue. Initial movements from various communities piqued the interest for government involvement.

Child health issues were a primary concern for the federal government. In 1989, Statistics Canada conducted a survey on behalf of the Health and Promotion Studies Unit of Health and Welfare Canada called the Alcohol and other drug use by Canadians: A National Alcohol and Other Drugs Survey. The one-time voluntary survey collected data on the negative consequences associated with drugs and alcohol. The results revealed that 72% of women of child-bearing age reported consuming alcohol. While the United States had instituted a law requiring all alcoholic beverages to contain a warning label under the “Alcoholic Beverage Labeling Act of 1988”, the Canadian government was divided on the matter. The Association of Canadian Distillers and the Brewers of Canada’s expressed concern about the efficacy of warning labels as an effective approach; proponents of warning labels pushed that they were effective in raising awareness.

1990’s: Early FASD Programming

In 1991, Canada became a signatory to the United Nations landmark document called “Convention of the Rights of the Child,” defining the inherent rights of children around the world. Section 24 of the Convention asserts “the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health," and indicates measures shall be taken to "ensure appropriate pre-natal and post-natal health care for mothers."

In 1992, the Standing Committee on Health and Welfare, Social Affairs, Seniors and Status of Women submitted a report to the House of Commons titled, "Foetal Alcohol Syndrome: A Preventable Tragedy," produced after a series of investigations and testimonials from FASD experts across the country. The federal government responded with a Joint Statement on Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects. One of the twenty-one recommendations of the report was to initiate a discussion with the provinces and territories to create a National Advisory Committee.

A symposium on FASD took place in Vancouver in September 1992. This was perhaps the first time that representatives from across the country gathered to address FASD in the Canadian context. The event pushed for FASD to be recognized as a national public health issue.

The Brighter Futures initiative was implemented by the Government of Canada in 1992, providing funding to First Nations and Inuit communities for community mental health, child development, injury prevention, parenting skills, and healthy babies' programs and services. The Community Action Program for Children (CAPC) was also created, which funded programs to promote healthy child development (birth to age six).

The creation of CAPC was instrumental in the success of Manitoba's FASD work. A call for proposals was issued for initiatives that could address FASD. Four organizations worked together to answer the call for proposals: Mount Carmel Clinic, Winnipeg Child and Family Services, Pregnancy Distress Services (now named Thrive Community Support Circle), and Children's Home of Winnipeg (now referred to as New Directions for Children, Youth, Adults, and Families). Their proposal was accepted, and in 1995, the FAS Inter-Agency Program- now called FASD Family Support, Education, and Counselling- was funded to work with children and families living in Winnipeg. This was the first time any program of its kind was implemented in Winnipeg, providing many children with FASD and their families with a place to go for support.

Manitoba FASD Coalition

In 1993, inspired by the 1992 national FASD symposium in Vancouver, a consultation took place in Manitoba with approximately one hundred people, including experts and those with lived and living experience of FASD. Together, these concerned community members shared their expertise, experiences, and perspectives to come up with practical solutions to support people impacted by FASD in Manitoba. One of the recommendations was to create a provincial working group: the Committee on Alcohol and Pregnancy (CAP).

The Public Health Agency of Canada provided a grant to the CAP to allow them to conduct community consultations throughout the province, including Northern Manitoba (another recommendation of the Manitoba consultation). Shortly after these consultations, new FASD working committees were created by concerned community members. These committees formed in communities all over Manitoba, large and small, to work on initiatives relevant to their communities. One early CAP member reflected, “Manitoba did not have a lot of funding so there was a vision and a willingness and quite a determination to work collaboratively across sectors.” In 1998, CAP evolved into the Manitoba Coalition on Alcohol and Pregnancy (MCAP), and then in 2016, became Manitoba FASD Coalition Incorporated.

FASD Awareness

Public awareness was increasing in Manitoba during this period. In the early 1990’s, Doctors Manitoba launched a public awareness campaign on alcohol use during pregnancy (Casiro et al, 1994), airing a 30-second television commercial and developing a print brochure. This campaign showed an increase of public awareness of the physical, mental, and behavioural harms that alcohol use during pregnancy can cause to a fetus.

In 1999, September 9 was declared International FASD Awareness Day. The significance of the date- the ninth day of the ninth month- symbolized the nine months of pregnancy. CAP members marked the day with public events to raise awareness about FASD. To this day, FASD coalitions across Manitoba plan special events and campaigns to raise awareness about FASD on September 9 and throughout the month of September.

Provincial Coordination and Program Development

In 1993, Manitoba Health published ‘Framework for a Vision of Healthy Child Development in Manitoba,’ a report aimed at addressing child health issues, including FASD. In response, the Manitoba government began to develop a child health strategy for the province. It was recognized at that time that child-related services were fragmented and uncoordinated. High-needs children and youth were being forced to fit the system, instead of having a system that met the total needs of children and youth. In 1994, the province of Manitoba announced the development of the Child and Youth Secretariat (later referred to as the Healthy Child Manitoba Office) to coordinate programs and initiatives for children and families, including those impacted by FASD.

Many programs were created and evaluated, with an initial focus on programming for children ages 0-6. The FASD Outreach Program was created to support caregivers to learn strategies to support and care for young children with FASD. Some of the work of this program, in partnership with the FAS Interagency Program, included the development of FASD training for service providers around the province. An FAS/FAE Resource Centre was established at the Addictions Foundation of Manitoba library. The Fetal Alcohol Family Association of Manitoba (FAFAM) was also established to provide advocacy, support, and education to families caring for, and professionals working with, children and adults with FASD.

Another ground-breaking, specialized program started in 1993/94 at the David Livingstone School in the Winnipeg School Division. The Bridges Program was developed in response to a number of Kindergarten students with FASD. By the fall of 2002, the province supported funding for the Winnipeg School Division for a full-day classroom for students with FASD. The Bridges Program featured a class designed to meet the specific academic and behavioural needs of its students, recognizing the strengths and challenges of each student with FASD and supporting their academic success. Several FASD classrooms developed in the Winnipeg School Division across all grade levels over the next 15 years, establishing Manitoba as a leader in strategies for educating children with FASD (Millar et al, 2014).

In 1995, a comprehensive study called “The Health of Manitoba’s Children Report” (Postl, Martin, Boulanger, & Isaac, 1995) provided direction for the Manitoba government to budget for additional funding to support children in the early years. The study also provided recommendations to support pregnant people using alcohol and provide neonatal services.

In 1997, the Child and Youth Secretariat (CYS) sanctioned a survey about FASD to almost fifteen hundred parents, caregivers, and service providers, asking about what services were needed to support those impacted by FASD. The CAP assisted CYS in administering this survey. It was recommended that the province focus on 1) prevention and early intervention services, 2) ensure programs and services have a foundation on best practices, 3) ensure all programs and services have benchmarks for evaluation and outcomes, 4) adapt to the changing needs of children and youth, and 5) individuals, families, and community should have control and ownership with regard to their choices. These recommendations formed an early strategic framework for the province’s work on FASD services.

In 1999, the province released a status report on Manitoba’s children, recognizing the provincial government and its community partners for making a significant impact in fostering healthy childhood development (Government of Manitoba, 1999). Importantly, along with the success of the community in creating partnership, awareness, and programs to help prevent FASD, more funding was secured to continue initiatives, including early identification and diagnosis. Additionally, to assist the medical community in becoming more aware of FASD, the Child and Youth Secretariat, in partnership with the medical community, created a resource for doctors, “What Doctors Need to Know about FASD” (Chudley & Moffatt, 1998).

Ms. G

A notable court case made headlines in 1996, increasing public discourse in Manitoba about substance use in pregnancy and the rights of pregnant people. Ms. G, as she was referred, was using substances while pregnant; a provincial judge ordered her to attend addictions treatment due to concerns about her unborn child. The case then went to the Supreme Court where the ruling was overturned, with the court determining that the fetus is not a person with legal rights, and Manitoba authorities could not force Ms. G to undergo treatment.

InSight Mentoring Program

Members of CAP were instrumental in bringing one of the first FASD prevention programs to Manitoba. Manitobans became aware of the Parent-Child Assistance Program (P-CAP), or “Birth to Three” program, in Seattle, Washington. The program supports people who are pregnant and/or recently post-partum, use substances, and are ineffectively connected to other community programs and services. Participants are paired with a mentor for a three-year period, during which mentors support participants to set and work on their own goals. This program model had been evaluated and proven effective to reduce the risk of alcohol use in pregnancy among participants.

In 1998, after several consultations with program experts in Washington, Manitoba became the first province in Canada to establish a P-CAP model program. The program, funded by the provincial government and originally named “Stop FAS,” was established in two sites in Winnipeg: the Aboriginal Health and Wellness Centre, and the NorWest Co-op Community Health Centre. The success of the program led to the development of sites in Thompson and The Pas in 2001, and Dauphin, Portage la Prairie, and Flon Flon in 2008. To help decrease the stigma many people feel when seeking supports for alcohol use in pregnancy, the program was eventually re-named the InSight Mentoring Program. In 2015, InSight was evaluated by the Manitoba Centre for Health Policy, and the program was shown to successfully reduce risk of alcohol-exposed pregnancy, increase prenatal health care, and strengthen connections to community services amongst people served by the program.

The federal government also began to fund First Nations communities to support the Parent-Child Assistance Program, referred to as the Success Through Advocacy and Role-modelling (STAR) Program. There are currently 28 First Nations communities in Manitoba where the STAR program is available.

Canada Northwest FASD Partnership

In 1998, an interjurisdictional partnership called the Prairie Partnership on FASD was formed between Manitoba, Saskatchewan, and Alberta. The purpose of the Partnership was to advance evidence-based FASD policy development and service design through the sharing of resources, challenges, solutions, and expertise. The Partnership is now called the Canada Northwest FASD Partnership, and has grown to seven jurisdictions, adding British Columbia, Yukon, Northwest Territories, and Nunavut.

The Partnership pools funds to host conferences and symposia throughout the Partnership jurisdictions, and to undertake other initiatives to forward the strategic priorities of the Partnership. Several Partnership events have been held in Winnipeg, including the first interprovincial FASD conference in May 2000 entitled “Come Together and Find a Solution,” symposia on FASD diagnosis (2008) and prevalence (2010), and a conference in 2014 entitled “Living Well: FASD and Mental Health.”

FASD Diagnostic Services

Initially, a FASD diagnostic clinic evolved from the High Risk Newborn Follow-Up program with representation from developmental pediatricians and geneticists. In 1994, the increased demand for diagnostic services prompted expansion to accept referrals from pediatricians, CFS, and community agencies. In 1999, an important partnership between the Genetics department and the Child Development Clinic at the Children's Hospital began, known as the Clinic for Alcohol and Drug Exposed Children (CADEC). CADEC began to see children ages 0 to 12 who had confirmation of prenatal alcohol exposure. They developed the first FASD Telehealth diagnostic clinic in partnership with Norway House First Nation. CADEC's expertise as a multidisciplinary assessment clinic led to numerous other provinces and territories, as well as other countries, asking for their assistance in developing clinics of their own (Square, 1997).

The diagnostic centre recognized that diagnosis alone was not enough to help families impacted by FASD. They became concerned that there were not enough follow-up supports or programs in place for children who received a diagnosis. An FASD educator was hired, who provided support to children's schools to understand and utilize the child's FASD assessment information after a diagnosis.

2000's: Further Development of Programming, Training, Collaboration, and Funding

Life's Journey

Vast development took place in the beginning of the new millenium. In 2001, an important community-led 'think tank' was held to discuss the support needs of adults with FASD. Up until this point, few specific supports for adults with FASD existed. The Association of Community Living and other leaders from disability communities were key participants in this discussion. The think tank resulted in the Community Mobilization Project, which received initial funding from the Association for Community Living and provided a range of supports for adults with FASD. This initiative grew into the organization FASD Life's Journey, now named Miikana Pimatiziwin- Life's Journey Inc.

FASD Youth Justice Program

Another unique partnership emerged between CADEC, provincial youth justice services, and the FAS Inter-Agency Program: the FASD Youth Justice Program. Original funding from a federal youth justice grant allowed this partnership to pilot a program to provide FASD assessment services and follow-up support to youth (ages 12-17) with criminal justice system involvement and possible FASD through the diagnostic, criminal sentencing, and post-sentencing processes while providing them with supports. Because of its success, the program was adopted by the province and is now fully funded by the provincial Department of Justice. The success of the program also helped to build youth FASD diagnostic capacity, which was a first step in the eventual expansion of FASD diagnostic services in Manitoba up to age 18. The FASD Youth Justice Program is now called FASD Justice Program as it has expanded to work with young adults, and continues to provide FASD training for many justice personnel including correctional officers.

Expansion to FASD Diagnostic Services

In 2005, the geneticist working with CADEC was a key player in bringing together a group of clinicians from across Canada to publish the Canadian Diagnostic Guidelines for FASD in the Canadian Medical Association Journal. This was done with representation from the FASD Advisory Committee, Health Canada, and the Public Health Agency of Canada (PHAC). These guidelines were recognized and used across Canada to help standardize the diagnostic process. In 2016 revised diagnostic guidelines were published.

In 2010, the diagnostic centre moved to a stand-alone site on Wellington Crescent. It was renamed the Manitoba FASD Centre, and expanded offer diagnostic services up to the age of 18. In the same year, in partnership with the Manitoba Government, the Manitoba FASD Centre developed the Manitoba FASD Diagnostic Network, funding ten diagnostic coordinator positions in health authorities across the province. Diagnostic coordinators would accept referrals from their regions, prepare children and families for assessment, provide a space for a multidisciplinary assessment to occur in the families' home community, and provide brief follow-up to those receiving a diagnosis. In 2016, the Manitoba FASD Centre moved to its current location within the Specialized Services for Children and Youth (SSCY) Centre.

Regional FASD Coalitions

Along with the Coalition on Alcohol and Pregnancy, now known as the Manitoba FASD Coalition, there are several grassroots regional FASD coalitions. These coalitions are comprised of individuals, caregivers, agencies, and professionals working in the area of FASD. They operate throughout rural and northern communities across Manitoba and are intended to increase community networking, share best practices, and provide support for awareness, prevention, and intervention efforts at the local level. The earliest regional coalitions formed in the early 2000's and are now spread all over the province. These areas include the areas of Dauphin, Brandon, Portage la Prairie, North Eastman, Selkirk, Steinbach, The Pas, Flin Flon, Thompson, Norway House, and Cross Lake. The regional FASD coalitions receive support through the Manitoba FASD Coalition to network, share information, and to plan local FASD Awareness Day events.

Canada FASD Research Network

The Canada Northwest FASD Partnership realized there was a great need for FASD research, as a relatively new disability area. There were many unknowns about how the brain was impacted by alcohol, how to support FASD prevention efforts, and how to support best practices working with individuals with FASD. In 2005, the Partnership created an FASD research network to promote FASD research across its jurisdictions.

The Partnership continues to provide annual core funding to the research network through the contributions of the Partnership jurisdictions. The research network grew in size and recognition, and in 2012 became its own national entity, now known as the Canada FASD Research Network, or CanFASD.

FASD Interdepartmental Committee

In 2005, the Manitoba government formally created the FASD Interdepartmental Committee (FASD-IC). This was important step that brought attention to how the priorities of departments' respective sectors- such as health, addictions services, justice, social services, education, and supports for Indigenous communities- intersect with the needs of people impacted by FASD. FASD became recognized as a shared responsibility across departments. The FASD-IC ensures that all departments work collaboratively to ensure a whole-of-government approach to FASD awareness, prevention, and support through the development and support of FASD initiatives.

Reviews of the Child and Family Services System and the Changes for Children Action Plan

In 2003 to 2006, deaths occurring in the child welfare system, including the tragic death of Phoenix Sinclair, resulted in six external reviews that examined Manitoba's Child and Family Services system and resulted in 295 recommendations for improvement. These reviews and reports highlighted unmet support needs of children and youth with FASD. Three reports published during this time found that a disproportionate number of children involved in the child welfare system had FASD or confirmed prenatal substance exposure (McEwan-Morris, 2006; Schibler & Newton, 2006), and that a high percentage of deaths involved children with FASD, particularly in cases of suicide (McEwan-Morris, 2006; Schibler & Newton, 2006). With FASD as a primary theme identified in findings, it had become more apparent that there was a need to prevent these outcomes experienced by those impacted by FASD and substance use during pregnancy through expanded FASD services, resources, and training. Schibler & Newton (2006) expressed concern for the safety of youth with FASD aging out of the child welfare system, stating that these youth were the most vulnerable in this system and most likely to put themselves in harms way.

A number of the recommendations made in these reports related to increased FASD supports, including funding for FASD specialists and comprehensive training in all child welfare agencies, expansion of the FASD Life's Journey program to Brandon and Thompson for youth exiting care, expansion of the STOP FAS (InSight Mentoring Program) and the establishment of an intervention committee to better support young, high-risk parents to reduce their substance use during pregnancy. The Advocate also recommended reforms to child welfare policies for extensions of care which typically supported young adults who attended school regularly or qualified for adult disability funding; the criteria often excluded young adults with FASD, leaving them without needed support. Additionally, it was stated that as per best practices, children who received an FASD diagnosis before the age of five and had safe, stable, consistent and non-violent homes were more likely to have better outcomes (Schibler & Newton, 2006).

In October 2006, the Government of Manitoba accepted and made a commitment to implement all 295 recommendations made by the external reviews through the Changes for Children Action Plan. The Changes for Children Action Plan recommended expansion of FASD prevention and intervention services, expanded training and education efforts to prevent FASD, and the creation of a comprehensive strategy to support children and families impacted by FASD.

Provincial FASD Strategy

In 2007, a formal Provincial FASD Strategy was announced. The FASD Interdepartmental Committee was given direction to implement and oversee the strategy. Healthy Child Manitoba was appointed to chair the FASD-IC and lead the development of the FASD Strategy. The following five goals were identified for the FASD Strategy:

1. Knowledge- increase awareness and understanding of FASD and the risks of alcohol use in pregnancy in Manitoba
2. Prevention- decrease alcohol use in pregnancy and ensure Manitobans have the information, support, and services they need before, during, and after pregnancy
3. Intervention- ensure people with FASD and their families have access to assessment, diagnosis, support, and services across the lifespan
4. Evidence- ensure FASD services are based on strong research, evaluation, and community input
5. Quality- train FASD service providers use best practice approaches

In the years following the launch of the FASD Strategy, the FASD-IC wrote joint Treasury Board submissions to create and expand FASD programming, and encouraged partnerships between departments to maximize the impacts of FASD services and training, and ensure all departments were up-to-date on their understanding of existing services and the latest knowledge and research in the field of FASD.

Initial highlights of the Provincial FASD Strategy included:

- Funding for Spectrum Connections, a program within Life’s Journey designed to help youth with FASD or possible prenatal alcohol exposure, especially youth in care or at risk of child and family services (CFS) involvement, transition into adulthood
- Creating FASD specialist positions within all four CFS authorities to provide support and training for front-line workers
- Increasing FASD diagnostic services up to age 18 through the Manitoba FASD Centre
- Expanding the InSight Mentoring Program to Flin Flon, Portage la Prairie, and Dauphin
- Development of print and digital FASD resources to support the public and service providers to learn about how to support individuals and families impacted by FASD

Stigma and the Looking After Each Other Project

In 2014, at a meeting of regional FASD coalitions, coalition members identified stigma as a key barrier to advancement of FASD awareness, prevention, and support in Manitoba. Continuing a long pattern of community-driven advancement of the cause of FASD in Manitoba, community members recognized a need and took action to create awareness and advocate for programs and funding. The group decided that a united effort should be made to reduce stigma associated with FASD and alcohol use during pregnancy, and to promote dignity and understanding. During a traditional Indigenous naming ceremony, the project was named ‘Looking After Each Other: A Dignity Promotion Project.’ More information about the many achievements of Looking After Each Other can be found at https://www.fasdcoalition.ca/looking-after-each-other-project/. The work of reducing stigma and promoting dignity for people impacted by FASD and alcohol use in pregnancy would continue to be a strong driver for the work of the FASD Strategy in Manitoba over the years to come.

Themes

Among the rich historical information shared in preparation for this report, themes emerged about the key successes and challenges that have shaped the FASD landscape in Manitoba.

Successes:

- Manitoba has come a long way in understanding FASD; community groups like MCAP and the provincial government assisted in disseminating information
- Over time, senior government leaders started to recognize that investment in FASD initiatives would garner successful outcomes
- Recognizing that a person with FASD is impacted by multiple systems- medical, justice, social services- and there needs to be a place to discuss supporting the individual from all of these angles
- Manitoba has done a lot with limited resources
- Recognition of the need to support teens and young adults
- Development of the diagnostic clinic, and all of the supports available including education and occupational therapy, as a leading model of care

Challenges:

- Some communities, especially those that are more isolated, still don’t have a good understanding of FASD, may have judgments about FASD, and don’t understand how to support people with FASD
- Addressing larger social issues: colonization, poverty, mental health, education, trauma- alongside addressing alcohol use in pregnancy
- Discrepancies between services available provincially and on reserve
- Ensuring health care professionals and addictions programs have the information and training they need to discuss alcohol use in pregnancy
- Continuing to see a strong need for service upon diagnosis

- Challenges building relationships and training when social service staff turnover is high
- Challenges in what services individuals can qualify for
- Ensuring true integration of children in schools
- Continued need for increased investment
- We need to work with other jurisdictions to strategize and share resources

Moving Forward

FASD programs continue to grow and evolve to support the needs of people with FASD across the lifespan, and families impacted by substance use in pregnancy. For a list of FASD services in Manitoba, please visit: https://www.gov.mb.ca/fs/fasd/pubs/fasdresources_en.pdf.

It is clear that when it comes to collaborating to create innovative FASD awareness, prevention, and intervention solutions, Manitoba has been a leader in the FASD world for several decades. Although we have come a long way, we must continue our efforts to increase awareness and support, reduce stigma, and promote dignity for people impacted by FASD.

References

Casiro, O.G., Stanwick, R.S., Pelech, A., Taylor, V., Child Health Committee, & Manitoba Medical Association. (1994). Public awareness of the risks of drinking alcohol during pregnancy: The effects of a television campaign. *Canadian Journal of Public Health, 85*(1), 23-27.

Chudley, A.E., & Moffatt, M.E. (1998). What doctors need to know about fetal alcohol syndrome (FAS) (Audio tape and CD). Winnipeg: College of Physicians and Surgeons of Manitoba, and Manitoba Children & Youth Secretariat.

Cook, J.L., Green, C.R., Lilley, C.M., Anderson, S.M., Baldwin, M.E., Chudley, A.E., Conry, J.L., LeBlanc, N., Loock, C.A., Lutke, J., Mallon, B.F., McFarlane, A.A., Temple, V.K., & Rosales, T. for the Canada FASD Research Network (2016). Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan. *Canadian Medical Association Journey, 188 (3),* 191-197.

Flannigan, K., Unsworth, K., & Harding, K (2018). The prevalence of Fetal Alcohol Spectrum Disorder (issue paper). Canada FASD Research Network. *Retrieved from* https://canfasd.ca/wp-content/uploads/publications/Prevalence-1-Issue-Paper-FINAL.pdf

Health and Welfare Canada. (1993). *Brighter futures: Canada's action plan for children* (Catalogue No. H74-47/1992E). Ottawa: Canada.

Jones, K.L. & Smith, D.W. (1973). Recognition of the fetal alcohol syndrome in early infancy. *The Lancet, 302(7826),* 999-1001.

Lemoine, P., Harousseau H., Borteyru, J.P., & Menuet J.C. (1968). Les enfants de parents alcooliques. Anomalies observees a propos de 127 cas (Children of alcoholic parents: Abnormalities observed in 127 cases) *Ouest Medical, 21*, 476 - 482.

Manitoba Government (1999). Province releases ChildrenFirst status report. *Retrieved from http://news.gov.mb.ca/news/index.html?item=24029&posted=1999-05-31*

Manitoba Health. (1993). *Framework for a vision of healthy child development in Manitoba.* Winnipeg: Manitoba.

McEwan-Morris. (2006). *"Strengthening Our Youth", Their Journey to Competence and Independence, A Report on Youth Leaving Manitoba's Child Welfare System.* Winnipeg: Manitoba.

Millar, J., Thompson, J., Schwab, D., Hanlon-Dearman, A., Goodman, D., Koren, G., & Masotti, P. (2014). Educating students with FASD: Linking policy, research and practice. *Journal of Research in Special Education Needs, 17(1),* 3-17.

National Symposium on Fetal Alcohol Syndrome. (1983). *Proceedings of a national symposium on fetal alcohol syndrome* (MMS ID: 99139519470001651). Winnipeg: Manitoba.

Postl, B.D., Martin, G., Boulanger, M., & Isaac, E. (1995). *The health of Manitoba's children.* Winnipeg: Manitoba Health.

Schibler & Newton (2006). *"Honouring their Spirits", The Child Death Review: A Report to the Minister of Family Services & Housing, Province of Manitoba.* Winnipeg: Manitoba.

Square, D. (1999). Fetal alcohol syndrome diagnosed by telelink in Manitoba. *Canadian Medical Association Journal, 160*(5), 627.

Square, D. (1997). Fetal alcohol syndrome epidemic on Manitoba reserve. *Canadian Medical Association Journal, 157(1),* 59-60.