Engage MB What We Heard

Manitoba Fetal Alcohol Spectrum Disorder (FASD) Strategy: 2021 Stakeholder Engagement

Project Overview

Manitoba's FASD Strategy was first implemented in 2007. The FASD Strategy ensures that all programs and initiatives, across all areas of government and community service, are working together towards the common goal of supporting those impacted by FASD. Manitoba government departments work together on the FASD Interdepartmental Committee (FASD-IC) using a coordinated and collaborative approach.

Manitoba's FASD Strategy has five key goals.

- **Knowledge:** Initiatives that share accurate information about how alcohol use during pregnancy can cause FASD, in ways that are supportive and non-judgmental.
- **Prevention:** Initiatives that aim to reduce alcohol use during pregnancy by supporting people with information, support and services before, during, and after pregnancy.
- **Intervention:** Initiatives that support people with FASD and their families by providing assessment and diagnosis, and supports and services across the lifespan.
- **Evidence:** Initiatives that ensure Manitoba's FASD services are based on strong research, evaluation, and community input.
- **Quality:** Initiatives that ensure Manitoba service providers in all sectors are trained and use best practice approaches in their work supporting people impacted by FASD.

In 2015, the FASD-IC held community conversations to identify what was going well with FASD initiatives in Manitoba, and where there were opportunities to expand or improve services. The priorities that emerged resulted in several new initiatives that strengthened the Manitoba FASD Strategy. In 2021 the FASD-IC decided to once again seek stakeholder feedback with the goal of renewing the provincial FASD Strategy.

Engagement Overview

Between April and June 2021, the FASD-IC undertook a series of conversations and online engagements with key stakeholders to explore the following questions:

1. What FASD initiatives in Manitoba are working well that we need to continue, or do more of?
2. How could FASD initiatives in Manitoba be improved?
3. Where can partnerships between service providers be built or strengthened to improve FASD initiatives in Manitoba?
4. How can FASD initiatives in Manitoba promote the dignity of people impacted by FASD?
5. What should be the top priorities of the Manitoba FASD Strategy going forward?

The primary method of engagement was virtual stakeholder group conversations. Stakeholders could also submit ideas in a written format after the meeting through the Engage MB Ideas page, or directly to the FASD-IC. Stakeholders who were unable to attend virtual conversations had the opportunity to complete an online survey through Engage MB for three weeks in June 2021. The online survey link was also sent out more widely to other stakeholders.

Stakeholder Conversations

Thirty-three virtual stakeholder conversations were held, with 312 participants. These conversations brought together small groups of stakeholders (20 people or less) from across Manitoba for in-depth and open conversations about the FASD Strategy, loosely structured around the five research topics identified above. Discussion questions were adapted to specific stakeholder groups.

The conversations took place with stakeholders from the following groups:

- FASD service providers: Funded agency staff; participants of FASD prevention programs; adults with FASD; caregivers of people with FASD; and Indigenous Elders who provide community support and are connected to FASD initiatives, including the Looking After Each Other Dignity Promotion Project
- Social services: Adult Disability Services agencies; organizations that support children and youth in care; housing support service providers; and homeless shelter program providers
- Health services: Addictions service providers; mental health service providers; and Manitoba FASD Centre service providers
- Justice system: Probation services; corrections services; court/judiciary stakeholders; police officers; crime prevention community organizations; and Community Mobilization Initiatives

- Education system: Student Services Administrators' Association of Manitoba members; Student Services Inclusive Education Committee; and Winnipeg School Division FASD classroom educators and administration
- Employment support services: Supported employment agency service providers; and Employability Assistance for People with Disabilities service providers

Engage MB: Ideas Page

Eight responses were received: six ideas were submitted on the Engage MB Ideas page, and two ideas were submitted directly to the FASD-IC. The three respondents who identified themselves by name also attended virtual stakeholder conversations.

Engage MB: Online Survey

Fifty three people completed the online survey: 18 (34%) identified themselves as caregivers of a person with FASD, and 35 (66%) as service providers. The majority of caregiver respondents indicated they cared for a person with FASD in a foster parent role, with others identifying as parents, informal caregivers, and respite workers. Service provider respondents indicated they worked primarily in the fields of disability services, mental health, justice, and addictions programming.

What We Heard

1. What FASD initiatives in Manitoba are working well that we need to continue, or do more of?

During the virtual conversations, stakeholders expressed that many existing FASD programs are meeting the needs of people impacted by FASD, and should be further promoted and/or expanded. Stakeholders articulated the approaches that they see as most effective when working with those impacted by FASD, including building relationships and trust, meeting people where they are at, identifying and celebrating people's strengths, consistency of support, collaboration between support systems, and ensuring that people impacted by FASD have input into the programming available to them.

Survey responses showed a generally high rate of self-reported FASD knowledge and training among caregivers and service providers. The majority indicated they had attended FASD training in the past.

Survey respondents generally rated their knowledge of FASD-related topics as high, particularly their knowledge of alcohol and fetal development, supporting people with FASD, and information to share with youth and adults about FASD prevention.

Survey respondents also indicated that they generally rate themselves as 'very' or 'somewhat' effective when supporting the needs of people with FASD/possible FASD.

Caregivers were asked to identify their experiences when seeking services for people in their care. FASD assessment and diagnosis, education, and health care services were all identified as being ‘usually helpful’ or ‘sometimes helpful’ in the majority of responses. Priorities identified included expansion of existing FASD initiatives to include broader age or geographical eligibility, and/or to reduce wait times for existing programs.

2. How could FASD initiatives in Manitoba be improved?

During the virtual conversations, many recommendations around improving FASD initiatives focused on expanding existing program models: increasing program capacity and reducing wait list times, expanding age eligibility criteria, and expanding geographic eligibility for programs. Stakeholders also shared their priorities for service expansion, such as increased support for those with addictions and mental health concerns, increased housing support, Indigenous-led programming and cultural initiatives, employment support for people with FASD, and increased supports for adolescents and young adults.

Stakeholders also reflected on a need for increased training and information sharing. Many service sectors were identified as needing to be more FASD-informed in the way they provide services. Stakeholders recommended increasing FASD training availability, including online and brief tailored modular/ topical training options. Finally, people with FASD and their caregivers indicated a need for increased service navigation support to help them to find and access available resources.

Survey respondents generally reported high knowledge and training on FASD. However, there were areas where they indicated benefits from more information or training:

- Adjusting expectations to reflect the person’s unique strengths and challenges
- Providing holistic supports that address the person’s physical, mental, emotional, and spiritual well-being
- Talking to a person with FASD about their disability in ways that promote dignity

Both service providers and caregivers also identified gaps in knowledge in the following areas:

- Supports for people who use substances in pregnancy
- Research on best practices for FASD prevention
- Ways to support caregivers of people with FASD
- Ease of access/navigation of FASD information and resources
- Information to share with youth and adults about alcohol use and contraception to reduce the risk of future alcohol-exposed pregnancy

Survey respondents identified that people with FASD/possible FASD, and people who use substances during pregnancy face barriers when seeking services and supports.

The systems/services where people with FASD face the most barriers were rated differently by service providers and caregivers:

As Rated by Service Providers

1. Mental Health Services
2. FASD Assessment and diagnostic services
3. Housing services
4. Adult disability services
5. Substance use/addictions services

As Rated by Caregivers

1. Educational Supports
2. (tied) FASD Assessment and diagnostic services
2. (tied) Income support services
3. Parenting supports
4. (tied) Mental health services
4. (tied) Adult disability services

The systems/services where people who are pregnant and use substances face the most barriers, as rated by service providers and caregivers, are:

1. Mental health services
2. (tied) Substance use/addictions services
2. (tied) Health care services
3. (tied) Child welfare services
3. (tied) Parenting supports

3. Where can partnerships between service providers be built or strengthened to improve FASD initiatives in Manitoba?

During the virtual conversations, stakeholders indicated that increased collaboration is especially important with service providers in rural, northern, and First Nations communities. Stakeholders also saw increased partnerships as a way to support successful transitions for youth entering adulthood, and to facilitate a holistic and multi-disciplinary approach to supporting people impacted by FASD.

In the survey, the majority of service providers reported that there were some successful collaborations, but overall their collaborative relationships with other services or systems need improvement. According to the majority of respondents, systems that need improved collaboration include child welfare, education, adult disability, cultural/spiritual supports, and parenting supports. Other respondents identified healthcare, mental health, justice, employment support, and income support as areas for improved collaboration.

4. How can FASD initiatives in Manitoba promote the dignity of people impacted by FASD?

In community conversations, stakeholders indicated that increasing awareness and information about FASD is the most important way to promote dignity. This includes promoting neurodiversity, telling stories of how people with FASD can find success with the right supports, and sharing information about FASD in culturally safe ways. People with lived experience of alcohol use in pregnancy also indicated that promoting dignity is essential to make services more accessible. For instance, in prenatal health care settings when people felt stigmatized for substance use, they felt unsafe and uncomfortable attending subsequent prenatal health care appointments.

Stakeholders were asked about whether they felt the name ‘Fetal Alcohol Spectrum Disorder’ was a source of stigma. Many stakeholders indicated that the name perpetuates stigma towards people with FASD and people who drink alcohol during pregnancy. Some stakeholders advocated a move towards using terms such as ‘neurodevelopmental disability’ or ‘neurodiverse.’ Others expressed concern that moving away from the use of the term ‘FASD’ may lead to less awareness and support, or that a name change would not address root causes of stigma.

There was also stakeholder feedback indicating concerns about racism tied to the name ‘FASD’ and the FASD diagnostic process. Stakeholders indicated concern regarding cultural and racial biases within the process of referrals for FASD assessment, such as Indigenous mothers being more likely to be asked about alcohol use during pregnancy by their health care providers. Several stakeholders indicated concern about public misconceptions that FASD is an issue that primarily involves Indigenous populations, leading to stigma and judgment. As a result, stakeholders indicated that the term ‘FASD’ carries negative and traumatic connotations for some within Indigenous communities. This impacts people’s willingness to seek supports, particularly if the name ‘FASD’ is associated with an event or program.

This feedback points to a need to examine the stigma and assumptions around FASD as they are experienced by Indigenous people and other Manitobans. Collaboration with Indigenous service providers, Elders, and other stakeholders is recommended to address concerns of racism and cultural/racial bias and to combat stigma and judgment towards any people impacted by FASD, but in particular towards Indigenous people and communities.

In the survey, the majority of service providers and caregivers indicated the name ‘Fetal Alcohol Spectrum Disorder’ causes stigma or judgment towards people with FASD, caregivers of people with FASD, and people who use substances during pregnancy. A higher percentage of service providers compared to caregivers reported the FASD name causes stigma.

In the survey, service providers and caregivers were asked to rate the level of stigma they see towards people impacted by FASD in different contexts. Service providers tended to rate stigma higher than caregivers. The top areas rated as having a high level of stigma towards people with FASD, caregivers of people with FASD, or people using substances while pregnant, were:

As Rated by Service Providers

1. Media
2. Language used when talking about FASD and substance use in pregnancy
3. Workplace environments/employers
4. (tied) Within the person's community
4. (tied) Health care workers
5. School environment and educational institutions

As Rated by Caregivers

1. School environment and educational institutions
2. (tied) Workplace environments/ employers
2. (tied) Within the person's family
3. Language used when talking about FASD and substance use in pregnancy

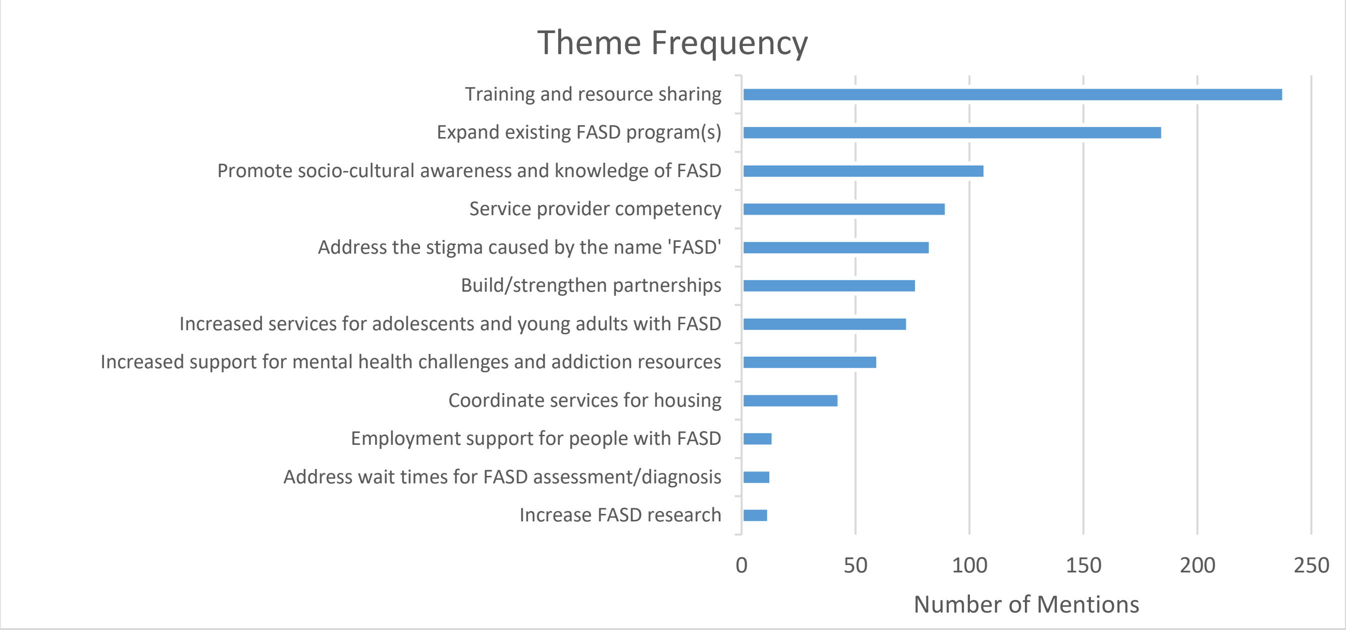
Service providers and caregivers provided suggestions as to how to better promote the dignity of people affected by FASD.

- *Perceptions of FASD*: Many service providers' suggestions were around addressing stigma through public education, for example to demonstrate that FASD is no different from other neonatal neurological disorders. One respondent noted that the label 'FASD' causes unnecessary stigma, particularly towards Indigenous children. Other suggestions were to focus on the person not the diagnosis, and that the term FASD enforces an inaccurate assumption that the person's mother did not care for them.
- *Promote strengths*: Service providers suggested including more positive stories and using a strength-based approach, promoting socio-cultural awareness and knowledge of FASD with culturally welcoming programs. Caregivers also suggested the importance of promoting strengths and providing education that is straightforward and not intimidating.
- *Lack of services and supports*: Service providers pointed out the need for increased support and diagnostic services for adults. In addition, the need was identified for more information/resource sharing around understanding cognitive impairments for people with FASD or possible FASD. Caregivers had several suggestions for increased training, services, and support, especially in schools. There were also suggestions to prioritize the expansion of existing FASD programs.

5. What should be the top priorities of the Manitoba FASD Strategy going forward?

Stakeholder Conversations & Ideas Page

Stakeholder conversation and Ideas page feedback on priorities of the FASD Strategy centred around the following 12 key themes.



A. Training and resource sharing: 238 mentions

Stakeholders identified training for service providers and resource sharing as beneficial. Stakeholders would like to see an increase in training opportunities to address staff turnover, such as more offerings of the two-day provincial FASD training. They also suggested different approaches to training such as online training modules, and easy to use "tool kits" to help service providers understand specific FASD-related topics. Additional ideas included:

- Targeted training to specific service provider sectors (health care workers, educators, CFS)
- Service navigation resources for adults with FASD to direct them to accessible supports
- Resource sharing through increased networking and communication among service providers
- Increased promotion and distribution of the FASD Services in Manitoba Resources List

"Training is needed across all systems to have a disability lens. (Service providers) need to understand the whole person, not just FASD. Stop generalizing, everybody is different. Right now, we are expected to change to fit the system." –Adult with FASD

B. Expand existing FASD programs: 185 mentions

Stakeholders identified a number of existing FASD programs that are successful in supporting the needs of people impacted by FASD and they recommended increasing program capacity, funding, eligibility, and/or geographic area of service (especially outside Winnipeg). The programs most commonly mentioned include Manitoba Key Worker, FASD diagnostic services (including adult FASD assessment), FASD Justice Program, FASD Court Docket, Starfish Program, Stepping Out on Saturdays, FASD

Family Support Program, InSight Mentoring Program, and Spectrum/Rural Connections. Additional ideas included:

- Additional post-diagnosis follow-up services from the FASD Centre, especially at transition ages
- Training specific primary health care providers to work with people with FASD
- Modified parenting program curriculum for parents with FASD
- Additional FASD Specialist positions within more school divisions
- Expanded mentorship support models

"If the person can't go to the city, why can't the city go to their community?"
–Service Provider

C. Promote socio-cultural awareness and knowledge of FASD: 107 mentions

Stakeholders recognize the ongoing importance of general public education about FASD and substance use in pregnancy. This includes awareness campaigns, community presentations, hearing the stories of people impacted by FASD, and culturally relevant materials on FASD for Indigenous and newcomer communities.

Stakeholders noted that to support Truth and Reconciliation Commission recommendations 33 and 34, Indigenous people impacted by FASD need to have their foundation in traditional Indigenous teachings, ceremonies, language, and medicines. Stakeholders also said that programming needs to recognize and value the effectiveness of Indigenous-led and culturally-grounded approaches to support people impacted by FASD. Additional ideas included:

- Develop relevant supports to all Indigenous communities: Métis, Inuit, and First Nations
- Remove systemic barriers to cultural supports, for example ensuring adequate space in schools, health care, and social service settings for Indigenous ceremonies
- Create an Indigenous Elders' Advisory for the FASD Strategy

"Culture first, then program – instead of the other way around." –Elder
"*We know what to do. Let us heal our children." –Elder*

D. Service provider competency: 90 mentions

Stakeholders would like to see an increase in the number of service providers in various social service sectors who can respond effectively and consistently to the needs of people impacted by FASD and related issues. Adults with FASD said that effective service provision is not just about understanding FASD and best practice strategies to support people with FASD. It is also about using person-centred approaches that are patient, non-judgemental and focus on establishing a relationship first. Stakeholders also identified many possible challenges or barriers that people with FASD/people who use substances in pregnancy may face in accessing services. Additional ideas included:

- Address systemic barriers and discrimination
- Adapt policies to best serve people with FASD, and people who are pregnant and use substances
- Seek input from people with FASD in program development

“Staff shouldn’t make blanket assumptions, not all people with FASD are the same.” –Adult with FASD

“Teach staff to learn about FASD, but also how to understand me as a person.” -Adult with FASD

“They made me feel comfortable; they didn’t judge me.” -FASD prevention program participant

E. Addressing the stigma caused by the name FASD: 83 mentions

Many stakeholders felt that the name FASD can be a source of stigma, specifically the term ‘Fetal Alcohol.’ Many suggested the idea of moving towards a term like “neurodevelopmental disability” which does not include the cause of the disability in the name. Some people expressed concern about changing the name if it resulted in a reduction of supports for people impacted by FASD or a reduction in public awareness of FASD and prenatal alcohol exposure. When adults with FASD were asked about the name ‘FASD,’ they indicated that they feel the name can cause a negative label and incorrect negative assumptions about them, and that it causes stigma towards their mothers. One person indicated they are hesitant to share their diagnosis because they have been shamed in the past. However, adults with FASD were concerned that if the name ‘FASD’ changed, it may lead to less support.

“Change the name ‘FASD’ for less focus on the diagnosis, and more focus on function-based supports through a neuro-diverse lens.” – Service Provider

“The name ‘FASD’ causes stigma towards biological moms, (and there are) lots of assumptions about people with FASD; I get shamed and judged. But I am concerned that a name change might lead to less support.” –Person with FASD

F. Build/strengthen relationships: 77 mentions

Stakeholders suggested strengthening partnerships between FASD service providers and those who support Manitobans impacted by FASD in a less direct role, such as Jordan’s Principle case managers, Crisis Help Line staff, child and family services workers, as well as First Nations community leaders, Elders, and service providers. Service providers indicated that stronger partnerships between service providers will result in more effective collaboration and less working in silos.

“We need opportunities to come together and learn from one another” –Service provider

G. Increased services for adolescents and young adults with FASD: 73 mentions

Stakeholders identified a decrease in service availability/eligibility for youth with FASD, especially if youth are transitioning to adulthood, leaving the child welfare system, living in rural or northern Manitoba, and/or requiring higher levels of support due to mental health or addictions. Additional ideas included:

- Create safe spaces for youth such as hub model services, drop in and recreational programming, and mentorship supports
- Address systemic barriers to smooth transitions from youth to adult services
- Increase services through school transitions, particularly for middle/high school students

"When I support youth, I think, 'What do these youth need from their grandmother?' They need what I need: they need love, they need to have some fun. Accept them for who they are. Don't make them feel inadequate- they've had enough of that. Tell them they're valuable in lots of different little ways. Celebrate the successes, even the little ones. […] We all need to belong, to feel like we have something to contribute, that we're valued, that we're accepted." –Elder

H. Increased support for mental health challenges and addiction resources: 60 mentions

Feedback highlighted a need for increased mental health and addictions supports and resources for people with FASD and people who use substances during pregnancy, especially for people living outside of Winnipeg. This included the need for more mental health supports for the whole family, including caregivers and siblings of people with FASD. Stakeholders also felt there was a need to improve connections between FASD, mental health and addiction resources. Additional ideas included:

- Expand addiction supports available to people with FASD, e.g. Starfish Program
- Improve service provision for people with dual diagnoses (FASD and mental health)
- Ensure people who are pregnant and using substances can access barrier-free addictions supports through strong service provider collaboration

"*It's a barrier when people need to be in the right place at the right time to get services." –Service Provider*

I. Coordinate services for Housing: 43 mentions

Stakeholders highlighted the need to increase the availability of safe and consistent housing and housing supports for people with FASD and women who use substances during pregnancy. Stakeholders identified a need for increased collaboration between service providers to address housing needs during key transition times, such as during the transition to adulthood or for people leaving custody. Additional ideas included:

- Increased housing availability for people with FASD and people who are pregnant and use substances, including supported/semi-supported housing and short-term transitional housing models that utilize no-barrier and harm-reduction service models
- Increased housing service navigation support for people with FASD, such as navigation coordinators and online housing resources

- Housing shelters to provide on-site program access and supports for people who are pregnant and use substances

"I need a consistent, safe place to be, in a neighbourhood where I won't get in trouble." - Adult with FASD

J. Employment for people with FASD: 14 mentions

Stakeholders recommended increased collaboration between FASD service providers, employment supports and employers to ensure people with FASD have more access to successful employment opportunities. Additional ideas include:

- Additional training for employers to understand how to best understand and support employees with FASD.
- Systemic changes to facilitate a more secure transition from receipt of income assistance to employment.

"I don't always mention my disability. It's easier to struggle at a job than mention you have FASD." –Adult with FASD

K. Address wait time for FASD assessment/diagnosis: 13 mentions

Stakeholders in some regions of Manitoba highlighted a need to reduce wait times for specific assessments such as Occupation Therapy, Speech and Language, and Psychology. It was also suggested that the Manitoba FASD Diagnostic Network be expanded into more First Nations communities, which would expedite assessments.

"To expand FASD diagnostic capacity, we need more people on the ground in communities to develop relationships." –Service Provider

L. Increase FASD research: 12 mentions

Stakeholders wanted to see more research on topics pertaining to FASD and alcohol use in pregnancy, and highlighted the need to include people with FASD in the research process. Additional ideas included:

- Better partnerships with researchers
- Research on nutrition as a protective factor against prenatal alcohol exposure
- Research on the experiences with the FASD diagnostic process

"FASD researchers should partner with people with FASD." –Service Provider

Online Survey

In the survey, service providers suggested prioritizing increased support for mental health challenges and addiction resources, and increasing services for people with FASD. Examples include:

- Make advocates available at health care facilities
- Decrease wait times for FASD assessment and diagnosis
- Increase adult services and supports to address the lack of adult diagnosis and accessible community programs for vulnerable adults

- Address stigma particularly around the FASD label used on Indigenous children
- Open an Indigenous-led assessment clinic for FASD and other disorders
- FASD specialists within Child and Family Services authorities to address the high number of children in care that have FASD or possible FASD
- Increase timely supports for youth to prevent criminal justice system involvement
- Increased FASD education and awareness
- Expand existing FASD programs
- Coordinate housing services for people with FASD
- Ensure diagnostic criteria adequately account for cultural considerations, adaptive functioning challenges
- Invest in early FASD intervention and prevention programming

In the survey, caregiver themes centred on increasing services/supports for children and families, including:

- Increased supports, training, and resource sharing in schools including supports to help children avoid the criminal justice system
- Financial support for caregivers
- Lower wait times for FASD assessment/diagnosis
- Increased supports for those without an FASD diagnosis
- Increase public awareness of FASD in ways that decrease stigma
- Therapy for family, counselling and classes
- Education on how to talk about FASD with loved ones
- Activities for FASD children under 12 years
- Training for caregivers on how to cope with raising a child with FASD
- Increase availability of FASD programming to people in rural and northern Manitoba

Next Steps

Overall, stakeholders feel that current FASD initiatives in Manitoba are working well. There was significant feedback recommending the expansion of many existing FASD programs to provide these services to more Manitobans.

The consultation also highlighted many ways in which Manitoba’s FASD Strategy can grow. The importance of training, especially training that is easily accessible and tailored to the audience, is a strong priority. There were many recommendations for ways that services for people with FASD could be improved: increasing culturally grounded programming for Indigenous people impacted by FASD, building partnerships between service providers to improve collaboration and support, addressing service gaps for youth/young adults with FASD, increasing mental health and addictions supports, increasing housing supports, and expanding employment opportunities.

The Manitoba government will use the stakeholder engagement findings to shape strategic priorities for a renewed Manitoba FASD Strategy. The renewed strategy will be launched in 2022.

Questions?

Please contact FASDinfo@gov.mb.ca.

This publication is available in alternate formats upon request.

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