

2020-2021

ANNUAL REPORT



WHO WE ARE

The Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) is a network of stakeholders from across Canada focused on addressing Fetal Alcohol Spectrum Disorder (FASD). We are a national and charitable organization that supports research and knowledge exchange initiatives to inform evidence-based policies and practices. CanFASD's unique partnership brings together researchers, students, practitioners, policymakers, families, and communities across Canada and internationally to address the complexities of FASD. Our research teams currently lead over 50 major projects in the areas of prevention, diagnosis, intervention, justice, and child welfare.

Together.
Finding answers.
Improving outcomes.



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In the spring of 2019, the CanFASD Board of Directors made a decision to undertake an external stakeholder engagement process to support the renewal of its strategic plan for 2020 to 2023. The Board of Directors used a participatory approach for this strategic planning process to capture the knowledge and experience of CanFASD's key stakeholders. Bringing multiple voices to the table was critical to helping shape and inform the strategic plan. The Board of Directors engaged 150 stakeholders to inform the development of the 2020-2023 Strategic Priorities Plan.



...all people, regardless of their background or relationship with FASD know that CanFASD is the place to go if they have research-based questions.

- CanFASD Stakeholder



CanFASD's research is of the highest quality and involves the voice of individuals with FASD and their families...I appreciate the ongoing effort to be inclusive.

- CanFASD Stakeholder

The stakeholder engagement process found that the majority of stakeholders endorse CanFASD's current vision and mission. All groups view CanFASD as the primary trusted source for FASD research in Canada.

Using information from stakeholders, the past strategic priorities, and updates within the field of FASD, the CanFASD Board of Directors identified eight key priorities and actions that have the potential to create positive results for Canadians. These eight key priorities make up our Strategic Priority Goals.



STRATEGIC Priority Goals

1

Increase and diversify the membership of CanFASD



2

Communication to the public



3

Diversify funding sources and increase funding levels to the Network



4

Provide leadership in the development of a National FASD Plan



5

Create and support opportunities for workforce development in FASD knowledge



6

Influence government and private sector policy



7

Increase the ability of CanFASD to be relevant and work effectively with Indigenous Peoples

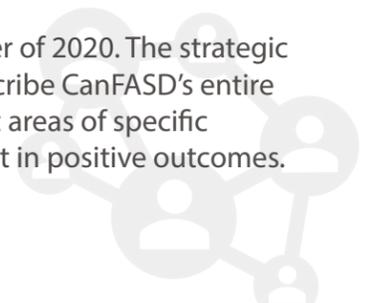


8

Facilitate and support a positive and effective environment for FASD research capacity in Canada



The [Strategic Priorities Plan](#) was released to the public in the summer of 2020. The strategic priorities identified in this plan are not intended to represent or describe CanFASD's entire scope of work over the next three years. They are meant to highlight areas of specific interest where additional attention or resource investment can result in positive outcomes.





Message from the BOARD OF DIRECTORS

I consider it a very deep honour to have been able to serve as Chair of the Canada FASD Research Network Board of Directors over the past year. Fetal Alcohol Spectrum Disorder

(FASD) continues to present significant challenges for all of those affected, including individuals, families, caregivers, and communities. CanFASD is playing a unique and primary role in increasing the level of understanding of the science behind FASD and thereby enabling a more comprehensive and effective range of supports and services including prevention, diagnosis, interventions and treatments.

The availability of Canadian, science-based information and knowledge on FASD, continues to grow exponentially due to the work of CanFASD and our many partners and supporters. The research and new learnings are available to individuals, families, caregivers, practitioners and policy makers. A great deal of our work in Canada is being used by our international partners to augment their research information and to help structure FASD programs and services in other countries.

I mentioned in my comments in last year's Annual Report that CanFASD had embarked on a broad consultation process as part of the renewal of the organization's strategic plan. That work has been completed and I would like to thank all of those who took the time to share their thoughts and perspectives and contribute to the 2020 to 2023 CanFASD Strategic Plan. The plan itself reflects the information that was gathered from a wide range of stakeholders and identifies important strategic priorities for the Board of Directors and the organization as a whole. I encourage you to visit the CanFASD website and review the complete plan. I look forward to seeing the achievements from the work in each priority area over the next three years. All of the work of CanFASD is in equal measure

driven and supported by the work of our very talented Research Leads, our Family Advisory Committee and the Alumni and Ambassador Committees who continue to work hand in hand with the Board to ensure that all of the activity the Network engages in has a direct benefit to families, caregivers and individuals, practitioners and policy makers. Behind all of this, of course, are our amazing staff, led by our Executive Director Audrey McFarlane, who take all the ideas and strategies and turn them into effective action and results. Truly without the exceptional competence and commitment of the Network staff there would not be a CanFASD.

As I have said in previous years, I would like to acknowledge that we, as members of CanFASD, are very aware we do not do this work alone. We have many partners, agencies, organizations, institutions and individuals that enable the work of the Network to carry on and to continue to grow and develop. We deeply appreciate the continued commitment and support of the Network by the Provinces and Territories of the Canada Northwest FASD Partnership, the Government of New Brunswick, the Government of Canada through the Public Health Agency and First Nations Inuit Health Branch, and our excellent stakeholders and partners in Ontario, Quebec, Nova Scotia, Newfoundland and Labrador, and Prince Edward Island. We are much more effective in preventing FASD and in providing research and evidence-based knowledge to support those persons with FASD, their families, caregivers and communities across Canada when we work collectively and collaboratively.

Finally, I do want to recognize that all Canadians continue to be in a very challenging time created by the impacts of COVID-19. I would like to further acknowledge the individuals with FASD, their families and caregivers as well as the agencies and service providers who are dealing with the additional challenges and stresses that the

pandemic creates. CanFASD has been closely monitoring the evolving situation and responding with measures that are within our ability and capacity to assist. Under the leadership of our Executive Director, Audrey McFarlane, CanFASD has made the online courses for educators free during part of this period. We have also developed and released a joint statement with the Centre of Excellence in Women's Health (Dr. Nancy Poole) on the *Prevention of FASD during COVID-19* and a statement on *Working with Individuals with FASD During COVID-19*. My sincere hope is for all to stay safe and well during this additionally trying time.

Sincerely,

Tim Moorhouse





Message from the

SENIOR RESEARCH LEAD

It is no doubt that this has been a unique year for everyone. In addition to impacting all aspects of our lives, COVID-19 has challenged researchers to think “outside the box” and seek meaningful understandings and opportunities for positive impact. Our Research Teams have embraced this challenge. They have not only maintained their research pace, but in many cases, increased their efforts and expanded ongoing work to consider the impact of COVID on individuals with FASD and their families.

Although we have missed the opportunity to physically engage with community members, through in-person events and conferences, we shifted quickly to online approaches to connection. With the help of the CanFASD communication staff, we increased our participation in webinar presentations and online conferences. We have seen our ability to bridge geographic barriers more easily and equitably than ever before. Although we do not see this as a replacement for face-to-face meetings, many Research Leads recognize the potential for expanding our ability to engage in meaningful knowledge translation, going forward, through a combination of virtual and in-person events.

The scope of research conducted by our Research Teams remains broad, and difficult to encapsulate in brief. However, I have endeavoured to capture a few highlights from the past year. One significant achievement, that reflected a highly collaborative initiative this year, was funding awarded to CanFASD

by Health Canada’s Substance Use and Addictions Program (SUAP). This project entails examination of needs related to substance use treatment for individuals with FASD, in order to identify best practices and development training to support implementation of those practices within programs across Canada. It is an example of work which will see involvement from multiple Research Leads, including my supervision of the post-doctoral student leading the project; sub-project work by Dr. McLachlan to inform screening efforts and Dr. Mela to enhance our understandings specific to cannabis use; and advisory input by Research Leads such as Dr. Poole.

Adding to this exciting news, Dr. Hanlon-Dearman has contributed to the successful launch of the FASD justice court in Manitoba, and Dr. Badry co-authored the book *Decolonizing Justice for Aboriginal Youth with FASD*, released in December 2020. Dr. Poole continues to lead and contribute to many prevention initiatives nationally and internationally. She has helped us to advance our thinking regarding labelling of alcoholic beverages, building off of her partnerships and consultation work in Australia. Dr. Cook continues to lead the National FASD Database project, a national database of clinical data that has been collected in collaboration with FASD assessment clinics from across Canada. Dr. Mela has seen his medication algorithm for people with FASD published, while also successfully advancing the need for FASD diagnosis in Canadian Correctional Institutions.

Perhaps one of the most enriching aspects of the work as a Research Lead is the opportunity to take on shared challenges and produce materials that reflect shared energies and ideas and cross fields of study. For instance, the completion of the *Unique Complexities of FASD* issue paper reflects on the aspects of FASD that differentiate it from other disabilities. From these multiple perspectives emerged a clear understanding that not only is FASD uniquely complex, but that this knowledge needs to permeate our prevention, intervention, and diagnostic efforts. Whether in the child welfare system, justice system, diagnostic systems, or other systems of support, this awareness has implications for how we engage in an integrated and strategic response to FASD. Recognizing this has provided Research Leads with an excellent opportunity to deepen our collaborative initiatives and explore ways in which FASD exists at the junction of neurodevelopment, social determinants of health and wellness, cultural contexts, and stigma. Understanding this will facilitate informed responses that leverage strengths of communities and individuals, to promote healthy outcomes.

I remain excited by the achievements and potential of the CanFASD Research community. As we grow together, I look forward to continued collaborative efforts that shape the field of FASD, and ultimately contribute to healthy outcomes for all communities.

Dr. Jacqueline Pei



MEET OUR TEAM

MANAGEMENT & RESEARCH Team



Audrey McFarlane
Executive Director



Kathy Unsworth
Managing Director



Dr. Jacqueline Pei
Senior Research
Lead & Intervention
Research Lead



Edward Swatschek
Manager of Corporate
Services &
Administration



Dr. Jocelynn Cook
Data Research
Lead



Dr. Kaitlyn McLachlan
Justice Research
Lead



Dr. Nancy Poole
Prevention Research
Lead



Dr. Dorothy Badry
Child Welfare
Research Lead



Dr. Ana Hanlon-Dearman
Diagnostics
Research Co-Lead



Dr. Mansfield Mela
Diagnostics
Research Co-Lead



Dr. Kelly Coons-Harding
Research Associate



Dr. Katherine Flannigan
Research Associate



Victoria Bailey
Communications
Coordinator



Andrew Wrath
Research Assistant



Lindsay Wolfson
Research Assistant

Board of DIRECTORS



Tim Moorhouse



Alan Bocking



Olecia Walker



Lisa Brownstone



Carol Anne Cheechoo



Wenda Bradley



Darren Joslin



David Brown



Christian Whalen



Update from the

FAMILY ADVISORY COMMITTEE



This has been an interesting year, to say the least, for members of the Family Advisory Committee (FAC) as we adapted to changes brought about by the COVID-19 pandemic. As we struggled to support individuals with FASD in both our personal and professional lives, many of the supports and services we counted on were withdrawn. We were again reminded of the importance of having a community of support as we navigated the challenges of working from home while supporting and supervising our children and trying to manage their on-line education. We continue to appreciate the support we receive from CanFASD Research Network staff and Research Leads and we enjoy the openness and collaborative spirit that this Network encourages.

There has been some public attention to the impact of the pandemic on people with disabilities and their caregivers, but no real action taken to address these concerns. COVID-19 has had a negative effect

on kids with FASD, especially to their education. These kids have lost at least one year or more of learning and, as a result, have become completely disengaged. This is one area that should be of focus for researchers, educators, and policymakers, as there will be serious repercussions in the years to come.

COVID-19 has also had a negative impact on the families of people with FASD. Along with providing care to their children, many members of the FAC work as service providers to people with FASD. Throughout the pandemic, many found themselves in the position of being one of the only providers that continued to serve their community and indeed, increased the level of services provided to our clients during this past year. This speaks to the resiliency of caregivers and service providers in the field of FASD and their unquestionable commitment to improving the lives of individuals. It reminds us, however, of the importance in bringing the voice

of individuals with lived experience in all aspects of research, policy development and governmental practices to address the needs of individuals with FASD and their families more effectively.

The mandate of the FAC includes advising the CanFASD Research Network on research priorities for families impacted by FASD, and to assist in translating results of research to ensure they are accessible to families. Since CanFASD is a virtual organization, our work did not slow down with the pandemic. We were involved in the creation and delivery of several CanFASD webinars, including ones on loss, grief, and resiliency and another on supporting self-regulation. FAC members also authored a number of blog posts for FASD Awareness Day on September 9th as well as a blog on the impact of the pandemic on caregivers of individuals with FASD. These blogs acknowledge the resilience of individuals with FASD and their support providers, while also drawing attention to the needs of families living with FASD and strategies for coping with the additional stress brought on by the pandemic.

We were also involved in several initiatives within the community, including an interview on a local podcast and a panel discussion at the close of the 2021 Saskatchewan FASD Network conference.

We have been involved in the development of a number of research projects that are of particular interest to caregivers of individuals with FASD, including projects on cannabis use and FASD and

the experience of caregivers of individuals with FASD. We are also excited that the *Psychotropic Medication Algorithm for Fetal Alcohol Spectrum Disorder* has finally been published. One of our members is also representing the CanFASD FAC on the research project "Nothing Without Us: COVID – 19 Policy Responses to Improve Mental Health of Youth with Disabilities and Their Families", which is currently in the data-gathering phase.

A major focus during the past year has been to initiate a subcommittee of the FAC consisting of adults with FASD. This committee, entitled the Adult FASD Expert Consultation Team (AFECT), currently consists of six individuals with FASD from across Canada. We are excited to have an active committed group of individuals with FASD to help guide our activities.

The members of the FAC continue to enjoy the collaborative nature of the CanFASD Research Network and the support we receive from staff and Research Leads. It is only by working together as individuals with FASD, caregivers, researchers, service providers, policy makers and all levels and jurisdictions of government that we can work toward better outcomes for individuals with FASD. This past year of the pandemic has demonstrated this need for collective action even more clearly.

Sincerely,

The Family Advisory Committee



Update from the

ADULT FASD EXPERT COLLABORATION TEAM

This year, the Family Advisory Committee (FAC) placed a strong focus on creating CanFASD's Adult FASD Expert Collaboration Team (AFECT). This is a group of adults with FASD across Canada who meet monthly with CanFASD members to talk about FASD research. Each AFECT member is supported by a mentor from the FAC.

The mission of the AFECT is to advise on priority areas of research for individuals with FASD and to help translate results of research to make sure they are understood by and available to people with FASD.

Research can help to improve outcomes for people with FASD. We use research to create programs and resources that are backed by evidence. However, in order for research to effectively help people, researchers need to understand the areas where individuals with FASD and their families are struggling.

In the past there was a big gap between FASD researchers, service providers, and people with lived experience. CanFASD wanted to bridge that gap. The AFECT was launched in the winter of 2020. Members of the AFECT are self-advocates. They don't speak for all people with FASD, but in speaking from their own experiences, they help researchers understand more about this disability.

The AFECT is currently made up of six incredible adults with FASD from across Canada.



OUTREACH and Communications

With more people online due to the COVID-19 global pandemic, we put a big emphasis on connecting with Canadians virtually this year. We've increased our presence on our social media channels and developed and implemented a number of targeted digital campaigns to improve awareness and understanding of FASD.

Our September FASD Awareness Month campaign was incredibly successful this year. We published a toolkit to help more people get involved and created a dedicated website for FASD Month activities. We also successfully advocated for FASD Awareness Month to be added to the Government of Canada's official Calendar of Health Promotion Days.

Our other popular initiatives include our CanFASD Holiday Art Competition in November and our 12 Days of Mocktails campaign in December. These initiatives will continue over the coming year, with additional campaigns being added as opportunity arises.

Our increased focus on outreach and communications has translated to a greater awareness of FASD in the community, with more Canadians taking our online courses, increased traffic to our website, increased following on our social media sites, and broader dissemination of our research and resources.

As of March 31, 2021 CanFASD had:

3,891
followers on
Facebook

1,834
followers on
Twitter

465
followers on
LinkedIn



NATIONAL SOCIAL MEDIA CAMPAIGN

Early on in the COVID-19 pandemic, CanFASD staff and researchers were concerned about a potential increase in the rates of FASD. Canadians were spending more time at home and many were turning to alcohol and substance use to cope with feelings of anxiety and stress related to the pandemic. CanFASD raised their concerns with the Public Health Agency of Canada and got funding to conduct a national social media campaign focused on FASD prevention.

Developed through consultation with researchers, experts, and people with lived experience, the campaign launched in July of 2020 and ran until the end of August. It consisted of both paid social media ads and organic posts that drove users to a dedicated website encouraging people to [think FASD](#). It targeted those at risk for alcohol-exposed pregnancies, including couples who are pregnant, trying to get pregnant, or having unprotected sex. It was centred around the key message “drinking and baby-making don’t mix”. The website provided additional information on FASD, COVID-19, and alcohol use during pregnancy as well as resources that Canadians could access for support. We also engaged influencers within the community, like Canada’s Chief Public Health Officer, Dr. Theresa Tam, to highlight the importance of going alcohol-free during pregnancy.

With more and more Canadians online due to the pandemic, we knew that social media was an important resource that we needed to tap into in order to spread our message more broadly. Since the launch of this campaign, additional research has come out supporting our hypothesis that Canadians, particularly women, are increasingly turning to alcohol and substances to cope. The concern over increased risk of alcohol-exposed pregnancies is still paramount.

This was the first national social media campaign for FASD in Canada. It was very successful, reaching over 800,000 people and receiving almost 1.95 million views during those two months. We learned a lot throughout this process and will take these learnings into our next campaign.



WEBINAR SERIES

This year, with in-person events cancelled, CanFASD switched to more digital formats to connect with our network. We created a webinar series to connect professionals and people with lived experience to our network and share information about FASD. We hosted a number of online webinars throughout the year, featuring presentations from individuals with FASD, caregivers, researchers, and service providers from across Canada. Our webinars included:

- *“It’s Ignorant Stereotypes”: Stakeholder Recommendations to Improve Canadian Discussions About FASD*
- *Towards Healthy Outcomes for Individuals with FASD: Advancing a Common Intervention Framework*
- *Loss, Grief, and FASD*
- *Understanding FASD in the Criminal Justice System: A Research Update*
- *Supporting Self-Regulation with Individuals with FASD*
- *Refreshing our Conversations about Alcohol as a Key Component of FASD Prevention*
- *Understanding and Managing Sleep for Children (ages 0-6) with FASD*
- *Pain as Experienced by People with FASD*
- *Identifying Best Practices for FASD Prevention, Intervention, and Support*
- *Assessing Preschoolers with Prenatal Alcohol Exposure*
- *Supporting Caregivers through Acceptance and Commitment Therapy*

From March 31, 2020 to March 31, 2021 we held:

11
webinars

with
over

1,800
attendees

National FASD STRATEGY

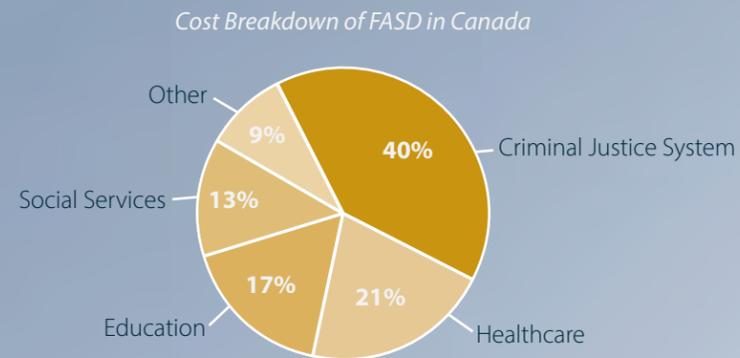
Canada needs a coordinated, national, evidence-based approach to address FASD that provides federal leadership and builds on the work that has already been done at the provincial, regional, and community levels. The Canada FASD Research Network is pushing for a National FASD Strategy to provide all of Canada with a coordinated approach to tackle the complexities of FASD.

A National FASD Strategy is a statement of leadership and commitment to Canadians. It tells Canadians that their government recognizes the enormous impact of this disability and is working to address it. The National FASD Strategy should be person-centred, evidence-based, and informed by lived-experience. It should also be culturally appropriate for the diversity of Canada's population and reflect the needs of Canada's northern, rural, and remote communities.

In 2018, the Government of Canada gave \$20 million over a five-year period to support people with Autism Spectrum Disorder (ASD), their families, caregivers and communities. In 2020, they invested \$1.46 million into the development of a National Autism Strategy. The prevalence of FASD in Canada is 2.5 times higher than Autism Spectrum Disorder, but Canada does not yet have a National FASD Strategy.



We cannot afford to wait much longer to address FASD at a national level. FASD is costly, due to increased need for services for individuals and families across sectors. When unsupported, the cost of FASD in Canada is estimated to be approximately \$9.7 billion per year. These costs include the impact of FASD on the criminal justice system, health care, education, and social services. The numbers don't take into account the intangible costs of FASD, such as the cost of pain, suffering, stress, and stigmatization.



Many of these costs can be reduced with effective policies and programs to support people with FASD and their families. A National FASD Strategy will provide the opportunity to reduce the economic burden on Canadian taxpayers by encouraging the implementation of such initiatives.

Individuals with FASD are disproportionately represented in the child welfare and criminal

justice systems. They experience extreme rates of mental health challenges, with over 90% of individuals with FASD experiencing at least one mental illness across their lifespan. Additionally, caregivers of individuals with FASD face unprecedented levels of stress. They rely heavily on both informal and formal supports, whose effectiveness and availability are dependent on the knowledge of FASD across professions and within communities.

The COVID-19 pandemic has only added to the challenges that people with FASD and their families are facing. Anecdotally, caregivers have reported a concern about lack of support, disruptions in daily routines, and mental health challenges for people with FASD. What's more, alcohol consumption is on the rise, raising

concerns about a potential increase in alcohol-exposed pregnancies.

Right now, support for people with FASD and their families varies widely. Some great work has been done at the provincial, regional, and territorial level, but there is no coordinated approach within the Federal Government to address FASD. A National FASD Strategy will give our provinces and territories an evidence-based direction that can improve FASD prevention, diagnosis and support to help Canadians with FASD reach their full potential. Without an organized strategy, people with FASD and their families do not have equal opportunities to achieve success.





ONLINE COURSES

CanFASD has a number of [online learning courses](#) available to improve professional and community understanding of FASD. Our courses are categorized by level of experience, where Level 1 courses provide a basic overview, Level 2 courses provide sector-specific training, and Level 3 courses provide expert training to FASD professionals.

LEVEL I COURSES

Foundations in FASD

Our introductory Foundations in FASD course is a basic training course designed to improve public understanding of FASD. It is our most popular training course, with over 15,000 learners. Approximately 5% of these learners are from countries outside of Canada.

The foundations course is so popular that it was purchased by NOFASD Australia to be adapted for an Australian audience. NOFASD Australia is a not-for-profit, parent-led organization that works to build knowledge capacity of FASD across Australia. In sharing our work, we ensure that information and language about FASD stays consistent both nationally and internationally.

LEVEL II COURSES

4,174
learners

FASD for School Staff: Practical Strategies for the School Environment

This online training program is intended for all professionals working within the school environment, including administrators, teachers, educational assistants, bus drivers, and school board personnel. It provides professionals with the skills needed to support students with FASD in an educational setting.

161
learners

The Prevention Conversation

This online training program for frontline health and social service professionals provides them with the knowledge and skills to engage their clients in supportive and non-judgemental conversations about alcohol use during pregnancy.

NEW

Best Practices for FASD Prevention, Diagnosis, and Support

Released in March 2021, this online training program is designed for professionals working in the substance use, mental health, housing, employment, justice, and other service-delivery fields. It will provide professionals with the knowledge to improve FASD prevention, diagnosis, and support initiatives. This course replaced Towards Improved Practice.

232
learners

FASD for Judicial and Legal Professionals

This online training program is an advanced course intended for all professionals working in the justice system. It provides evidence-based and practice-informed information that can be easily and effectively applied to your practice working with people with FASD.

968
learners

FASD for Solicitor General Professionals

This online training program is an advanced course intended for all professionals working in the Solicitor General systems. It provides evidence-based and practice-informed information that can be easily and effectively applied to your practice working with people with FASD.

LEVEL III COURSES

572
learners

Multidisciplinary Training for Diagnosis of FASD

This online training program is designed to assist professionals in developing the skills needed to be an effective member of a multidisciplinary diagnostic team.

As of March 31, 2021 CanFASD e-learning platform had:

20,517
total learners
in Canada

↑ 113%
from March
2020

21,608
total learners

↑ 106%
from March
2020

Influence
POLICY & PRACTICE

ISSUE PAPERS

Each year CanFASD publishes a number of issue papers on different topics, summarizing information through the lens of policy development. These documents are intended to help policy makers understand various issues related to FASD by sharing related research and providing recommendations for how to move forward.

This year we published eight issue papers on the following topics:

- FASD and Child Welfare
- Mothers' Experiences of Stigma
- Alcohol and Breastfeeding
- FASD and Adversity
- Parenting with FASD
- The Unique Complexities of FASD
- Provincial and Territorial Strategies
- The Canada FASD Research Network

CLAUDETTE BRADSHAW FASD
INNOVATION AWARD

The Claudette Bradshaw Innovation Award recognizes the work of individuals and organizations who are using innovative approaches to improve the lives of individuals with FASD. The award is named in honour of Mme. Claudette Bradshaw to recognize her dedication and impact to the fields of FASD, early childhood education, and homelessness. It is intended to encourage innovation in the development of FASD programs and practices.

The Asante Centre in British Columbia is the recipient of this year's award for their Peer Mentorship Program. This is a youth and community-driven program that provides support for youth with FASD aged 13-25 in British Columbia through weekly meetings that foster mental wellness, self-advocacy, and resiliency.



INDIGENOUS

Relations

OUR COMMITMENT TO INDIGENOUS PARTNERSHIP,
RECONCILIATORY RESEARCH, AND ACTION

It is important for CanFASD to be responsive to the needs of our many Network members, including our Indigenous partners and stakeholders. We are committed to aligning our research priorities and actions with those guided by the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) and the Truth and Reconciliation Calls to Action (TRC). Both outline the need for meaningful understanding of the impacts of colonization on Indigenous peoples, further engagement and reconciliatory relationship building, and the integration of Indigenous values, knowledge, and worldviews into research, knowledge exchange, and policy action.

The TRC Calls to Action #33 and #34 have acted as a driver of new and renewed action on FASD prevention and support in Indigenous communities and urban Indigenous populations. In partnership with Indigenous and non-Indigenous researchers, community organizers and collaborators, CanFASD has developed two frameworks for action:

- Consensus Statement: Eight Tenets for Enacting the Truth and Reconciliation Commission's Call to Action #33 (referred to as "the Consensus Statement"); and,
- Truth and Reconciliation Call to Action #34: A Framework for Action (herein referred to as the "Framework for Action").

In our own Network, CanFASD has made the following commitments to partnership, reconciliatory research, and action with Indigenous peoples and in Indigenous communities:

- 1 Understanding the impact of colonization and subsequent assimilatory policies and practices on intergenerational trauma, substance use, addictions, and FASD.
- 2 Building meaningful partnerships with Indigenous peoples and communities that are based on the values of reconciliation.
- 3 Developing research that is guided by community needs, values, and knowledge systems.
- 4 Advocating for Indigenous-led research through sustainable and long-term funding

WORKING WITH INDIGENOUS PEOPLES TOWARDS EFFECTIVE SUBSTANCE USE TREATMENT PROGRAMS

In 2020, CanFASD received funding from the Substance Use and Addiction Program of Health Canada to develop best practices for supporting the success of individuals with FASD in substance use treatment programs in Canada. A key element of this project is to understand how to support Indigenous Peoples with FASD with substance use challenges.

There is very little research available on how to support Indigenous individuals with FASD who are in substance use treatment. Studies have documented serious disparities in drug and alcohol-related morbidity and mortality among Indigenous populations compared to other ethnic groups in Canada, despite high rates of abstinence in these groups. Further complicating these health disparities are barriers to accessing evidence-based treatments that are culturally appropriate and acceptable.

For many women, substance abuse offers a means of coping with trauma, such as childhood abuse, partner violence, and, for Indigenous women, the intergenerational effects of colonization. Although Indigenous mothers and their children are at high risk for poor outcomes, they remain understudied and underserved in addiction treatment research and practice.

The higher rate of abstinence from substances among Indigenous peoples in comparison to the general population suggests considerable strength and resiliency that can be drawn upon to address problematic substance use. This project will identify best practices for supporting people with FASD, including Indigenous peoples, through substance use treatment by leveraging what we know about the importance of using culturally specific strategies and supports.

Two Indigenous community members sit on the Advisory Committee for this project to provide their expertise and support. In addition, an Indigenous student from the Faculty of Native Studies at the University of Alberta has been hired as a Research Assistant. The project is currently in the development stage, where we've put a focus on (1) fostering partnerships with Indigenous-led community organizations toward better understanding Indigenous perspectives on substance abuse interventions with people who have FASD; and (2) conducting a realist review of healing practices that are used with Indigenous peoples with substance abuse, following an iterative process with input from community partners.

The support of an Indigenous faculty member, Research Assistant, and community members will prompt consideration of ways that the team can shape procedures, research questions, and knowledge mobilization to not only reflect cultural sensitivity but to infuse Indigenous perspectives throughout all phases of the project.

This type of research has the potential to move the field forward, inform policy makers and service providers, reduce costs and, ultimately, improve the health and well-being of this high-risk population through enhanced service delivery.



Support RESEARCH

In 2020/2021, CanFASD Research Network completed:

68

research projects

9

book chapters

52

presentations

38

published articles

3

books

24

technical reports

DR STERLING CLARREN FASD RESEARCH AWARD

The Dr. Sterling Clarren Research Award is named in honour of Dr. Sterling Clarren to recognize his pioneering contribution and leadership in the field of FASD. The award is presented annually to an individual in recognition of a completed study that has made a substantial contribution to understanding the human dimensions of FASD.

The 2021 recipient of the CanFASD Sterling Clarren Research Award is Dr. Brianne Redquest. Dr. Redquest is a postdoctoral fellow with the Azrieli Adult Neurodevelopmental Centre at the Centre for Addiction and Mental Health. She has a strong interest in participatory research in the area of physical and mental health promotion for adults with developmental disabilities, as well as their family members. Her research looks at the effect of Acceptance and Commitment Therapy (ACT) on supporting the well-being of caregivers of individuals with FASD.

Caregivers of people with FASD report high levels of stress and a need for support. However, there are very few interventions that specifically target their well-being. Dr. Redquest conducted in person and virtual focus groups with caregivers of people with FASD to understand whether ACT would have an impact on caregiver stress levels. Preliminary results suggest that ACT training can significantly reduce stress and improve psychological well-being for caregivers. It can also help caregivers of people with FASD to feel supported and valued.

THE UNIQUE COMPLEXITIES OF FASD

FASD is a neurodevelopmental disability, like Autism Spectrum Disorder, Down Syndrome, Cerebral Palsy, and Tourette's Syndrome. An estimated 4% of Canadians have FASD, making it more common than all of those other neurodevelopmental disabilities combined. However, knowledge and awareness of FASD in the general public and amongst professionals and policy makers continues to lag behind.

What's more, FASD is a uniquely complex disability compared to other neurodevelopmental disabilities. There are a lot of factors that make FASD complex:

1

FASD is Socially Rooted

Social, economic, and environmental factors influencing health increase the likelihood of alcohol use during pregnancy. Evidence-based and informed initiatives are needed to support women's overall health and well-being.



2

FASD is Intergenerational

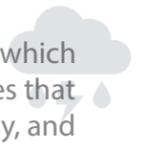
Complex biological, behavioural, interpersonal, socio-cultural, and historical factors exacerbate the health and economic disparities that increase risk for FASD, with potential intergenerational impacts. Policy and practice initiatives need to address the systemic inequities that put multiple generations at risk for FASD.



3

High Rates of Adversity

People with FASD experience disproportionately high rates of adversity across the lifespan, which can have long-term impacts on their health and well-being. They need supports and services that are delivered early and are family-focused, holistic, and long term to promote safety, stability, and well-being.



4

High Rates of Mental Health Co-Morbidities

Mental health challenges are exceptionally common among people with FASD, which can make it difficult for professionals to understand and address their underlying needs. We need better supports and services, as well as improved education for professionals to address the multi-faceted needs of people with FASD.



5

Multi-Layered Stigma

Stigma associated with FASD is multi-layered and compounded at individual, maternal, familial, and socio-cultural levels. We need targeted efforts to reduce stigma associated with FASD at all levels to make sure that people with FASD, their families, and women who use alcohol during pregnancy are better understood, respected, and supported.



6

Family Impacts

Caregivers of people with FASD experience stressors that are unique and, in some cases, more severe than those with other disabilities. We need specific, evidence-based interventions for caregivers and families that take into account their unique needs and strengths, and leverage community resources.



FASD is unique because these complex factors often happen in combination, at greater magnitudes, and with compounding effects. The more we understand FASD as a uniquely complex disability, the better we can identify people with FASD, support successful outcomes, and develop meaningful policies.

Jurisdictional Membership

CanFASD offers jurisdictional membership opportunities for provincial and territorial governments in Canada. This membership is a unique opportunity for governments in Canada to benefit from the expertise of a national network devoted to FASD. The membership connects governments with a trusted agency to turn to for answers about important policy questions.

Provinces and territories who become members of CanFASD are significantly advanced in their response to FASD. They benefit from increased research capacity, advice and assistance in evidence-based policy and program development, and collaboration with other member jurisdictions. Membership for governments also offers the potential to reduce longer-term costs associated with FASD diagnosis, prevention and intervention.



Jurisdictional Member Benefits:

Get the Answers

- Policy-relevant information and recommendations on topics and issues related to FASD tailored to your jurisdiction's needs and priorities upon request
- Opportunities to collaborate on research and have input into CanFASD's research priorities

Build Connections

- Intra-provincial networking and learning opportunities with other member jurisdictions to build on experience and expertise from across Canada
- Annual learning events, such as presentations, workshops, and/or symposia, held in your jurisdiction
- Regular visits and presentations by CanFASD staff to improve your knowledge of FASD

Improve Practice

- Foundations in FASD online course free for residents of your jurisdiction
- Discounts to CanFASD online courses for residents of your jurisdiction
- Claudette Bradshaw FASD Innovation Award open to residents of your jurisdiction

Provincial Representation

- Travel awards available to researchers and students in your jurisdiction to fund their participation in national and international events
- Jurisdictional representation on CanFASD's Family Advisory Committee to speak on behalf of the caregivers in your province



Individual Membership

In 2021, CanFASD will be expanding our membership options with the addition of our individual membership program. This membership will give individuals the opportunity to become more involved with the CanFASD network. Citizens in both CanFASD member and non-member provinces and territories will benefit equally from this new program.

SUPPORT Our Work

CanFASD is a registered charity, funded by leading health and policy organizations across Canada. Your financial support helps to develop and share the evidence needed to inform the policies and programs for people with FASD, their families, and pregnant and parenting women.

Decision-makers in governments, communities, and families need to know which initiatives will have the most impact and which are the most cost-effective. Sound data provides a compass to guide those decisions. CanFASD is Canada's only national network focused on FASD. We bring a multi-disciplinary approach to the study of this disability, which brings together the findings of researchers, parents and caregivers, clinicians, service providers, community advocates, program planners, government officials and individuals with FASD.

Our goal is to ensure the scope of our approach is reflected in the breadth of our funding base so that we can continue to have a national reach. You have an important role to play in making sure the knowledge developed at CanFASD reaches the stakeholders who need it to make effective policy decisions, provide the best supports, and make the healthiest choices possible.

Partners & Stakeholders



FINANCIAL Snapshot

CANADA FETAL ALCOHOL SPECTRUM DISORDER RESEARCH NETWORK
Balance Sheet
March 31, 2021 with comparative figures for March 31, 2020

| | 2020 | 2021 |
|--|---------------|---------------|
| Assets | | |
| Current assets: | | |
| Cash | \$ 291,895.39 | \$ 362,024.99 |
| Investments | 161,499.78 | 161,453.04 |
| Accounts receivable | 177,665.80 | 270,812.11 |
| HST receivable | 16,674.08 | 15,457.09 |
| Prepaid expenses | 81,020.47 | 69,898.31 |
| | 728,755.52 | 879,645.54 |
| Capital assets | | 9,280.22 |
| Intangible assets | 7,379.31 | 63,750.00 |
| | 807,384.83 | 952,675.76 |
| Liabilities and Net Assets: | | |
| Current Liabilities: | | |
| Accounts payable and accrued liabilities | \$ 72,467.70 | \$ 48,178.85 |
| Deferred capital contributions | 71,250.00 | 63,750.00 |
| Deferred contributions | 172,794.19 | 120,003.71 |
| | 316,511.89 | 231,932.56 |
| Net assets | | |
| Unrestricted net assets | 490,872.94 | 720,743.20 |
| | 807,384.83 | 952,675.76 |

