FASD Research:
Learning Together

August 29 & 30, 2016

CanFASD
CANADA FASD RESEARCH NETWORK

Message from the Chairs

We hope that you enjoy reading this Final Report for the workshop, FASD Research: Learning Together. We imagine that the audience for this report will be the participants who attended, so we would like to start by thanking you — the participants. You were key to the workshop's success by bringing your wisdom, resilience, and compassion to the table, and we are grateful you shared yourselves so freely.

This workshop was designed to build on what Canada FASD Research Network (CanFASD) does best: bringing researchers, parents, front-line workers, policy makers, and individuals with FASD together to work collaboratively. We know there are many challenges facing individuals with FASD and those who care for them. The workshop was funded by an initiative by the Canadian Institutes of Health Research that focuses on bringing researchers and "patients" together — we were fortunate to receive funding for this event to help us further our efforts to improve the lives of those with FASD.

Over the past year, an article entitled *Life Expectancy of People with Fetal Alcohol Syndrome* (FAS) revealed jarring findings including a diminished life expectancy for people living with FAS. This study reminds us of the urgent need to work collaboratively to address the social justice issues associated with FASD. Concurrently, a research project led by three adults living with FASD is collecting data from hundreds of people and identifying otherwise under-studied health conditions associated with FASD. Both of these studies were topics of discussion at the Learning Together workshop. It was evident from the workshop discussions that not only is more research needed on FASD as a lifelong, whole body disorder, but there is urgency in this research to help secure appropriate supports and services necessary to help people live healthier and longer lives.

The workshop was focused on facilitating collaboration by putting researchers, frontline workers, policy makers, people with FASD, and their caregivers all into discussion. This challenge was taken up enthusiastically as evidenced by the information contained in this report and the commitment by participants to continue the work. In the coming months, CanFASD will be releasing a series of tools and resources that are a direct result of the feedback by participants. We look forward to rolling up our sleeves and continuing this important work with you.

The University of Regina was a wonderful location and partner in this workshop. Many thanks to Street Culture Kidz for catering our lunches; they are a shining example of a strengths-based initiative. We were fortunate to have Katy Flannigan, Alexandra Johnson, Leslie Sabiston, and Aamena Kapasi take excellent notes. Special thanks to Knowledge Keeper Noel Starblanket who started us off in a good way, and to Dr. Vianne Timmons for sharing her story with the audience. We will close by again thanking the participants, the Canadian Institutes of Health Research, and CanFASD for making this event possible.

Sincerely,

Dorothy Reid
Dorothy Reid, CanFASD
Family Advisory Committee Co-Chair

Michelle
Michelle Stewart, CanFASD Researcher

Key Findings

The two-day workshop brought together over 60 participants with discussions in four key areas.

- **FASD as a Whole Body Disorder** was a discussion that builds on the need to understand FASD as more than a brain-based injury. Conversations included the following subthemes:
  - Multiple Medical Conditions
  - Mental Health
  - Non-Medical Interventions
  - Lack of FASD Awareness
  - Quality and Continuity of Care
- **Aging and Transitions** was a focus of discussion that includes consideration about what it means to age with a disability and the impact of aging caregivers. Discussions included:
  - Autonomy
  - Lifespan Development
  - Social Determinants of Health
  - Barriers to Continuity of Supports
  - Challenging Systems
  - Aging Caregivers
- **Strategies and Supports** that are appropriate for those living with FASD can be very challenging to access and maintain. Discussion included the following subthemes:
  - Caregiver Needs
  - Supporting Function
  - Brain and Body
  - The Role of Relationships
  - Strengths and Hope
- **Advocating for Supports** is key to not only accessing appropriate supports and services but also enhancing and expanding those supports. As an emerging discussion, the subthemes included:
  - Training and Education
  - Stigma
  - Justice Interventions
  - Prevention
  - Defining Success for FASD

Pre-Workshop and Information-Gathering

The Family Advisory Committee (FAC) of the CanFASD Research Network was developed to advise the Network on research priorities for families impacted by FASD, and to assist in translating results of research to ensure they are accessible to families.

One of the goals of the FAC is to identify and inform emerging research priorities as they relate to those who provide support to individuals with FASD. As part of meeting this mandate, the FAC in conjunction with CanFASD Researchers held this workshop aimed to engage caregivers, individuals with FASD and researchers in a two-way discussion of research priorities. In order to learn as much as possible about the priorities of caregivers, CanFASD engaged in two information-gathering processes before the workshop.

National Survey

The first information-gathering process was a national survey attached to the electronic workshop announcement. The announcement was broadly distributed and recipients were invited to answer three questions related to their experience with FASD research (see Appendix 1 for questions). Sixty-one responses were received from caregivers and FASD service providers, and were categorized to identify common themes.

FASD Community Discussions

The second information-gathering process involved small group discussions with caregivers in the community. Three additional questions were added to the original questions, focusing on support strategies, issues related to aging with FASD, and physical or health-related concerns (see Appendix 1 for questions) because of the frequency that they were raised in the national survey. Forty-nine individuals participated in small group discussions or virtual discussion groups.

Emerging Themes

Four key themes emerged throughout the survey and community discussions: FASD as a Whole Body Disorder, Aging and Transitions with FASD, Strategies and Supports, and Advocating for Supports.

CanFASD used the analogy of a tree to assist in the collection and sharing of information gathered throughout the workshop, with each main theme becoming the trunk of a tree. It is important to note that participants expressed overwhelmingly positive feedback about the workshop, and 97% of participants confirmed that the four themes presented were consistent with their experiences (see Appendix 2 for a full description of participant feedback).

Workshop Overview

The workshop was held at the University of Regina on August 29 and 30, 2016. There were 60 participants, including caregivers, individuals with FASD, FASD service providers, government and policy representatives, FAC members, and CanFASD researchers and staff.

The goals of the workshop were to:

- Share and discuss new knowledge about FASD prevention, diagnosis, and intervention tailored to the concerns and interests of people living with this disability, their families, and caregivers
- Initiate an accessible and ongoing dialogue between FASD researchers, families, and people with FASD to inform CanFASD's future research and knowledge exchange priorities

The workshop provided the opportunity to:

- Identify emerging issues and knowledge translation priorities for families and individuals living with FASD that could guide future research
- Identify needs, gaps, and opportunities in the FASD health research landscape, priority policy issues and/or priority research questions, where such common understanding is currently lacking or requires further development

Day 1 Overview

The workshop was organized around the themes identified in the survey and community discussions groups. In the opening session of the workshop, the event co-chairs consulted with participants about the chosen themes, and small groups were formed to discuss each theme, facilitated by a CanFASD researcher and a FAC member. Participants shared their perspectives and asked questions of the researchers, and identified subthemes within each theme, which became the branches of the trees. Specific issues or questions identified by caregivers and individuals with FASD became the leaves covering the tree branches (see Appendix 3 for full list of leaves). The final discussions on Day 1 were strategy sessions where participants further explored issues related to each theme and generated specific questions, which were also added as leaves to the tree branches.

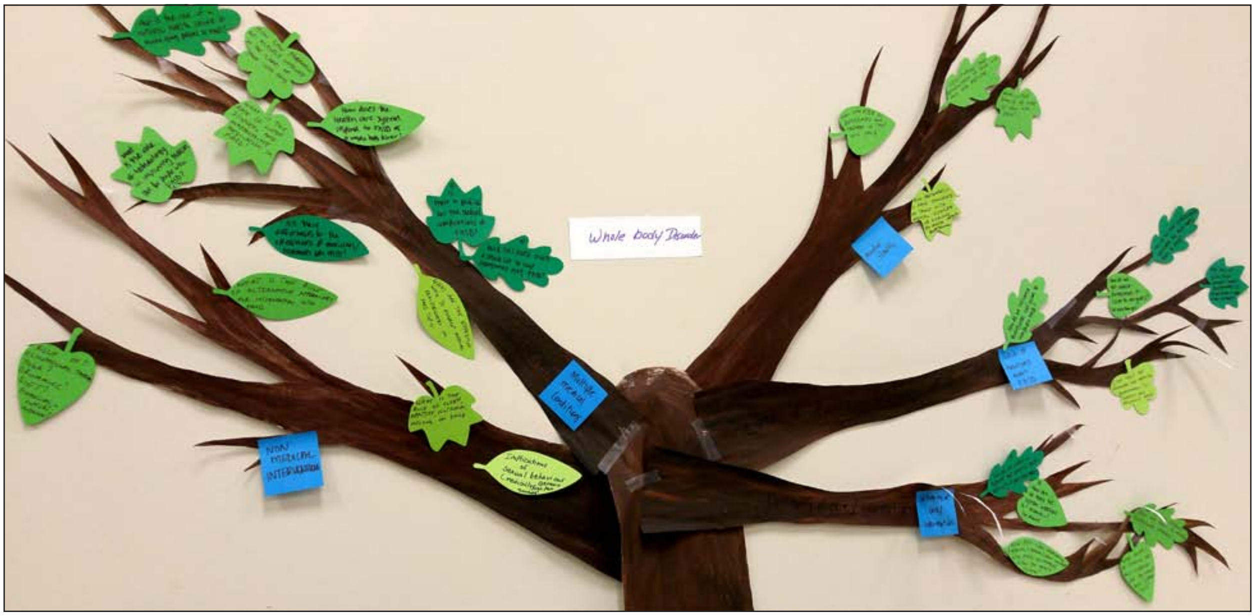
Day 2 Overview

Day 2 began with the CanFASD researchers sharing with participants some of the key research projects that they are involved in, pertaining to the discussions that arose on Day 1. This was followed by small group sessions focusing their discussions around effective collaboration and next steps for advancing FASD research in Canada.

Workshop Findings and Discussion

FASD as a Whole Body Disorder

The first tree reflects the fact that FASD impacts not only the brain, but also many systems within the body.

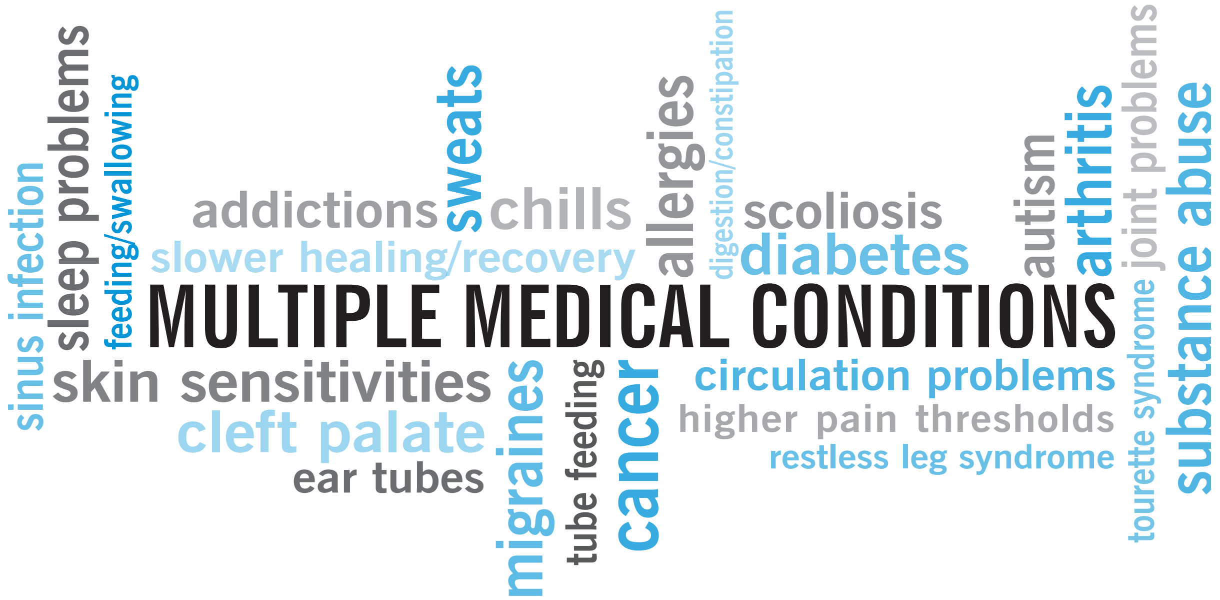


Multiple Medical Conditions

One branch of the whole body tree related to the multiple conditions commonly experienced by individuals with FASD. In addition to questions around brain development and brain-based intervention strategies, participants discussed common physical and behavioural conditions, ranging from problems with sleeping and eating, to migraines, skin sensitivities, sexual health, and even cancer. Conversation arose around the possibility of identifying a medical profile associated with FASD, which may be used by health care providers as a potential screening tool. A number of participants explained that a holistic health care system — including providers from multiple professions, and addressing all facets of the disability — would be ideal for individuals living with FASD. Another topic of conversation related to medication management, with participants wondering whether certain medications may have unique effects for people living with FASD. They shared stories of their loved ones with FASD growing tired of feeling like “lab rats” from constant medication changes, and some relying on “self-medicating” with substances to alleviate physical and emotional discomforts. They also expressed interest about the use of medical marijuana in FASD.

Mental Health

Another whole body branch discussed by the participants dealt with the fact that individuals with FASD often experience mental health



challenges in addition to the physical conditions related to the disorder. Trauma, stress, addictions, self-harm, and suicide were noted as particular areas of concern for participants, as well as concurrent behavioural disorders such as Attention Deficit Hyperactivity Disorder, Reactive Attachment Disorder, and Oppositional Defiant Disorder.

Non-Medical Interventions

Within this branch of the whole body tree, participants discussed their experiences with non-medical interventions, reflecting on how effective these approaches may be in managing physical and mental health, as well as brain-based challenges. Specifically, participants spoke of alternative and cultural activities such as meditation, yoga, reiki, drumming, art therapy, physical exercise and movement, occupational therapy, and diet and nutrition as potential areas for exploration.

Lack of FASD Awareness

Unfortunately, despite these complex health issues, participants commented on the lack of awareness related to FASD, and at times, a cultural bias, among some health care professionals and their support staff. Within this branch of the tree, participants reported that service providers tend not to recognize the connection between FASD and physical issues that may accompany the disability. Participants spoke of the need for health care providers to be better engaged and involved with individuals with FASD and their caregivers. Suggestions for how this may be achieved included FASD-informed changes to training curricula, exposure to the “real lives” of individuals and families living with FASD (e.g., eating dinner together or attending camp for kids with FASD), and listening to personal stories of individuals and their families.

Quality and Continuity of Care

Another branch of the tree was centred on the notion of quality and continuity of health care. Participants spoke of the hesitation that individuals and families often experience when working with health care professionals, stemming from histories of not feeling “heard.” They explained that building stronger, trustful relationships with professionals and working

together to identify and overcome barriers could help to reduce this hesitation. Adequate funding and advocacy were noted as especially important for ensuring quality and continuity of care, and questions arose around the role of technology in improving care. Another key issue brought forward was the importance of strong communication between individuals and families living with FASD and their health care providers. Participants emphasized that information must be shared effectively and continually in order to support high-quality care across the lifespan. However, participants noted that patient confidentiality and protection of personal information is a significant priority.

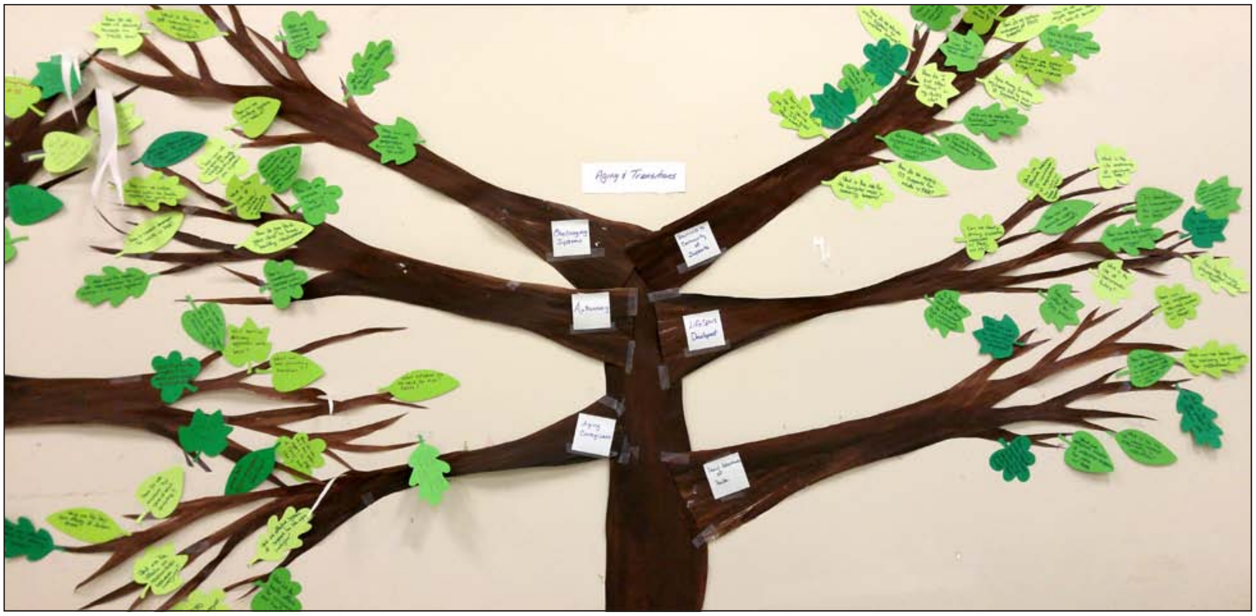
Related Research and CanFASD Issue Papers

There are several papers available relating to the conversations described above. Full references for research articles are provided in Appendix 4.

Authors	Study Title
Popova and colleagues, 2016	Comorbidity of FASD: A systematic review and meta-analysis
Stade and colleagues, 2006	Health-related quality of life of Canadian children and youth prenatally exposed to alcohol
Chen and colleagues, 2012	Sleep problems in children with FASD
Werts and colleagues, 2014	Inappropriate feeding behaviors and dietary intakes in children with FASD or probable prenatal alcohol exposure
Masotti and colleagues, 2015	Integrating care for individuals with FASD: Results from a multi-stakeholder symposium
Thanh and Jonsson, 2016	Life expectancy of people with Fetal Alcohol Syndrome
Grant and colleagues, 2013	The impact of prenatal alcohol exposure on addiction treatment
	CanFASD Issue Papers
Green and Salmon	FASD, stress, and mental health
Patten and colleagues	Nutritional supplementation and FASD
Clarren and Cook	Dose-response effect of alcohol consumption during pregnancy and prenatal alcohol exposure
Clarren and Cook	Meconium screening for FASD in pregnancy

Aging and Transitions

Within the next tree, participants explored the challenges and issues associated with aging and transitions for people living with FASD.



Autonomy

Participants spoke of ways to enhance self-advocacy among youth and adults living with FASD, and that interdependence with other people and systems is necessary for fostering positive outcomes. It was noted as essential to help youth and adults with FASD understand how the condition impacts their lives and that caregivers and other adults have the potential to be educators for people living with FASD. Suggested strategies for fostering autonomy included training on life skills, money management, and transportation and driving. Emphasis was also placed on ensuring safety and protecting against the dangers of social media and internet, self-harm, and theft and fraud, and supporting healthy sexual development and behavior.

Another issue that arose within the branch of autonomy was justice-involvement among youth and adults with FASD. Difficulties navigating the justice system were noted as a concern, and participants wondered about the long-term implications of incarceration. Participants suggested that correctional interventions and alternative justice programs should be explored for people living with FASD.

Lifespan Development

Discussions in this branch were focused on how lifespan development may be different for people with FASD. For instance, questions arose around life expectancy, dementia, and quality of life among the elderly, and concerns were brought forward that our adult systems and services may not be equipped to appropriately support people with FASD as they age.

Participants wondered whether this service gap might lead to increased risk for self-medication during times of transition. Environmental influences on the process of aging (e.g., stress, trauma) were discussed, and participants wondered whether FASD-related issues such as mental health, adaptive functioning, sensory processing, and sexuality change with time or vary depending on gender. Participants agreed that updated research is needed on "secondary disabilities" associated with FASD.

Social Determinants of Health

Participants spoke of enhancing a range of social determinants of health for people with FASD. For instance, access to education, job training and employment, housing, secure income, positive social interactions, and other meaningful activities (e.g., recreational programming) were deemed as crucial for supporting people with FASD as they age.

Conversation focused on supporting people living with FASD and addictions. Participants emphasized the need for programming that is FASD-informed, women-centred, and strengths-based, involving mentorship and exploring alternative ways of coping to replace self-medication. Questions also arose around how peer pressure might influence substance use for people with FASD.

Barriers to Continuity of Supports

Participants spoke of both system- and individual-level barriers that interfere with the provision of adequate supports for people with FASD as they age (see table below).

Despite these challenges, potential strategies for reducing barriers included better integration of services, adopting a person-centred approach, offering mentorship, and linking administrative data across agencies to improve continuity of supports.

System-Level	Individual-Level
■ Lack of FASD knowledge ■ Geographic limitations to service access ■ IQ-based eligibility criteria ■ Limited financial assistance for families ■ Lack of ability to deal with mental health and behavioural issues ■ Poor inter-agency communication ■ Ongoing stigma ■ Long waitlists for assessment (individuals with prenatal alcohol exposure may pass away before receiving a diagnosis) ■ Risk of FASD "getting lost" within new cross-disability approaches	■ Difficulties assisting clients who have "burned bridges" in the past ■ Client breaches that interfere with service access ■ Service providers with unrealistic expectations of clients ■ Language limitations, and lack of understanding and support for communication-based needs (e.g., completing paperwork) ■ Loss of supports when people with FASD "age out" of pediatric services or experience successes

Challenging Systems

Participants reflected on how geographic barriers could be reduced, what role families might play in improving systems, how systems and services may become better informed about FASD, and how supporting self-advocacy might assist them in confronting some of these challenges. Participants emphasized the role of research in informing the system, and suggested that redefining success would improve our work with people with FASD.

Aging Caregivers

The final branch moved beyond the individual with FASD, to issues affecting caregivers as they age. Participants discussed challenges of generational parenting, parenting with FASD, family breakdown, supporting adults who are undiagnosed, respecting rights and freedoms for adults with FASD while maintaining some control, and navigating the processes of trusteeship, power of attorney, and will-planning.

Related Research and CanFASD Issue Papers

Authors	Study Title
Temple and colleagues, 2011	Comparing daily living skills in adults with FASD to an IQ matched clinical sample
Burnside and Fuchs, 2013	Bound by the clock: The experiences of youth with FASD transitioning to adulthood from child welfare care
Chatterley-Gonzalez, 2010	The experiences and needs of young people with FASD: Silenced voices from youth in care
Lynch and colleagues, 2015	Prenatal alcohol exposure, adaptive function, and entry into adult roles in a prospective study of young adults
Rangmar and colleagues, 2015	Psychosocial outcomes of FASD in adulthood
	CanFASD Issue Papers
Green and Lakeland Centre for FASD	FASD and employment
Green and colleagues	FASD and the criminal justice system
Popova and colleagues	Social and economic cost of FASD

Strategies and Supports

The third tree that emerged from participant feedback was effective intervention strategies and supports.

Caregiver Needs

Similar to the aging and transition tree, participants spoke within this branch of the experiences and needs of caregivers supporting individuals with FASD. They discussed the impact of stress on caregiver aging and health, and concerns related to inheritance and family continuity. Respite support was an important topic of conversation: participants expressed the view that good respite across the lifespan is critical, and barriers to respite in small communities must be reduced (e.g., mobile respite). Other needed services included parent support groups, financial assistance, strategies for coping with mental health issues, supported parenting models, resilience building, and support for grief and mourning. Intergenerational issues were again discussed, such as the prevalence of multi-generational FASD and the effects of putting children in the role of parent. Participants suggested looking to other fields of disability research and practice to learn what work has been done regarding caregiver support.

Supporting Function

The second branch of this tree focused on how to best support the needs of individuals living with FASD. At a broad level, participants spoke of the need for changing general perceptions of FASD, reducing stigma, recognizing invisible barriers, changing media portrayals of FASD, and implementing mandatory FASD training for all service providers working with this population. Participants emphasized the importance of using a comprehensive assessment of function across domains to develop individualized support plans. They spoke of early identification and intervention for FASD that is individualized, low cost, and tailored to whatever function that a challenging behaviour might be serving. Structure and repetition, using trial and error to find strategies that work, and providing a safe and supportive environment were also highlighted.

Brain and Body

Another branch on this tree explored the idea of changing the brain, and involving caregivers and individuals in the implementation of brain-based interventions (e.g., helping children understand how their brain works). Participants also noted curiosity about strategies to support the physical, emotional, and cognitive aspects of FASD through brain-based interventions. Exercise, sports, and nutrition were also explored as potential interventions. Participants stressed the importance of identifying medical issues and physical health concerns. In general, participants wondered if individuals with FASD react differently to interventions than those without FASD.

The Role of Relationships

Discussions within this branch were focused on supporting healthy friendships and relationships for people with FASD across the lifespan. Questions arose about whether social support influences life outcomes for people with FASD, and how the role of relationships might differ between males and females with FASD. The importance of attachment was also emphasized, and participants wondered about the role of caregivers in contributing to social development and success.

There were a number of specific areas of intervention where participants expressed interest:

- Day-to-day strategies and environmental supports
- How to support comorbid conditions
- School- and community-based interventions
- Sensory integration strategies
- Insight-oriented therapy
- FASD camps
- Peer support
- Volunteer roles for people with FASD
- Culturally-informed interventions
- Adolescent services
- Supports across the lifespan
- Sex education, sexuality and gender
- Prevention of alcohol use
- Teaching money management
- Technology (i.e., cell phone apps)
- Animal therapy
- FASD and PTSD
- Partnering with police officers

Strengths and Hope

Throughout conversations within this whole tree, participants highlighted the need for a strengths-based, person-centred approach when working with people with FASD. They discussed the importance of debunking the myths of hopelessness within the FASD field, and how hope-based practices may have the potential to change daily functioning. They noted that it is essential to listen to the voices of those living with FASD in order to understand their lived experiences, develop FASD training practices, and build awareness of FASD. Learning from the experiences of other parents and caregivers was also noted as important for understanding how best to support people with FASD and build confidence, self-esteem, and self-advocacy.

Related Research and CanFASD Issue Papers

Authors	Study Title
Pei and colleagues, 2016	Interventions for FASD: Meeting needs across the lifespan
Murawski and colleagues, 2015	Advances in diagnosis and treatment of FASD: From animal models to human studies **Note article has practical applications in areas like intervention*
Rutman and Bibber, 2010	Parenting with FASD
Kapasi, 2015	Caregivers' experiences raising a child with FASD
	CanFASD Issue Papers
Baugh and colleagues	Caregiver needs and stress in caring for individuals with FASD
Green and colleagues	Computer game interventions for individuals with FASD
Green and colleagues	Why is FASD diagnosis important?

Advocating for Supports

The final tree that emerged from participant feedback related to advocating for effective supports for people living with FASD.

Training and Education

Participants expressed that additional training and greater awareness of issues related to FASD would in turn build a better landscape for advocating for people living with FASD. Some of the potential outcomes of increased training and education would be reducing parent isolation, securing funding, keeping families together, and recognizing different indicators of success. Participants recommended that training be collaborative and peer-driven. Questions also arose about how to evaluate the effectiveness of training programs.

Stigma

Conversations centred on ways to reduce stigma and blame, use research to counter negativity, and explore how attitudes impact the provision of services. Another priority identified by participants was educating the public about the trauma that is often part of the FASD picture.

Justice Interventions

Participants suggested that another avenue for advocacy involved a shift in the justice system in a way that allows for flexibility, creativity, individualization, sensibility, and realistic expectations rather than punitive approaches for working with offenders with FASD. The Truth and Reconciliation Commission (TRC) was discussed, with participants wondering how recommendation #34 (i.e., reforming the justice system to be more appropriate for offenders with FASD) might be carried out.

Prevention

Research to inform prevention strategies was identified as another significant priority in advocating for effective services. In this branch, participants stressed the need to openly discuss alcohol consumption and screen for use among all women, and for changes in the medical community around ensuring safe drinking levels and harm reduction for all demographic groups, not only those deemed to be "high-risk." It was noted that government has a responsibility to promote awareness about alcohol consumption during pregnancy (e.g., nutritional labeling, information about the toxicity of alcohol). The TRC was again discussed, this time in relation to item #33 (partnering with Aboriginal people in implementing FASD prevention programs in culturally appropriate ways), which was noted by participants as a step towards advocating for reform. Participants expressed that wrap-around prevention strategies are needed, and that all people working in the FASD field need to continually affirm that no woman ever intends to harm her baby.

Defining Success for FASD

The final branch of the advocacy tree involved discussions around defining and measuring success for people with FASD. Participants explored different approaches to evaluating parenting strategies, individual outcomes, service delivery, and support strategies. Unfortunately, participants noted that one of the ways that outcomes are currently assessed is through cost analysis, which results in people with FASD being portrayed as a burden. There were also conversations around how to ensure continuity of information and care to promote success for people with FASD, and the potential benefits of designating system-navigators, and identifying FASD specialists to support success. Supporting self-advocacy was identified as another priority within this branch. Research is needed to provide data to support effective interventions in schools, supported employment, and life-long services, and to secure funding to support wellbeing. Research on successful outcomes must be practical, interconnected across multiple systems, country-wide rather than region-specific, and always involve consultation with individuals living with FASD and their families. The ultimate hope is that our systems might one day develop the capacity to recognize the unique needs of each individual and value different forms of success for people living with FASD.

Related Research and CanFASD Issue Papers

Authors	Study Title
Hundert and colleagues 2016	Usability testing of guided internet-based parent training for challenging behaviour in children with FASD (Strongest Families FASD)
Eggertson, 2013	Stigma a major barrier to treatment for pregnant women with addictions
Di Pietro and colleagues, 2013	Treatments for neurodevelopmental disorders: Evidence, advocacy, and the internet
Currie and colleagues, 2016	Adults with FASD: Factors associated with positive outcomes and contact with the criminal justice system
	CanFASD Issue Papers
Poole and colleagues	Prevention of FASD: A multi-level model
Green and colleagues	Stigma, discrimination, and FASD
Thomas and colleagues	The effectiveness of alcohol warning labels

Effective Collaboration

Day 2 of the engagement workshop involved a discussion about the essentials of effective collaboration. The goal of the session was to identify elements and roles within collaborations that are required for research to move forward. Participants were also asked to report on how they prefer to receive research information.

What does meaningful FASD collaboration look like to you?

- **Structure.** Effective collaboration is based on a foundation of agreed upon and measurable goals with well-established timelines, common understanding of accountability, and a clear framework for evaluation. Flexibility, responsivity, creativity, and "people-oriented" goals are essential. Emphasis should be placed on team development, ensuring that team efforts lead to positive outcomes.
- **Respect.** Another key element is appreciating each individual's perspectives, valuing them equally, and acknowledging that each team member has unique and important expertise to offer.
- **FASD knowledge and training.** Each member of the team should have a basic understanding of FASD, including how it impacts the daily lives of those affected.
- **Communication.** Sharing information and experiences, telling stories while respecting privacy, using language that is respectful and understandable, and *listening* to what each member has to say. Feedback from all members of the team should be encouraged, and messages about research findings should be tailored to the audience with sensitivities to the power of language to include or exclude, support or blame.
- **Inclusiveness.** Collaborations require a safe space for engagement. Individuals with FASD and their caregivers need to be included in partnerships with front-line service providers, community agencies, researchers, government stakeholders, and funders.
- **Relationships.** Support, kindness, investment, commitment, trust, connectedness, openness to learn from one another, non-judgment, and willingness to advocate were described as paramount to effective collaboration.
- **Resources.** Team members should be compensated for their time and efforts, and resources should be offered to prevent burnout and promote self-care (e.g., regular respite). Time and space are both required for collaborative relationships to develop.
- **Strengths-based.** Collaborations should focus on positive outcomes and share successes, rather than emphasize challenges and barriers.

What do you see as your role in an effective collaborative approach to FASD?

Participants shared their views on the roles that they play in FASD collaborations.

knowledge sharer, clinician, researcher, facilitator, advocate, knowledge translator, caregiver, adult mentor, decision maker, recruiter, liaison, consumer, participant, knowledge user, information recipient, program developer, communicator, advisor, experimenter, networker, supporter, barrier crasher, educator, administrative support, learner, enabler, coordinator, teacher, integrator, listener, mediator, solution seeker, role model, contributor, documenter, recorder, note-taker, connector, storyteller, comedian, barrier smasher, conductor, visitor

How do you want to receive information going forward?

Strategies for sharing information were proposed, centering on four core ideas.

Brief	Multiple Modalities	Centralized	Relevant
■ Brief summaries of research and policy changes ■ Targetted key messages ■ Short reviews ■ Focused issue papers	■ Visual (e.g., infographics) ■ Written (e.g., reports) ■ In person (e.g., face-to-face conversation, especially in isolated communities) ■ Electronic (e.g., social media, online forums)	■ Central hub for information sharing ■ All information in one place ■ Linking multiple FASD organizations ■ “Crisis toolkit” explaining where to start looking for information	■ Implications clearly explained ■ Message tailored to the audience

Next Steps

The workshop concluded with CanFASD committing to sharing the results of the workshop with participants and to work closely on a go-forward basis with individuals with FASD and their caregivers in prioritizing research questions.

The Learning Together workshop was followed immediately by a Research Priority Setting Day with representatives of government and policy makers. A preliminary report of the findings from this workshop was given and there was great interest by all those in attendance as to the outcome and research needs identified by individuals with FASD, their families and caregivers. CanFASD also has committed to enhancing its repository of information related to FASD and developing effective tools for knowledge translation as identified by the participants in this workshop. Where knowledge on certain aspects related to FASD identified by the workshop participants as being important is available, CanFASD has also committed to the creation of additional issue papers on those topics and sharing those with the participants and other interested individuals. Where more research is required, CanFASD will explore the feasibility of supporting and facilitating those lines of investigation. Finally, the workshop was seen as one step along the journey that researchers, individuals with FASD, their families and caregivers are experiencing and CanFASD is committed to continuing the dialogue that has started leveraging the experience, strength, and resiliency of the Family Advisory Committee.

Examples of potential avenues for continued knowledge translation include:

- Ongoing publication of issue papers
- Electronic newsletters
- CanFASD blogs
- Highlighting FASD agencies/programs
- Video series/whiteboard animations
- Presentation of workshop findings at a CIHR summit in Ottawa
- Disability tax credit resources posted on the CanFASD website

A list of selected FASD resources are listed in Appendix 5.

Upcoming and Potential Issue Papers

Whole Body Disorder	Aging and Transitions	Strategies and Supports	Advocating for Supports
▪ Prevalence of FASD ▪ Pharmacology and FASD	▪ Best Practices for Supporting Transitions ▪ Homelessness and FASD	▪ Supported Housing ▪ Sexuality and FASD	▪ FASD and Child Welfare ▪ FASD Prevention from an Aboriginal Perspective

Appendix I: Pre-Workshop Questions

Prior to the workshop, CanFASD solicited feedback from individuals and partners across Canada. The CanFASD website included a link to registration and an anonymous survey that asked three questions. Preliminary feedback from the survey was taken into consideration when hosting local community meetings and virtual discussions. For those community discussions, three additional questions were explored to collect another layer of feedback prior to the Regina workshop event.

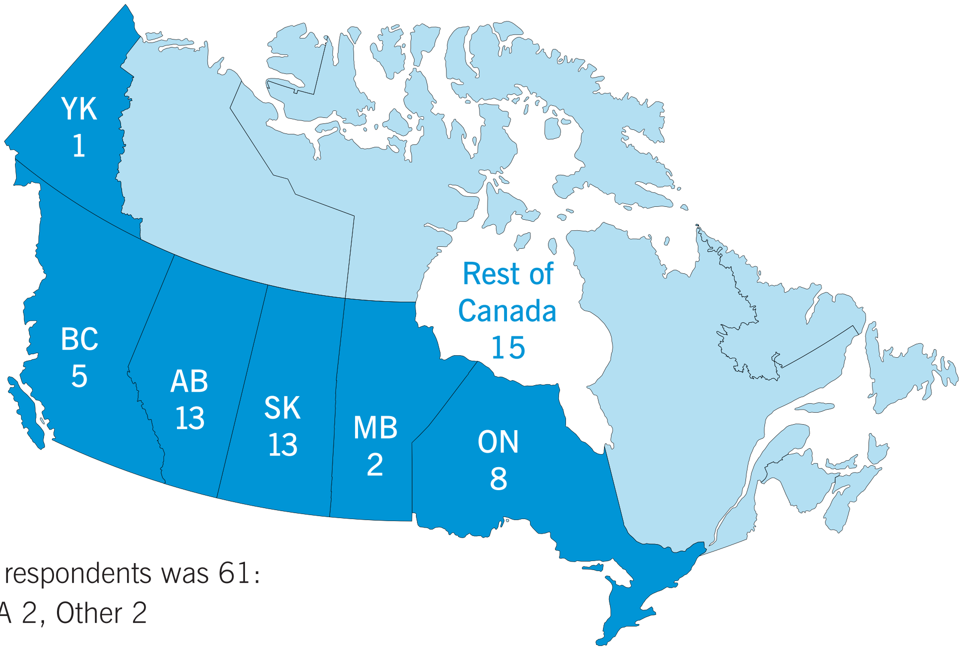
Survey Questions

- What kind of FASD research has been the most useful for you in the past?
- What aspects of living with FASD would you like to see more research done on?
- What would be your ideal way of receiving FASD research results?

Community Discussion Questions

- What kind of FASD research has been the most useful for you in the past?
- What aspects of living with FASD would you like to see more research done on?
- What would be your ideal way of receiving FASD research results?
- What kinds of strategies and supports for people with FASD would you most like to see researched?
- What do you think are the most pressing concerns for people with FASD as they age that we might explore through research?
- What do you see as emerging physical or health-related issues for people with FASD?

Location of Respondents



Total number of respondents was 61:
Canada 57, USA 2, Other 2

Appendix 2: Workshop Feedback

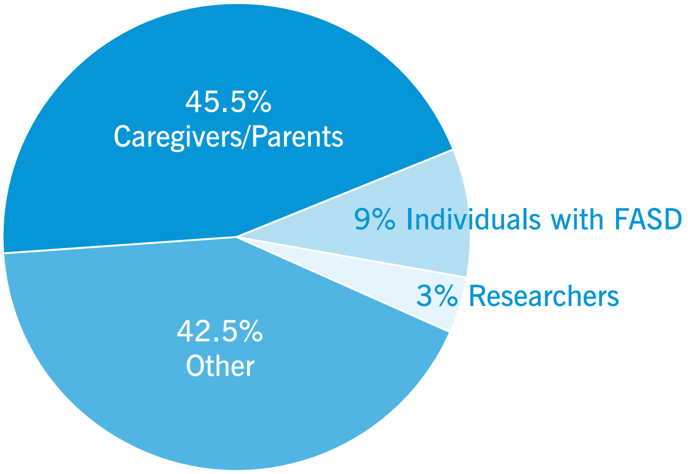
The satisfaction of participants was determined using evaluative questionnaire, including both fixed response and open-ended measures. The responses to the evaluations of the workshop were overwhelmingly positive. Overall, individuals indicated that the key themes and discussions aligned with their experiences, that their ideas were incorporated into the discussions, that it was a good use of their time, and that the sessions themselves were useful.

The questionnaires revealed that there were 15 caregivers/parents, 3 individuals living with FASD, 1 researcher, and 14 individuals who identified themselves as “other” in attendance. It should be noted that some individuals identified within multiple categories. The majority of individuals who identified as “other” were professionals working with individuals with FASD. Not all participants completed the workshop questionnaire.

When asked why they wanted to attend the workshop, the most common response was to learn about FASD. Other common responses included: to discuss strategies regarding FASD (including prevention, intervention, and supports), to share experiences, and to network with other individuals.

There were a variety of responses to what individuals believe to be the most pressing issues that must be addressed when discussing FASD. It is noteworthy that the majority of these responses can be incorporated into the four overarching themes that were determined through the survey responses: FASD as a Whole Body Disorder, Aging and Transitions, Strategies and Supports, and Advocating for Supports including special considerations of addictions and mental illness. In addition to this, many individuals also suggested that awareness and/or prevention were the most pressing issues when discussing FASD.

Questionnaire Respondents



Appendix 3: Full Transcription of Tree Leaves

The following is a full transcription of all of the tree leaves which represent the different ideas that were discussed within the themes and subthemes.

FASD as a Whole Body Disorder

Multiple Medical Conditions

- What are effective ways to engage medical practitioners on FASD topics?
- Is there a profile for the medical complications of FASD and could this profile create a check-list to help professionals flag FASD?
- Are there differences in the effectiveness of medicines/treatments with FASD?
- What is the role of technology in improving medical care for individuals with FASD?
- What is the rate of sleep disorders and inappropriate medication in FASD?
- How does the health care system respond to FASD as a whole body disorder?
- How can pharmacists be actively involved in the care of those with FASD?
- What is the role of a holistic health centre in managing people with FASD?

Mental Health

- How can PTSD be recognized and treated in individuals with FASD?
- Identification and rehabilitation of those with FASD and addiction
- What is the quality of life of those with FASD?
- How often is FASD diagnosed in those with mental disorders or dismissed by mental health professionals?

Non-Medical Interventions

- What is the role of sleep, appetite, nutrition, and housing on FASD?
- What is the role of occupational therapy? Yoga? Drumming? Diet? Financial support? Nutrition?
- What is the role of alternative approaches for interventions with FASD?
- What are the implications of sexual behavior (e.g., medical, sensory, high pain threshold)?

Lack of FASD Awareness

- How do we influence professional curricula to incorporate FASD?
- How do we get medical professionals to listen to caregivers “who know them best”?
- How do we help professionals understand the whole body effects of FASD?
- How can we build trust between medical professionals and individuals with FASD and their caregivers?
- Can tools be developed for professionals to identify and recognize FASD?

Quality and Continuity of Care

- How do we create a system that ensures better continuity of care/information? How can we make this system accessible by researchers?
- How best can information (physical and health) about individuals with FASD be shared within the health system?
- How do we support those with FASD to maintain nutritional balance?
- What models of funding are most supportive for the whole body approach?

Aging and Transitions

Aging Caregivers

- What are the health effects for caregivers over time?
- PTSD for caregivers?
- What are effective systems of support for aging caregivers?
- What are effective supports for planning will, estates?
- What are the long term effects of chronic stress?
- How do we account for generational parenting?

Autonomy

- How is comprehension assessed within various systems?
- What are the models of representation for adult children in various systems?
- How is consent developed with adults with FASD?
- How can we address barriers within the health system for adults with FASD?
- What are effective models for support for individuals with FASD in making informed decisions?
- What is the role of caregivers in educating systems?
- How do you teach children to have healthy relationships?
- How do you promote “buy-in” to services?
- What are the communication/language needs of adults? How do these needs translate within systems?

Challenging Systems

- How can we confront geographic barriers to service?
- What is the role of families in challenging systems?
- How can we challenge systems with research?
- What are effective models of education within systems?
- What is the role of self-advocacy in challenging systems?
- How do we look at service delivery through an FASD lens?

Barriers to Continuity of Supports

- How can we mitigate the loss of services due to IQ-based requirements?
- How do we mitigate success/growth resulting in loss of services?
- What is the role of mentorship in connection to services?
- How can we mitigate loss of services due to lack of diagnosis?
- How do we educate within systems to improve outcomes?
- How can we track medical information across regions?
- What is the role of stigma in access to service?
- How do I put other stars in my child ‘s life?
- Is there a role for specialized FASD services?
- What are the ways in which we can facilitate communication across systems for the benefit of individuals?
- How do we sustain involvement of FASD supports?
- How do we mitigate breaches resulting in loss of services?
- How do we establish the need for occupational therapy involvement past adolescence?
- How can we assist individuals who “burn bridges” with agencies?
- How many families buy homes due to lack of supportive housing?
- What are the models for facilitating inter-agency communication?
- Can we re-evaluate the requirements for financial assistance?
- What are effective supportive living models for individuals with FASD?
- What is the role of the navigator model in sustaining supports?

Lifespan Development

- Can we identify primary disabilities associated with FASD and aging?
- What are effective models of communication of expectations for individuals with FASD within systems?
- What is the life expectancy for individuals with FASD?
- How can we evaluate coping mechanisms?
- Is dementia an increased concern for individuals with FASD?
- How can we help/support individuals in identifying triggers?
- How does sensory disorder affect sexuality in men and women?
- Do sensory issues change over time?
- How does the aging process affect individuals with FASD?

- What is the role of environmental factors?
- Does gender affect the aging process?
- Is there an increased risk for self-medication during the transition from adolescence to adulthood?

Social Determinants of Health

- How can we ensure access to meaningful education and employment?
- How can we implement secure income for individuals with FASD?
- How frequently is self-medication with substances used as a coping method by individuals with FASD?
- How can we build on resilience in supports for addictions?
- What is the role of peer pressure in substance use?
- What is the role of women-centred programming in reducing or preventing addictions?
- What are effective models of addiction supports for individuals with FASD?
- How can we make supportive programs related to the social determinants of health, FASD friendly?

Strategies and Supports

Caregivers Needs

- What can we learn from the literature on children put in parental roles because of parents needs? How do we support them?
- What could a supported parenting model look like for parents with FASD (instead of apprehension)?
- How do we help people better understand the needs of FASD and their caregivers?
- What kinds of respite supports are working? How can we reduce the barriers to good respite across the lifespan?
- How can we implement strengths-based/person centred approaches?
- What is the impact of caregiver stress on aging and health?
- Would mobile respite support work? Or considering non-western models?
- How do we support caregivers as they grieve/mourn loss of a child at an early age?
- How common is the intergenerational experience of FASD? How prevalent? What kind of caregiving?
- How to plan wills and continuity of care (legacy planning)?
- How do we understand traumatic stress and the impact on caregivers?
- What can we learn from other fields where caregivers experience trauma?

Supporting Function

- How do we impact how media portrays FASD?
- How could we motivate women to reduce alcohol intake i.e., highlighting the medical conditions associated with alcohol use?
- How do we adapt sex education for people with FASD?
- How can we reflect gender differences in the area of FASD strategies and supports?
- What strategies and supports are available without having a diagnosis?
- How to support generational loss (i.e., grandmother grieving in their lives and their grand children)?

Strengths and Hope

- To what extent are training practices hope based, and do they change daily practice?
- Access to updated, evidence-informed information.
- Listen to those with lived experience to help inform education and raise awareness.

Brain and Body

- What kind of additional vulnerabilities are associated with FASD and LGBTQ?
- How can health care professionals support and identify those physical health issues?
- How do the physical health issues impact life?
- What is the impact of physical activity on the multiple medical conditions across the lifespan?

- How do we roll out brain-based interventions in homes, schools, communities?
- What can we learn from brain research and use it with our children with FASD? Help them recognize what happens in their brain?
- How do we capitalize on the work being done in physical activity and cognitive development?
- What are the physical health issues present in FASD?
- How can we prevent some of the medical conditions seen in FASD?
- How can we better screen and support individuals with FASD for the most common medical conditions?

The Role of Relationships

- How can we understand attachment and how to better support?
- How can we help people with FASD develop healthy friendships across the lifespan?
- Are there gender differences in how healthy friendships are formed?
- How can caregivers contribute to a child's growth, success, confidence?
- What is the impact of social support as an alternative to formalized programs?

Advocating for Supports

Training and Education

- Peer-delivered collaboration and training
- Ensure that all people involved are part of the support delivery
- Peer training and exemplary parenting practices
- Paradigm shift – information sharing and understanding FASD
- Understanding and addressing parental isolation
- Educating the leadership
- How to secure funding
- Use stories to understand success and barriers to break isolation
- How to speak honestly about bad training because it causes damage
- Parenting training and support to keep families together

Stigma

- How understanding trauma can impact stigma?
- How to build awareness?
- How to reduce blame?
- How to impact the attitudes of professionals?
- How to create awareness and harm reduction strategies?

Justice Interventions

- Zero tolerance approaches don't work, they only punish people with disabilities
- Create conditions that are realistic and relevant and not punitive
- How to implement TRC #34?
- Shift the sensibility in the justice system
- Punishment doesn't work!
- How to give the system the flexibility to meet the needs of the person and generate solutions that work for the individual?

Prevention

- Wrap around
- Apply the screening tools evenly to all women
- Micro Board
- How to foster upstream-thinking?
- Affirm that no woman intentionally harms her baby
- How to ensure continuity of support across the life span?
- Hold the medical community accountable for evenly distributing the safe drinking guidelines?

Defining Success for FASD

- How to provide support for people with FASD to self-advocate?
- What delivery approaches work best?
- What are best parenting practices for children with FASD?
- What outcomes we (they) want for children? Adults with FASD?
- What does better support for people with FASD look like?
- What does life-long support look like?
- Develop the capacity in systems to recognize and value different forms of success

Appendix 4: Further References

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Appendix 5: Selected Additional Resources

National Organizations and Resources

Canada FASD Research Network:
http://canfasd.ca/

CanFASD Intervention blog:
https://fasdintervention.wordpress.com/

CanFASD Prevention blog:
https://fasdprevention.wordpress.com/

KnowFASD website:
https://knowfasd-webpro.ualberta.ca/

FASD Research Project – Connecting Resources to Communities: https://fasdresearchproject.com/

Kids Brain Health Network (formerly known as NeuroDevNet): http://www.neurodevnet.ca/

FASLink Fetal Alcohol Disorders Society:
http://www.faslink.org/index.htm

Provincial Networks and Agencies

Fetal Alcohol Syndrome Society Yukon (FASSY):
http://fassy.org/

Northwest Territories Stanton Territorial FASD Support Program:
http://www.stha.hss.gov.nt.ca/outpatient-services/child-development-team/fasd-clinic-community-support

BC Ministry of Education FASD Provincial Outreach Program: https://www.fasdoutreach.ca/

Community Living BC Supporting Success for Adults with FASD:
http://www.communitylivingbc.ca/learn-more/other-publications/supporting-success-for-adults-with-fasd/

Alberta Government FASD Resources:
http://fasd.alberta.ca/

Edmonton Regional Learning Consortium – Supporting Students with FASD:
http://www.engagingalllearners.ca/il/supporting-students-with-fasd/

Saskatchewan FASD Network:
http://www.skfasnetwork.ca/home

Manitoba FASD Centre:
http://fasdmanitoba.com/

Healthy Child Manitoba FASD Resources:
http://www.gov.mb.ca/healthychild/fasd/resources.html

FASD Ontario Network of Expertise:
http://www.fasdontario.ca/cms/

FASD Network Newfoundland and Labrador:
http://www.fasdnl.ca/

Resources for Caregivers and Individuals

Caregiver Curriculum on FASD:
http://www.fasdchildwelfare.ca/learning/caregivers

Lakeland Centre for FASD – Tips for Parents and Caregivers:
http://lcfasd.com/fasd-tips-for-parents-and-caregivers/

Healthy Child Manitoba – What Parents and Caregivers Need to Know about FASD:
https://www.gov.mb.ca/healthychild/fasd/fasd_caregivers.pdf

FASD and the Justice System:
http://fasdjustice.ca/

Living with FASD: Drawing Hope – a collection of five comics, based on stories told by members of the Whitecrow Village community. This book is available through public libraries or can be ordered online at http://thehealthyaboriginal.net/portfolio-item/living-with-fasd-drawing-hope/

Living with FASD – Myles Himmelreich speaks to what it is like to live with Fetal Alcohol Spectrum Disorder on a daily basis, what his journey has been growing up, and what he needs in order to have success today https://www.youtube.com/watch?v=6QgZKkv_Pck

FASD Life Skills video series created by Whitecrow Village
https://www.youtube.com/playlist?list=PL6C087DB84D8EA953&feature=plcp

I Can Be Safe Online developed by Community Living BC
http://www.icanbesafeonline.com/

So You Have Been Diagnosed with FASD – Now What? A handbook of hopeful strategies for youth/young adults developed by Boyle Street Education Centre
http://www.bsec.ab.ca/pdf/fasd.pdf

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10/16