

Workshop on August 29 & 30, 2016
Updated April 2022

Fetal Alcohol Spectrum Disorder Research:

LEARNING TOGETHER

An Update on Research & Resources



Message from the CanFASD Family Advisory Committee

Greetings from the Family Advisory Committee of CanFASD Research Network.

In August 2016, with funding from the Canadian Institutes of Health Research and support from the University of Regina, we hosted a 1.5 day workshop 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.

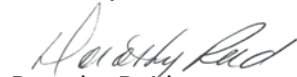
The workshop was a tremendous success and provided CanFASD staff, researchers, and the Family Advisory Committee valuable information on the priorities of caregivers, services providers and individuals with for FASD research.

After the workshop, a final report was prepared to outline those priorities as well as to provide information on research that had already been published but may not have been widely distributed.

Now, six years later, we thought it would be a good idea to update this report to provide updated references to the research completed in these areas. It is exciting to note that the amount of FASD research being done is increasing rapidly as you will see from the updated resources.

We think it is important to note that this workshop fundamentally changed the way CanFASD does business. The workshop demonstrated the importance, not only of conducting FASD research, but in ensuring that this information gets into the hands of those who need it the most – policy makers, service providers, caregivers and most importantly individuals with FASD. The organization is very aware of their role as the leading resource for FASD related information in Canada and is working collaboratively with those with lived experience to ensure better outcomes for all. We thank CanFASD researchers for their thoughtful and diligent work.

Sincerely,



Dorothy Reid,
CanFASD Family Advisory Committee Co-Chair

Tammy Roberts,
CanFASD Family Advisory Committee Co-Chair

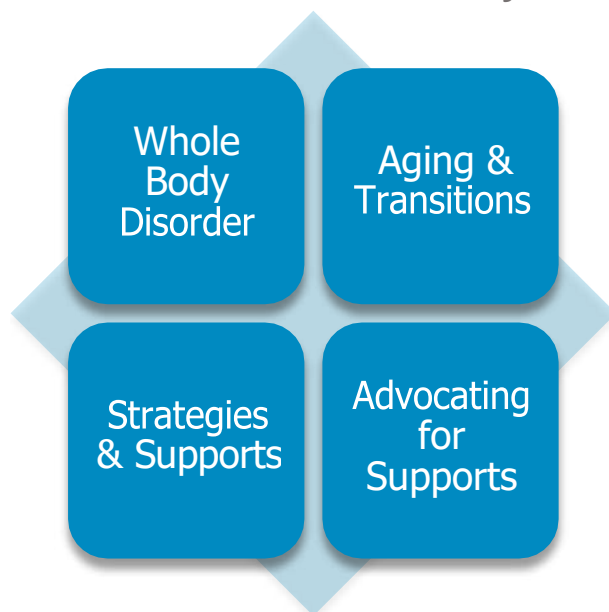
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Key Findings

The two-day workshop on August 29-30 in 2016, 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

2016 Workshop Findings & 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.

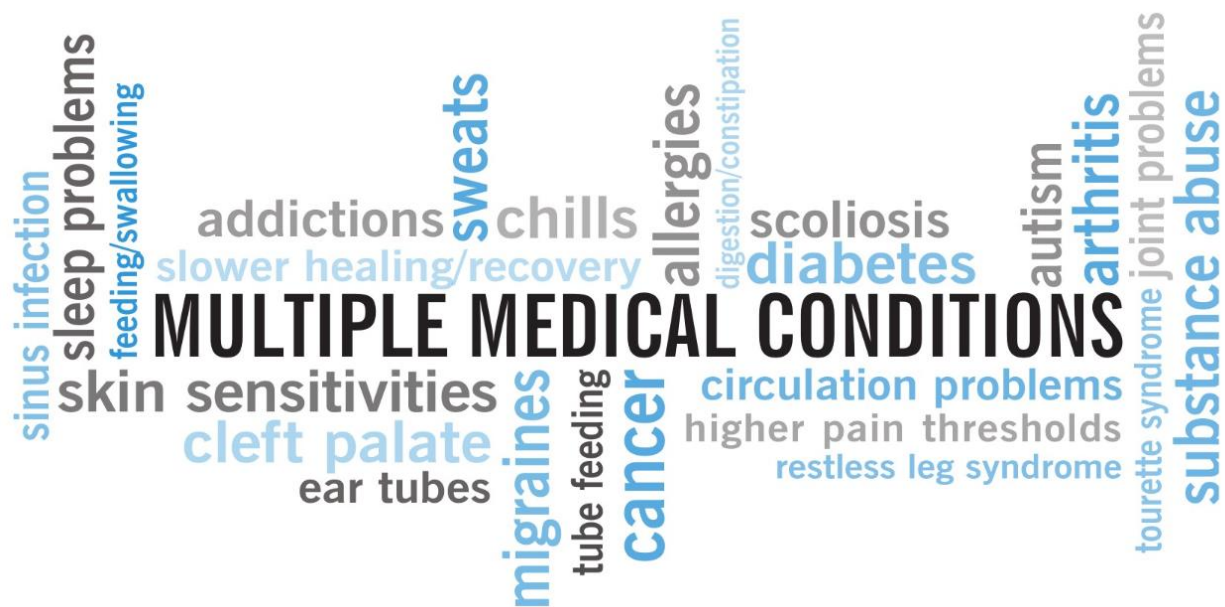
Multiple Medical Conditions

Participants of the workshop noted 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. 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 from constant medication changes, and some relying on “self-medicating” with substances to alleviate discomforts. They also expressed interest about the use of medical marijuana in FASD.

Mental Health

Mental health challenges were noted as a significant challenge for many individuals with FASD. 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

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, participants commented on the lack of awareness related to FASD, and at times, a cultural bias, among some health care professionals. 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

Concerns were noted with the 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, and better communication 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. 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.

2021 Research Update

There are numerous papers available relating to the conversations described above some of which are listed in Table 1. Full references for these research articles are provided in [Appendix 4](#).

Table 1. Related Articles: “FASD as a Whole-Body Disorder”		
Multiple Medical Conditions & Mental Health; Non-Medical Interventions; Lack of FASD Awareness; Quality and Continuity of Care		
Sub-theme	Authors	Study Title
FASD as a Whole-Body Disorder		
Conditions in different body systems	Himmelreich, Lutke, and Hargrove (2020)*	The lay of the land: Fetal alcohol spectrum disorder (FASD) as a whole-body diagnosis
	N. Reid, Hayes, Young, Akison, and Moritz (2020)	Caregiver-reported physical health status of children and young people with fetal alcohol spectrum disorder
	Amos-Kroohs et al. (2016)	Abnormal eating behaviors are common in children with fetal alcohol spectrum disorder
	Werts, Van Calcar, Wargowski, and Smith (2014)	Inappropriate feeding behaviors and dietary intakes in children with FASD or probable prenatal alcohol exposure
	Chandler-Mather, Occhipinti, Donovan, Shelton, and Dawe (2021)	An investigation of the link between prenatal alcohol exposure and sleep problems across childhood
	Chen, Olson, Picciano, Starr, and Owens (2012)	Sleep problems in children with fetal alcohol spectrum disorders
	Cook, Lynch, and Coles	Association analysis: Fetal Alcohol Spectrum

	(2019)*	Disorder and hypertension status in children and adolescents
Multiple Medical Conditions & Mental Health		
Comorbidities & Mental Health	V. K. Temple, Cook, Unsworth, Rajani, and Mela (2019)*	Mental health and affect regulation impairment in fetal alcohol spectrum disorder (FASD): Results from the Canadian national FASD database
	Lange, Rehm, Anagnostou, and Popova (2018)	Prevalence of externalizing disorders and Autism Spectrum Disorders among children with Fetal Alcohol Spectrum Disorder: Systematic review and meta-analysis
	Weyrauch, Schwartz, Hart, Klug, and Burd (2017)	Comorbid mental disorders in fetal alcohol spectrum disorders: A systematic review
	Popova et al. (2016)	Comorbidity of FASD: A systematic review and meta-analysis
Lack of FASD awareness		
Lack of awareness	Choate, Badry, MacLaurin, Ariyo, and Sobhani (2019)*	Fetal alcohol spectrum disorder: What does public awareness tell us about prevention programming?
	Badry and Choate (2015)*	Fetal Alcohol Spectrum Disorder: A disability in need of social work education, knowledge and practice
Non-Medical Interventions		
Non-Medical Interventions	Flannigan, Coons-Harding, Anderson, et al. (2020)*	A systematic review of interventions to improve mental health and substance use outcomes for individuals with prenatal alcohol exposure and fetal alcohol spectrum disorder
	(Aamena Kapasi et al., 2020)*	Exploring self-regulation strategy use in adolescents with FASD (Occupational Therapy-based program)
Quality of life and Continuity of Care		
Quality of life	Skorka, McBryde, Copley, Meredith, and Reid (2020)	Experiences of children with fetal alcohol spectrum disorder and their families: A critical review
	N. Reid and Moritz (2019)	Caregiver and family quality of life for children with fetal alcohol spectrum disorder
	Stade, Stevens, Ungar,	Health-related quality of life of Canadian

	Beyene, and Koren (2006)	children and youth prenatally exposed to alcohol
Continued care after diagnosis	Pei, Baugh, Andrew, and Rasmussen (2017)*	Intervention recommendations and subsequent access to services following clinical assessment for fetal alcohol spectrum disorders
	Masotti et al. (2015)	Integrating care for individuals with FASD: Results from a multi-stakeholder symposium
	Hanlon-Dearman, Green, Andrew, LeBlanc, and Cook (2015)*	Anticipatory guidance for children and adolescents with Fetal Alcohol Spectrum Disorder (FASD): practice points for primary health care providers

*Studies published by CanFASD or collaborative studies with CanFASD or studies in which CanFASD researchers were involved.

CanFASD Issue Papers

In addition, CanFASD published several issue papers discussing the topics related to the key themes identified above ([Table 2](#); [Appendix 4](#)).

Table 2. CanFASD Issue Papers: “FASD as a Whole-Body Disorder”	
Multiple Medical Conditions & Mental Health; Non-Medical Interventions; Lack of FASD Awareness; Quality and Continuity of Care	
Authors	Study Title
Flannigan, McLachlan, et al. (2020)	Fetal alcohol spectrum disorder and adversity
Flannigan, Harding, et al. (2020)	The unique complexities of fetal alcohol spectrum disorder
Glowatski and Stewart (2018)	Victimization in people with FASD
Anderson, Harding, Reid, and Pei (2018)	FASD and inappropriate sexual behaviour
Green and Salmon (2015)	FASD, stress, and mental health
Green, Cook, and Salmon (2015)	Why is FASD diagnosis important?
Patten, Christie, Green, and Cook (2014)	Nutritional supplementation and FASD

Clarren and Cook (2013a)	Dose-response effect of alcohol consumption during pregnancy and prenatal alcohol exposure
Clarren and Cook (2013b)	Meconium screening for FASD in pregnancy

CanFASD Resources

The CanFASD resources listed below (Table 3) are related to the theme 'FASD as a Whole-Body Disorder'. They can be found in the CanFASD website: <https://canfasd.ca/> and/or CanFASD blog: <https://canfasd.ca/blog/>.

Table 3. CanFASD Resources: 'FASD as a Whole-Body Disorder'			
Multiple Medical Conditions & Mental Health; Non-Medical Interventions; Lack of FASD Awareness; Quality and Continuity of Care			
Sub-category	Type of Resource	Authors	Title
Whole-body/ Conditions in other body systems	Webinar Summary	CanFASD (February 10, 2021)	Pain and FASD
	Webinar	Birnie, Sue, Himmelreich, and Lutke (December 7, 2020)	Pain as experienced by people with FASD
Mental Health	Blog post	CanFASD (July 8, 2020)	Alcohol, pregnancy and your mental health during COVID-19
	Blog post	CanFASD (May 5, 2020)	Mental Health and COVID-19
	Blog post	CanFASD (May 7, 2020a)	Mental health for caregivers of individuals with FASD
	Blog post	CanFASD (May 7, 2020b)	Mental health for individuals with FASD
	Blog post	CanFASD (May 6, 2020)	FASD and mental health for professionals
Non-Medical	Blog post	CanFASD (December 21,	Article Summary:

Interventions		2020)	Community-based interventions for adults with FASD (Recommends involving occupational therapists in supporting adults with FASD using a holistic treatment approach)
	Blog Post	CanFASD (May 27, 2017)	Article Summary: Interventions, cultural considerations, and access information
FASD Awareness	Webinar	Aspler (May 4, 2020)	"It's Ignorant Stereotypes": Stakeholder Recommendations to Improve Canadian Discussions About FASD
	Blog Post – FASD Awareness Month	CanFASD (September 30, 2020)	Next steps for FASD awareness
	Blog Post – Feature Friday	CanFASD (February 14, 2020a)	#FeatureFriday – Provincial FASD awareness surveys
Quality and Continuity of Care			

The CanFASD resources listed below are related to the theme 'FASD as a Whole-Body Disorder'. They can be found in the CanFASD website: <https://canfasd.ca/> and/or CanFASD blog: <https://canfasd.ca/blog/>.

Aging and Transitions

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, and finally, justice involvement. 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

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 older people with FASD. 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-centered, and strengths-based, involving mentorship and

exploring alternative ways of coping to replace self- medication, and dealing with peer pressure.

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 (Table 3). Despite these challenges, potential strategies for reducing barriers included better integration of services, adopting a person-centered approach, offering mentorship, and linking administrative data across agencies to improve continuity of supports.

Table 3. System- and individual-level barriers to supports	
System-Level	Individual-Level
<ul style="list-style-type: none">• 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	<ul style="list-style-type: none">• 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

Issues affecting caregivers as they age were noted. 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.

2021 Research Update:

Related Research

Listed below are some of the research studies (Table 4) that are relevant to the challenges identified related to the theme 'Aging and Transitions'.

Table 4. Related Research Studies: Aging and Transitions'		
Sub-category	Authors	Study Title
Autonomy positive outcomes, self-advocacy, peer-mentors, employment, money management training, life skills training, preventing justice involvement and help after justice involvement, protection from self-harm and victimization,		
Positive outcomes	Burns et al. (2021)*	Comparing outcomes of children and youth with fetal alcohol spectrum disorder (FASD) in the child welfare system to those in other living situations in Canada: Results from the Canadian National FASD Database
	K. Temple, Prasad, Popova, and Lindsay (2020)	Long-term outcomes following Fetal Alcohol Spectrum Disorder (FASD) diagnosis in adulthood
Self-advocacy		
Facing stigma	P. W. Corrigan et al. (2018)	Addressing the public health concerns of Fetal Alcohol Spectrum Disorder: Impact of stigma and health literacy
Peer-mentors		
Education/Training		
Life skills development	K. Temple, Shewfelt, Tao,	Comparing daily living skills in adults with fetal alcohol spectrum disorder (FASD) to an IQ matched clinical sample

/ employment	Casati, and Klevnick (2011)	
Understandi ng justice involvement / Support / Intervention s	Popova et al. (2020)	Health, social and legal outcomes of individuals with diagnosed or at risk for fetal alcohol spectrum disorder: Canadian example
	Brown, Asp, Carter, Spiller, and Bishop- Deaton (2020)	Suggestibility and confabulation among individuals with Fetal Alcohol Spectrum Disorder: A review for criminal justice, forensic mental health, and legal interviewers
	Mansfield Mela et al. (2020)*	Neurocognitive function and fetal alcohol spectrum disorder in offenders with mental disorders
	Brownell et al. (2019)*	Health, social, education, and justice outcomes of Manitoba First Nations children diagnosed with fetal alcohol spectrum disorder: A population-based cohort study of linked administrative data
	McLachlan et al. (2019)*	Prevalence and characteristics of adults with fetal alcohol spectrum disorder in corrections: A Canadian case ascertainment study
	Brintnell et al. (2019)	Corrections and connection to the community: A diagnostic and service program for incarcerated adult men with FASD
	Flannigan, Pei, Stewart, and Johnson (2018)*	Fetal alcohol spectrum disorder and the criminal justice system: A systematic literature review
	Bower et al. (2018)	Fetal alcohol spectrum disorder and youth justice: A prevalence study among young people sentenced to detention in Western Australia
	Tait, Mela, Boothman, and Stoops (2017b)*	The lived experience of paroled offenders with fetal alcohol spectrum disorder and comorbid psychiatric disorder
	Stewart (2015)	Environmental scan: FASD and the justice system in Canada

	Brown et al. (2014)	Fetal alcohol spectrum disorders in the criminal justice system: A review
Self-care & protection		
Lifespan Development life expectancy, dementia, and quality of life, insufficient adult systems and services, service/resource gap, increased risk for self-medication, impact of stress and trauma, impact of gender and time, "secondary disabilities" associated with FASD		
Changes through lifespan	Jacobson et al. (2020)	Evolution of the physical phenotype of fetal alcohol spectrum disorders from childhood through adolescence
Life expectancy	Oh et al. (2020)	Hospitalizations and mortality among patients with fetal alcohol spectrum disorders: a prospective study
	Dirks et al. (2019)	Substance use, comorbid psychiatric disorders and suicide attempts in adult FASD patients
	Thanh and Jonsson (2016)	Life expectancy of people with Fetal Alcohol Syndrome
Dementia		
Quality of life	McLachlan, Flannigan, Temple, Unsworth, and Cook (2020)*	Difficulties in daily living experienced by adolescents, transition-aged youth, and adults with fetal alcohol spectrum disorder
Impact of stress and trauma	Kambeitz, Klug, Greenmyer, Popova, and Burd (2019)	Association of adverse childhood experiences and neurodevelopmental disorders in people with fetal alcohol spectrum disorders (FASD) and non-FASD controls.
	Flannigan et al. (2021)*	Characterizing adverse childhood experiences among children and adolescents with prenatal alcohol exposure and Fetal Alcohol Spectrum Disorder
Services/	Banerji and	Ten-year experience of fetal alcohol spectrum disorder;

Resources	Shah (2017)	diagnostic and resource challenges in Indigenous children
Impact of gender and time,		
"Secondary disabilities" associated with FASD		
Social Determinants of Health Access to education, job training and employment, housing, secure income, positive social interactions, addiction, FASD-informed, women-centered, and strengths-based methods, coping mechanisms		
Access services (challenges and novel methods)	Cox (2016)	FASD in a Canadian Aboriginal community context— An exploration of some ethical issues involving the access to FASD service delivery
Addiction & Coping & Self-regulation	Anderson, Mela, Rotter, and Poole (2019)*	A qualitative investigation into barriers and enablers for the development of a clinical pathway for individuals living with FASD and mental disorder/addictions
	Ryan, Ammerman, and O'Connor (2018)	Marijuana use during pregnancy and breastfeeding: Implications for neonatal and childhood outcomes
	Brown, Mitten, Charette, and Rohret (2017)	Fetal alcohol spectrum disorder (FASD) in detoxification centers: A call on withdrawal management professionals to become FASD-informed
	Anderson, Mela, and Stewart (2017)*	The implementation of the 2012 mental health strategy for Canada through the lens of FASD

FASD-informed, women-centered, and strengths-based methods	Quan, Brintnell, and Leung (2019)	Elements for developing community-based interventions for adults with fetal alcohol spectrum disorder: A scoping review
	Tremblay et al. (2017)*	Development of a clinical practice model for serving clients with fetal alcohol spectrum disorder
	(Rutman, Hubberstey, Poole, Hume, & Van Bibber, 2016)	Developing and using a common framework to evaluate FASD programs: Results of a three-year Canadian project
	Rutman (2016)	Becoming FASD informed: Strengthening practice and programs working with women with FASD
	Center for Substance Abuse Prevention (2014)	Addressing Fetal Alcohol Spectrum Disorders (FASD): Treatment Improvement Protocol (TIP) Series, No. 58.

Challenging Systems

Geographic barriers, Role of families in improving systems, FASD-informed systems and services, Supporting self-advocacy, Role of research in informing the system, Redefining success

Geography & Sub-populations	Popova, Lange, Poznyak, et al. (2019)	Population-based prevalence of fetal alcohol spectrum disorder in Canada
	Popova, Lange, Shield, Burd, and Rehm (2019)	Prevalence of fetal alcohol spectrum disorder among special subpopulations: A systematic review and meta-analysis
Remote access	Del Campo, Beach, Wells, and Jones (2021)	Use of telemedicine for the physical examination of children with fetal alcohol spectrum disorders (FASD)
	Whittingham and Coons-Harding (2020)	Connecting people with people: Diagnosing persons with fetal alcohol spectrum disorder using telehealth

Foster care, adoption & welfare systems	Bakhireva et al. (2018)	Challenges of diagnosing fetal alcohol spectrum disorders in foster and adopted children
Challenges in confirming PAE	Oni, Buultjens, Abdel-Latif, and Islam (2019)	Barriers to screening pregnant women for alcohol or other drugs: A narrative synthesis See article summary: https://canfasd.ca/2021/01/25/article-summary-13-barriers-to-screening-for-alcohol-and-drug-use/
	Petryk, Siddiqui, Ekeh, and Pandey (2019)	Prenatal alcohol history - Setting a threshold for diagnosis requires a level of detail and accuracy that does not exist
Redefining success	Alberta Education Learning and Teaching Resources Centre (January 1, 2009)	Re-defining success: A team approach to supporting students with FASD: A strategy guide for mentors and coaches working in schools
Gaps within the continuum of care	Tait, Mela, Boothman, and Stoops (2017a)	The lived experience of paroled offenders with fetal alcohol spectrum disorder and comorbid psychiatric disorder
Aging Caregivers Issues affecting aging caregivers, Generational parenting, Parenting with FASD, Family breakdown, Supporting undiagnosed adults, Respecting rights and freedoms, Navigating the processes of trusteeship, Power of attorney, and will-planning		
Grandparents	Quan et al. (2019)*	Adaptation in families raising children with fetal alcohol spectrum disorder. Part I: what has helped
	Clement, Harding, and Watson (2013)*	Grandparents raising grandchildren with fetal alcohol spectrum disorder: Unique challenges and a "second chance"
Concerns for	(Watson, Hayes,	" I'm hoping, i'm hoping...": Thoughts about the future from families of children with autism or fetal alcohol

future	Radford-Paz, & Coons, 2013)*	spectrum disorder in Ontario
Parenting with FASD	Rutman and Van Bibber (2010)	Parenting with Fetal Alcohol Spectrum Disorder

*Studies published by CanFASD or collaborative studies with CanFASD or studies in which CanFASD researchers were involved.

CanFASD Issue Papers

Listed below are some of the CanFASD issue papers ([Table 5](#)) that are relevant to theme 'Aging and Transitions'.

Table 5. CanFASD Issue Papers: 'Aging and Transitions'		
	Authors	Study Title
Autonomy positive outcomes, self-advocacy, peer-mentors, employment, money management training, life skills training, preventing justice involvement and help after justice involvement, protection from self-harm and victimization,		
	Badry and Harding (2020)	Fetal alcohol spectrum disorder and child welfare
	Morrison, Wolfson, Harding, and Poole (2020)	Mothers' experiences of stigma: Multi-level ideas for action
Lifespan Development life expectancy, dementia, and quality of life, insufficient adult systems and services, service/resource gap, increased risk for self-medication, impact of stress and trauma, impact of gender and time, "secondary disabilities" associated with FASD		
Secondary disabilities associated with FASD	Flannigan, Harding, et al. (2020)	The unique complexities of fetal alcohol spectrum disorder
	Morrison, Harding, and Wolfson (2019)	Individuals with fetal alcohol spectrum disorder and experiences of stigma
Understanding justice	Pei, Flannigan, Keller, Stewart, and Johnson	FASD and the criminal justice system: A review

involvement / Support / Interventions	(2018)	
	Glowatski and Stewart (2018)	Victimization in people with FASD
	Green, Cook, Stewart, and Salmon (2017)	FASD and the criminal justice system
Impact of stress & trauma	Green and Salmon (2015)	FASD, stress, and mental health
Social Determinants of Health access to education, job training and employment, housing, secure income, positive social interactions, addiction, FASD-informed, women-centered, and strengths- based methods, coping mechanisms		
Access to education	Brett, Harding, and The Family Advisory Committee (2018)	Current strategies and educational supports for students with FASD
Addiction & Coping	K. D. Harding and Poole (2018)	Cannabis use during pregnancy
	Anderson et al. (2018)	FASD and inappropriate sexual behaviour
FASD-informed, women-centered, and strengths-based methods		
Barriers to Continuity of Supports		
Challenging Systems Geographic barriers, Role of families in improving systems, FASD-informed systems and services, Supporting self-advocacy, Role of research in informing the system, Redefining success		
Geographic barriers &	Flannigan, Unsworth, and Harding (2018a)	FASD prevalence in special populations

subpopulations (E.g. welfare)	Flannigan, Unsworth, and Harding (2018b)	The prevalence of fetal alcohol spectrum disorder
Role of research in informing the system	Canada FASD Research Network (2020)	Canada FASD Research Network's commitment to indigenous partnership, reconciliatory research, and action
	Unsworth and McFarlane (2020)	The Canada Fetal Alcohol Spectrum Disorder Research Network: Understanding and benefiting from collaboration, experience and expertise
Self-advocacy	Coons and Makela (2017)	The impact of Jordan's Principle on children with Fetal Alcohol Spectrum Disorder
Aging Caregivers Issues affecting aging caregivers, Generational parenting, Parenting with FASD, Family breakdown, Supporting undiagnosed adults, Respecting rights and freedoms, Navigating the processes of trusteeship, Power of attorney, and will-planning		
	Flannigan, Coons- Harding, Turner, et al. (2020)	Parenting with fetal alcohol spectrum disorder: Needs, challenges, and opportunities for support and research

CanFASD Resources

The CanFASD resources listed below (Table) are related to the theme 'Aging and Transitions'. They can be found in the CanFASD website: <https://canfasd.ca/> and/or CanFASD blog: <https://canfasd.ca/blog/>.

Table 3. CanFASD Resources: 'Aging and Transitions' Autonomy, Lifespan Development, Social Determinants of Health, Barriers to Continuity of Supports, Challenging Systems, Aging Caregivers			
Sub-category	Type of Resource	Authors	Title
Autonomy positive outcomes, self-advocacy, peer-mentors, employment, money management training, life skills training, preventing justice involvement and help after justice involvement, protection from self-harm and victimization,			

§caregiver perspectives in a guest blog were considered as peer mentoring			
Positive outcomes	Webinar	Pei (June 8, 2020)	Towards healthy outcomes for individuals with FASD: Advancing a common intervention framework
Justice involvement	Webinar	(McLachlan, Grub, & Mullally, August 14, 2020)	Understanding FASD in the criminal justice system: A research update
Employment	Report	(Makela, Kapasi, Pei, & McFarlane, 2018)	Supporting employment in individuals with FASD: A guide for employment professionals
Lifespan Development			
Changes across lifespan	Interactive website	CanFASD, University of Alberta, Dr. J. Pei's research team,	http://knowfasd.ca/
Social Determinants of Health			
Barriers to Continuity of Supports			
Challenging Systems			
Aging Caregivers			
Succession Planning	Document Guide	CanFASD (2019b)	SUCCESSION PLANNING: What parents & caregivers of a loved one with FASD need to know

The following table has CanFASD resources that are related to the theme 'Aging and Transitions' (Table 6).

Table 6. CanFASD Resources: 'Aging and Transitions'			
Subcategory	Type	Authors	Resource
Autonomy positive outcomes, self-advocacy, peer-mentors, employment, money management training, life skills training, preventing justice involvement and help after justice involvement, protection from self-harm and victimization,			
§caregiver perspectives in a guest blog were considered as peer mentoring			
Peer mentors	Blog post	D. Reid (September 25, 2020)§	What FASD is: A caregiver’s perspective
	Blog post	(Beland, September 11, 2020)§	What FASD means to me
Understanding justice involvement / Support / Interventions	Book	Blagg et al. (2021)	Decolonizing Justice for Aboriginal Youth with Fetal Alcohol Spectrum Disorders
	Webinar	McLachlan (2020, August 7)	Understanding FASD in the criminal justice system: A research update
	eLearning Course	CanFASD	FASD for Judicial and Legal Professionals Level II https://estore.canfasd.ca/fasd-for-judicial-professionals-level-ii
			FASD for Solicitor General Professionals Level II https://estore.canfasd.ca/fasd-for-solicitor-general-professionals-level-ii
			Towards Improved Practice: An online curriculum https://estore.canfasd.ca/towards-improved-practice
Lifespan Development			

life expectancy, dementia, and quality of life, insufficient adult systems and services, service/resource gap, increased risk for self-medication, impact of stress and trauma, impact of gender and time, “secondary disabilities” associated with FASD			
Life expectancy			
Dementia	Guest Blog Post		
Quality of life			
Impact of stress and trauma	Blog post	(CanFASD, November 4, 2020)	Fetal alcohol spectrum disorder and stress
Services/ Resources			
Social Determinants of Health			
Access to education			
Job training and employment / Secure income			
Housing/ Homelessness			
Addiction & Coping & Self-regulation	Report	Canadian Centre for Substance Abuse (2016)	Addiction and mental health care: Resources to support collaboration
	Blog post	CanFASD (November 25, 2020)	Language matters: National Addictions Awareness Week

	Webinar	(Pei, Mastrangelo, & Noah, August 28, 2020)	Supporting self-regulation with individuals with FASD
	Blog post	CanFASD (November 4, 2020)	Fetal alcohol spectrum disorder and stress
	Report	Bell and The Alberta FASD Cross Ministry Committee (2020)	The FASD patient journey
	Blog post	CanFASD (November 27, 2018)	Canadian Centre on Substance Use and Addiction: The Low-Risk Alcohol Drinking Guidelines Communications Toolkit
FASD-informed, women-centered, and strengths-based methods	Report	Bell and The Alberta FASD Cross Ministry Committee (2020)	The FASD patient journey
Barriers to Continuity of Supports			
Challenging Systems			

Geographic barriers, Role of families in improving systems, FASD-informed systems and services, Supporting self-advocacy, Role of research in informing the system, Redefining success			
Need for research	Guest Blog Post	(Brownstone & Reid, July 3, 2019)	Adults with FASD – Priorities for Research
Aging Caregivers E.g., grandparents Issues affecting aging caregivers, Generational parenting, Parenting with FASD, Family breakdown, Supporting undiagnosed adults, Respecting rights and freedoms, Navigating the processes of trusteeship, Power of attorney, and will-planning			

Strategies and Supports

What are effective intervention strategies and supports.

Caregiver Needs

Participants spoke 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

Discussions 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

Brain based interventions were seen as a promising avenue for research. 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

The importance of supporting healthy friendships and relationships for people with FASD across the lifespan was identified. 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

Strength and Hope

Throughout conversations participants highlighted the need for a strengths-based, person-centered 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

There are numerous research studies that discuss important findings related to the subthemes identified described above and some of them are listed in [Table 7](#).

Table 7. Related Research Studies: 'Strategies and Supports'		
Caregiver Needs; Supporting Function; Brain and Body; The Role of Relationships; Strengths and Hope		
Category	Authors	Study
Caregiver Needs	Kautz, Parr, and Petrenko (2020)	Self-care in caregivers of children with FASD: How do caregivers care for themselves, and what are the benefits and obstacles for doing so?
	Flannigan, Coons-Harding, Turner, et al. (2020)*	Parenting with fetal alcohol spectrum disorder: Needs, challenges, and opportunities for support and research
	N. Reid and Moritz (2019)	Caregiver and family quality of life for children with fetal alcohol spectrum disorder
	Bobbitt et al. (2016)	Caregiver needs and stress in caring for individuals with fetal alcohol spectrum disorder
	A. Kapasi (2015)*	Caregivers' experiences raising a child with fetal alcohol spectrum disorder
Supporting Function	Pruner, Jirikowic, Yorkston, and Olson (2020)	The best possible start: A qualitative study on the experiences of parents of young children with or at risk for fetal alcohol spectrum disorders
	Petrenko and Alto (2017)	Interventions in fetal alcohol spectrum disorders: An international perspective
	Pei, Flannigan, Walls, and	Interventions for FASD: Meeting needs

	Rasmussen (2016)*	across the lifespan
	Millians (2015)	Educational needs and care of children with FASD
Brain and Body (importance of diagnosis, understanding how their brain & body work)	Flannigan, Coons-Harding, Turner, et al. (2020)*	A survey of measures used to assess brain function at FASD clinics in Canada
	Murawski, Moore, Thomas, and Riley (2015)	Advances in diagnosis and treatment of fetal alcohol spectrum disorders: From animal models to human studies
	Todorow, Paris, and Fantus (2012)	Ethical considerations when communicating a diagnosis of a fetal alcohol spectrum disorder to a child
The Role of Relationships	Brackenreed (2015)	Persons with FASD: Disability and sexuality
	Schonfeld, Paley, Frankel, and O'Connor (2009)	Behavioral regulation as a predictor of response to children's friendship training in children with fetal alcohol spectrum disorders
Strengths and Hope	McLachlan et al. (2017)*	Unpacking the heterogeneity of cognitive functioning in children and adolescents with fetal alcohol spectrum disorder: Determining the role of moderators and strengths
	Rogers, McLachlan, and Roesch (2013)	Resilience and enculturation: Strengths among young offenders with Fetal Alcohol Spectrum Disorder

*Studies published by CanFASD or collaborative studies with CanFASD or studies in which CanFASD researchers were involved.

CanFASD Issue Papers

CanFASD has published several issue papers addressing the challenges associated with the theme 'Strategies and Supports' and discussing the potential solutions and recommendations. Some of these issue papers are listed in [Table 8](#).

Table 8. CanFASD Issue Papers: 'Strategies and Supports'

Caregiver Needs; Supporting Function; Brain and Body; The Role of Relationships; Strengths and Hope		
Category	Authors	Study
Caregiver Needs	Flannigan, Coons-Harding, Turner, et al. (2020)	Parenting with fetal alcohol spectrum disorder: Needs, challenges, and opportunities for support and research
Supporting Function	Badry and Harding (2020)	Fetal alcohol spectrum disorder and child welfare
	Burns, Harding, Flannigan, Kathy Unsworth, and McFarlane (2020)	Provincial and territorial strategies for fetal alcohol spectrum disorder in Canada
	Brett et al. (2018)	Current strategies and educational supports for students with FASD
	Green, Cook, and Pei (2014)	Computer game interventions for individuals with FASD
Brain and Body (importance of diagnosis)	Green et al. (2017)	Two recent approaches to FASD diagnosis: An issue paper
	Green et al. (2015)	Why is FASD diagnosis important?
The role of relationships	Anderson et al. (2018)	FASD and inappropriate sexual behaviour
Strengths and Hope	Flannigan, Harding, Reid, and The Family Advisory Committee (2018)	Strengths among individuals with FASD
	Coons and Makela (2017)	The impact of Jordan's Principle on children with Fetal Alcohol Spectrum Disorder

CanFASD Resources

The CanFASD resources listed below (Table) are related to the theme 'Strategies and Supports'. They can be found in the CanFASD website: <https://canfasd.ca/> and/or CanFASD blog: <https://canfasd.ca/blog/>.

Table 3. CanFASD Resources: 'Strategies and Supports' Caregiver Needs; Supporting Function; Brain and Body; The Role of Relationships; Strengths and Hope			
Sub-category	Type of Resource	Authors	Title
Caregiver Needs			
Training & Education	Updated Caregiver Curriculum on FASD	Children's Aid Society of Toronto, Child Welfare Institute	FREE Caregiver Curriculum on Fetal Alcohol Spectrum http://www.childwelfareinstitute.torontocas.ca/training
	eLearning Course	CanFASD	Level 1: Basic FASD Training Foundations in FASD https://estore.canfasd.ca/foundations-in-fasd
Resources for different needs	Infographic	CanFASD	I am a caregiver for a person with FASD https://canfasd.ca/wp-content/uploads/2019/03/Caregiver_ENG_2019-Final.pdf *available in both English and French
	Document (Guide)	Badry and Hickey (2018)	I Am a Caregiver! For a person with FASD—Caregiver Resource Guide
	Web Resource	(HCMO & NCCAH, November 20, 2017)	Four new resources for First Nations and Metis parents and caregivers in Manitoba
	Document Guide	Family Advisory Committee (2017)	A resource for family members looking for information about Educational supports for their children
	Document Guide	Family Advisory Committee (2016)	A resource for family members looking for information about financial and other supports for their children
	Document	CanFASD (January	A caregiver's guide to FASD diagnosis

	Guide	2020)	(Provides information on where to find support for your child or a child in your care)
Supporting Function			
Brain and Body			
Helping children understand how their brain works	Report	CanFASD (2019a)	How to explain an FASD diagnosis to your child
The Role of Relationships			
Strengths and Hope			
	Webinar	Badry, Himmelreich, and Laplante (July 31, 2020)	Loss, Grief, and FASD

Advocating for Supports

Training and Education

Participants expressed that additional training and greater awareness of issues related to FASD could reduce parent isolation, secure funding, keep families together, and recognize different indicators of success. Training should be collaborative, peer-driven and evaluated.

Stigma

Conversations centered 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

It was 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

Discussion revolved 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

Listed below are some of the research studies ([Table 10](#)) that are relevant to the challenges identified related to the theme 'Advocating for Supports'.

Table 8. Related Research Studies: 'Strategies and Supports'		
Training and Education; Stigma; Justice Interventions; Prevention; Defining Success for FASD		
Category	Authors	Study
Training and Education for parents and caregivers	Gibbs (2019)	An evidence-based training and support course for caregivers of children with foetal alcohol spectrum disorder (FASD) in New Zealand
	Hundert et al. (2016)*	Usability testing of guided internet-based parent training for challenging behavior in children with fetal alcohol spectrum disorder (strongest families FASD)
	Kable, Coles, Strickland, and Taddeo (2012)	Comparing the effectiveness of on-line versus in-person caregiver education and training for behavioral regulation in families of children with FASD
Training and Education of professionals	N. Reid, White, et al. (2020)	Outcomes and needs of health and education professionals following fetal alcohol spectrum disorder-specific training

	Brown and Harr (2019)	Perceptions of fetal alcohol spectrum disorder (FASD) at a mental health outpatient treatment provider in Minnesota
	Landgraf et al. (2018)	Fetal alcohol spectrum disorders (FASD)—What we know and what we should know—The knowledge of German health professionals and parents
Stigma	Roozen, Stutterheim, Bos, Kok, and Curfs (2020)	Understanding the social stigma of fetal alcohol spectrum disorders: From theory to interventions
	Key, Ceremony, and Vaughn (2019)	Testing two models of stigma for birth mothers of a child with fetal alcohol spectrum disorder
	Patrick W. Corrigan et al. (2019)	Stakeholder perspectives on the stigma of fetal alcohol spectrum disorder
	Eggertson (2013)	Stigma a major barrier to treatment for pregnant women with addictions
Justice Interventions	Blagg et al. (2021)	Decolonizing Justice for Aboriginal Youth with Fetal Alcohol Spectrum Disorders
	Brintnell et al. (2019)	Corrections and connection to the community: A diagnostic and service program for incarcerated adult men with FASD
	Pei, Leung, Jampolsky, and Alsbury (2016)*	Experiences in the Canadian criminal justice system for individuals with fetal alcohol spectrum disorders: Double jeopardy?
	Currie, Hoy, Legge, Temple, and Tahir (2016)	Adults with fetal alcohol spectrum disorder: Factors associated with positive outcomes and contact with the criminal justice system
Prevention	Pei, Carlson, Tremblay, and Poth (2019)*	Exploring the contributions and suitability of relational and community-

		centered fetal alcohol spectrum disorder (FASD) prevention work in First Nation communities
	Wolfson, Poole, et al. (2019)*	Collaborative action on fetal alcohol spectrum disorder prevention: Principles for enacting the Truth and Reconciliation Commission Call to Action #33
	Rutman and Hubberstey (2019)*	National evaluation of Canadian multi-service FASD prevention programs: Interim findings from the Co-Creating Evidence study
	Zizzo and Racine (2017)	Ethical challenges in FASD prevention: Scientific uncertainty, stigma, and respect for women's autonomy
	Nancy Poole, Schmidt, Green, and Hemsing (2016)*	Prevention of fetal alcohol spectrum disorder: Current Canadian efforts and analysis of gaps
Defining Success for FASD	Aamena Kapasi, Makela, Flannigan, Joly, and Pei (2019)*	Understanding employment success in adults with Fetal Alcohol Spectrum Disorder

*Studies published by CanFASD or collaborative studies with CanFASD or studies in which CanFASD researchers were involved.

CanFASD Issue Papers

The Table below summarizes some of the related CanFASD issue papers that discuss theme 'Advocating for Supports' (Table 5).

Table 5. CanFASD Issue Papers: 'Advocating for Supports'		
Training and Education; Stigma; Justice Interventions; Prevention; Defining Success for FASD		
Subcategory	Authors	Study Title
Advocacy	Coons and Makela (2017)	The impact of Jordan's Principle on children with Fetal Alcohol Spectrum Disorder

Training and Education of professionals & Research in collaboration with parents and caregivers	Unsworth and McFarlane (2020)	The Canada Fetal Alcohol Spectrum Disorder Research Network: Understanding and benefiting from collaboration, experience and expertise
	Canada FASD Research Network (2020)	Canada FASD Research Network's commitment to indigenous partnership, reconciliatory research, and action
	Badry and Harding (2020)	Fetal alcohol spectrum disorder and child welfare
	Mela, Coons-Harding, and Anderson (2019)	Policy action paper: Toward a standard definition of fetal alcohol spectrum disorder in Canada
	Rajani (2017)	Alcohol consumption and FASD
Stigma	Morrison et al. (2020)	Mothers' experiences of stigma: Multi-level ideas for action
	Morrison, Harding, et al. (2019)	Individuals with fetal alcohol spectrum disorder and experiences of stigma
Prevention	Wolfson, Harding, and Poole (2019)	The role of partners in fetal alcohol spectrum disorder prevention
	Liyanage-Zachariah and Harding (2019)	Genetic and epigenetic perspectives on the role of fathers in fetal alcohol spectrum disorder
	Morrison, Wolfson, and Harding (2019)	The efficacy of warning labels on alcohol containers for fetal alcohol spectrum disorder prevention
	Thomas, Cook, Poole, and Gonneau (2014)	The effectiveness of alcohol warning labels for reducing drinking in pregnancy: A brief review
	Clarren and Cook (2013b)	Meconium screening for FASD in pregnancy
	N. Poole and Network Action Team on FASD Prevention (2013)	Prevention of Fetal Alcohol Spectrum Disorder (FASD): A multi-level model
Justice Interventions	Jacqueline Pei et al. (2018)	FASD and the criminal justice system: A review
Defining Success for	Green and Cook (2014)	Employment and fetal alcohol spectrum disorder: Strategies for success

FASD		
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CanFASD Resources

The CanFASD resources listed below (Table) are related to the theme 'Advocating for Supports'. They can be found in the CanFASD website: <https://canfasd.ca/> and/or CanFASD blog: <https://canfasd.ca/blog/>.

Table 3. CanFASD Resources: 'Advocating for Supports' Training and Education, Stigma, Justice Interventions, Prevention, Defining Success for FASD			
Sub-category	Type of Resource	Authors	Title
Advocation	Document	CanFASD (2018)	FASD caregiver/ community advocacy resources
	Blog post	Wolfson (October 23, 2018)	Conference highlights from learning, and growing: Imagining the future of Jordan's Principle
Training & Education			
Training & Education of parents and caregivers	Updated Caregiver Curriculum on FASD	Children's Aid Society of Toronto, Child Welfare Institute	FREE Caregiver Curriculum on Fetal Alcohol Spectrum http://www.childwelfareinstitute.torontocas.ca/training
	eLearning Course	CanFASD	Level 1: Basic FASD Training Foundations in FASD https://estore.canfasd.ca/foundations-in-fasd
	Document Guide	Family Advisory Committee (November 2020)	FASD – Online Education Opportunities
	Webinar	Ogourtsova, Majnemer, Cohen, and	The Coach Approach: Supporting families of children with disabilities

		O'Donnell (June 21, 2018)	
Training and Education of professionals & Research	eLearning Course - General	CanFASD	Level 1: Basic FASD Training Foundations in FASD https://estore.canfasd.ca/foundations-in-fasd
	eLearning Course - For front-line health and social service providers & professionals	CanFASD	<u>Level 2: Sector/Special Interest FASD Training</u> The Prevention Conversation https://estore.canfasd.ca/prevention-conversation Towards Improved Practice (TIP) https://estore.canfasd.ca/towards-improved-practice FASD for Community and Social Services Professionals Level II (coming soon)
	eLearning Course - For School Staff	CanFASD	<u>Level 2: Sector/Special Interest FASD Training</u> FASD for School Staff Level II: Practical Strategies for the School Environment https://estore.canfasd.ca/fasd-for-school-staff-level-ii
	eLearning Course – Justice Professionals	CanFASD	<u>Level 2: Sector/Special Interest FASD Training</u> FASD For Judicial and Legal Professionals Level II https://estore.canfasd.ca/fasd-for-judicial-professionals-level-ii FASD for Solicitor General Professionals Level II https://estore.canfasd.ca/fasd-for-solicitor-general-professionals-level-ii
	eLearning Course – For clinical and allied health professionals	CanFASD	<u>Level 3: Specialized/Expert FASD Training</u> Multidisciplinary Team Training for Diagnosis of FASD: An online curriculum https://estore.canfasd.ca/multidisciplinary-team-training-for-diagnosis-of-fasd
Stigma			
Stigma & discrimination	Blog post (Events & Holidays)	CanFASD (February 28, 2020)	Zero Discrimination Day

	Article summary	(CanFASD, December 6, 2018)	Article Summary: Stereotyping and stigmatizing disability: A content analysis of Canadian print new media about Fetal Alcohol Spectrum Disorder
Attitudes/ perceptions affecting service provision	Article summary	CanFASD (January 15, 2020)	Article summary – How personal perspectives shape health professionals’ perceptions of FASD and risk
	Article summary	CanFASD (December 4, 2018)	Article Summary: Midwives’ knowledge, attitudes and practice about alcohol exposure and the risk of fetal alcohol spectrum disorder
Justice Interventions			
Prevention			
Looking at the big picture	Webinar	N. Poole and Wolfson (October 2, 2020)	Refreshing our conversations about alcohol as a key component of FASD prevention
First Nation Community Perspectives	Article summary	CanFASD (August 3, 2019)	Article Summary: Exploring the contributions and suitability of relational and community-centered fetal alcohol spectrum disorder (FASD) prevention work in First Nation communities
Impact of gender	Blog post (Feature Friday)	CanFASD (February 14, 2020b)	#FeatureFriday – Provincial FASD Awareness Surveys Note: The results suggest lesser awareness of FASD among males than females. Prevention methods should be addressed to both males and females
Screening for PAE & Prevention of FASD	Article summary	CanFASD (August 21, 2019)	Article Summary: Prenatal alcohol screening during pregnancy by midwives and nurses
Role of media	Blog post (Media Week)	(E. Harding, April 18, 2019)	Media week #3: “You don’t want to drink? What are you, pregnant?!”: Representations of alcohol use during pregnancy on television Note: This is an example of the resources available for the Media Week. Find more at ‘Introduction to our Media Week Series!’ (CanFASD, April 15, 2019)

Defining Success for FASD			
	Webinar	Badry et al. (July 31, 2020)	Loss, Grief, and FASD
	Blog post	CanFASD (December 11, 2020)	Article summary: Employment success in adults with FASD
	Blog post	CanFASD (January 22, 2020)	Experiences in Education: Today we're taking a look at FASD and our education system through the lens of three different people: The student, the teacher, and the caregiver.

Update on Suggested Topics

In the 2016 Learning Together report, the following topics were suggested as potential areas of interest to develop issue papers or helpful resources. Currently, CanFASD and collaborators have developed many resources pertaining to these topics.

Theme	Suggested topic	Authors	Title
Whole Body Disorder	Pharmacology and FASD (Medication management)	Webinar with Dr. Mela on the medication algorithm	
		M. Mela et al. (2020)	Treatment algorithm for the use of psychopharmacological agents in individuals prenatally exposed to alcohol and/or with diagnosis of fetal alcohol spectrum disorder (FASD)
		Blog post: CanFASD (September 28, 2020)	Experts publish the first medication guidelines for people with FASD
		Infographics: Mela (2020)	Using a medication algorithm to support people with fetal alcohol spectrum disorder
		Infographics: Mela (2018)	Psychotropic medication algorithm for FASD/Prenatal Alcohol Exposure: Summary for caregivers
Aging and Transitions	Best Practices for Supporting Transitions	Article: Coons-Harding, Azulai, and McFarlane (2019) Article Summary: CanFASD (October 28, 2020) Infographic: Coons-Harding (2019)	State-of-the-art review of transition planning tools for youth with fetal alcohol spectrum disorder in Canada
	Homelessness and FASD	Badry, Walsh, Bell, and Ramage (2018)	The linkage between FASD and homelessness for individuals with a history of child welfare care
		CanFASD (March 29, 2018)	Article summary: Housing interventions for homeless, pregnant/parenting women with

			addictions: A systematic review Krahn, Caine, Chaw-Kant, and Singh (2018)
		Report: Milaney, Ramage, Fang, and Louis (2017)	Understanding mothers experiencing homelessness: A gendered approach to finding solutions for family homelessness
Strategies and Supports	Supported Housing & Preventing Homelessness	Blog pot: CanFASD (March 6, 2019) Report: J. Pei et al. (2018)	Creating Intersections: A systematic and person-centered harmonizing framework for housing individuals with FASD
		Report: Dolan et al. (May 4, 2012)	Literature review and best practices for the housing and supports framework; housing and supports initiative; and creating connections: Alberta's addiction and mental health strategy
		Canada NWFASD Partnership Symposia	
	Sexuality and FASD	Issue paper: Anderson et al. (2018)	FASD and inappropriate sexual behaviour
Advocating for Supports	FASD and Child Welfare	Issue paper: Badry and Harding (2020)	Fetal alcohol spectrum disorder and child welfare
		Article summary: CanFASD (October 28, 2020)	Article summary – Outcomes of children with FASD in the child welfare system
		Research paper: Burns et al. (2021)*	Comparing outcomes of children and youth with fetal alcohol spectrum disorder (FASD) in the child welfare system to those in other living situations in Canada: Results from the Canadian National FASD Database
	FASD Prevention from an Aboriginal Perspective	The CanFASD online Prevention Conversation course is being updated to include an Indigenous	Indigenous approaches to FASD prevention: Why collaborative action is important

		perspective – ready summer 2022.	
		Unsworth and McFarlane (2020)	The Canada Fetal Alcohol Spectrum Disorder Research Network: Understanding and benefiting from collaboration, experience and expertise

Appendix 4: Further References

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