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# Integrated Service Delivery in Fetal Alcohol Spectrum Disorder (FASD): A Review of the Alberta FASD Service Network Model

Prestation de services intégrés pour le trouble du spectre de l'alcoolisation fœtale (TSAF) : un examen du modèle de réseau de services TSAF de l'Alberta

#### **Author Information**

Katherine R. Flannigan,<sup>1</sup> Andrew J. Wrath,<sup>1</sup> Audrey McFarlane <sup>1</sup> Lisa Murphy <sup>2</sup> Lisa Rogozinsky <sup>3</sup>

<sup>1</sup>Canada Fetal Alcohol Spectrum Disorder Research Network, Vancouver, BC <sup>2</sup>Lakeland Centre for Fetal Alcohol Spectrum Disorder, Cold Lake, AB <sup>3</sup>Edmonton and Area Fetal Alcohol Network, Edmonton, AB

# **Correspondence:**

katy.flannigan@canfasd.ca

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#### **Abstract**

Fetal alcohol spectrum disorder (FASD) is one of the most common neurodevelopmental disabilities in North America. Stemming from the brain- and bodybased impacts of prenatal alcohol exposure, individuals with FASD experience a range of challenges with physical, cognitive, behavioural, and social-emotional functioning. Most individuals with FASD require ongoing assistance to support day-today living and protect against negative life outcomes. Service needs for individuals with FASD often span across multiple areas of functioning, necessitating a range of supports from various disciplines and sectors. The complexity of needs experienced by individuals with FASD underscores the importance of integrated services, however, there is currently a lack of research on integrated service delivery approaches in the FASD population. The Alberta FASD Service Network model is a unique integrated FASD service delivery approach established in 2007 which facilitates the delivery of coordinated FASD supports and programs across Alberta. The aim of the current study was to review the evidence pertaining to this model. We identified 45 relevant documents, the findings of which were synthesized to better understand the aims and scope, impacts, and challenges of the Alberta FASD Service Network model and inform future work in FASD research, practice, and policy.

#### Résumé

Le trouble du spectre de l'alcoolisation fœtale (TSAF) est un des troubles neurodéveloppementaux les plus communs en Amérique du Nord. En raison des effets de l'exposition prénatale à l'alcool sur le cerveau et le corps, les personnes avant un TSAF sont confrontées à des défis liés au fonctionnement physique, cognitif, comportemental et socioémotionnel. La plupart des personnes ayant un TSAF ont besoin d'un soutien continu pour les aider dans leur quotidien et favoriser leur réussite. Les besoins de services pour les personnes ayant un TSAF couvrent souvent de multiples domaines de fonctionnement, ce qui nécessite un éventail de soutiens provenant de divers secteurs et disciplines. La complexité des besoins vécus par les personnes ayant un TSAF souligne l'importance de services intégrés. Cependant, il y a actuellement un manque de recherche sur les approches de prestation de services intégrés auprès de la population TSAF. Le modèle de réseau de services pour le TSAF de l'Alberta est une approche de prestation de services intégrée unique, établie en 2007, qui facilite la prestation de soutiens et de programmes coordonnés pour le TSAF dans l'ensemble de Alberta. L'objectif de la présente étude était d'évaluer les données probantes relatives à ce modèle. Nous avons identifié 45 documents pertinents et synthétisé leurs conclusions pour mieux comprendre les objectifs, la portée, les effets et les défis du modèle de réseau de services pour le TSAF de l'Alberta et pour éclairer les travaux futurs concernant la recherche, la pratique et les politiques sur le TSAF.

**Mots clés** : trouble du spectre de l'alcoolisation fœtale, prestation de services intégrés, conscientisation, prévention, évaluation et diagnostic, intervention, soutien familial

#### Introduction

Fetal alcohol spectrum disorder (FASD) is a life-long brain- and body-based disability affecting an estimated 4% of the Canadian population (Popova et al., 2019; Thanh et al., 2014). FASD is a diagnostic term used to describe the array of challenges resulting from prenatal alcohol exposure (PAE) including physical, cognitive, learning, socio-emotional, and behavioural difficulties (Cook et al., 2015). Although, by definition, all individuals with FASD experience significant and pervasive brain impairment (Cook et al., 2015), the scope and nature of the disability is highly variable, and individuals with FASD often demonstrate unique needs, challenges, and strengths. FASD is also associated with a high degree of postnatal environmental adversity, including trauma, abuse, instability, and ongoing victimization (McLachlan et al., 2020; Price et al., 2017; Streissguth et al., 2004). Without adequate services and supports, these complex challenges can extend throughout the lifespan. Adolescents and adults with FASD often experience problems with school and employment, independence, housing, parenting, legal issues, and mental health and substance use (McLachlan et al., 2020; Streissguth et al., 2004). FASD can also place substantial demands and stressors on caregivers and families (Bobbitt et al., 2016; Domeij et al., 2018).

#### **Integrated Services and Supports for FASD**

Early identification of FASD and access to appropriate services and supports are important for mitigating the negative outcomes associated with FASD (Streissguth et al., 2004). Due to the complex challenges and experiences of individuals with FASD, service needs often span across

disciplines and evolve over the life course (Brownell et al., 2013; Masotti et al., 2015; Pei et al., 2017a). Integrated models of service delivery have been promoted in various settings and populations (Duffy et al., 2017; Hebert et al., 2003; Schmied et al., 2012), particularly those with complex needs (Goodwin, 2016) including children with disabilities and their families (King & Meyer, 2006). There are many benefits to these integrated approaches, such as improved client experiences and outcomes; increased effectiveness and efficiency of services; enhanced consistency and continuity of care; decreased burden on caregivers; and potential for cost-reduction (Crocker et al., 2020; Hazarika & Purdy, 2015; Hébert et al., 2003; Menear et al. 2017). Despite these known benefits, there is currently a lack of research on integrated service delivery approaches for individuals with FASD (Masotti et al., 2015; Pei et al., 2021). Investigation of existing models of FASD service delivery is needed to better understand what approaches are being implemented; what impacts they have had on individuals with FASD, their families, and their communities; and what gaps exist in the literature that may inform future directions for FASD research, practice, and policy.

## **Canadian Response to FASD**

Canada has played a leading role in advancing FASD research, practice, and policy. Although there is currently no federal FASD strategy, several Canadian provinces and territories have acknowledged the need to support this population through formal plans and frameworks (Burns et al., 2020), and the Alberta government has demonstrated a particularly notable commitment in this area. Based on the estimated national prevalence rate of 4%, approximately 174,000 individuals in Alberta are believed to have FASD (Government of Alberta, 2020a). The estimated daily economic cost for the provincial government to support individuals with FASD in Alberta is up to \$316,000, much of which has been attributed to health care utilization, correctional programming, social services, and education (Thanh & Jonsson, 2009). In a study of young Albertans (0 to 25 years) with FASD, researchers reported that this group experienced higher special education needs and lower educational achievement; more service use (including disability support, financial assistance and income support, social services, child intervention); lower socioeconomic status; increased criminal involvement; greater mental health concerns; and more residential instability than young Albertans without FASD (PolicyWise for Children and Families, 2017). This evidence highlights the complex and chronic nature of challenges and needs experienced by individuals with FASD in Alberta, as well as the necessity for ongoing, cross-sectoral, and integrated supports and services.

#### The Alberta FASD Service Network Model

Beginning in the 1990s, impetus grew to address the challenges associated with FASD in Alberta, driven largely by caregivers and social workers concerned about the wellbeing of children in provincial care (Shankar, 2015). This momentum resulted in increased socio-political pressure for government recognition and support, and the eventual establishment of an Alberta FASD Cross-Ministry Committee (FASD-CMC) in the early 2000s (Milne et al., 2011, 2013; Shankar, 2015). The FASD-CMC was comprised of stakeholders from provincial ministries and other agencies ranging from health and wellness to justice (Government of Alberta, 2008). Together, the FASD-CMC developed a comprehensive 10-Year FASD Strategic Plan, launched

in 2007, to "provide a coordinated approach for a unique made-in-Alberta framework for addressing FASD" across the lifespan (Government of Alberta, 2008).

The goals of the FASD Strategic Plan evolved over time and were ultimately divided into five strategic pillars. The first four pillars targeted FASD service delivery in the areas of awareness (Pillar 1), prevention (Pillar 2), assessment and diagnosis (Pillar 3), and support for individuals and caregivers (Pillar 4). The fifth pillar was focused on developing the FASD learning organization (Pillar 5), including research and evaluation, strategic planning, training and education, and stakeholder engagement. Within each pillar, specific outcomes, strategies, and leading stakeholders were identified. To carry out the four service delivery pillars, the FASD-CMC initiated the Alberta FASD Service Network model. Through this model, 12 regional FASD Service Networks were developed, each providing single-point access to integrated FASD resources, programs, and supports covering the entire geographic area of Alberta.

# **Current Study**

Integrated service delivery approaches for individuals with FASD are important for meeting the complex needs of this population, however, the evidence base in this area is limited (Masotti et al., 2015; Pei et al., 2021). Numerous research studies and evaluations have been conducted related to various elements of the Alberta FASD Service Network model since its inception, but this knowledge has not yet been collectively summarized. Consolidated evidence related to integrated service delivery approaches such as the Alberta FASD Service Network model is important for better understanding whether and how these approaches are meeting the needs of individuals with FASD, their families, and their communities. Moreover, the consolidation and dissemination of this knowledge will help to guide future research, evaluation, and evidence-based FASD practice within Alberta, as well as inform the initiation and advancement of FASD service delivery models and policies elsewhere.

The purpose of the current study was to review, consolidate, and synthesize the evidence related to the Alberta FASD Service Network model with the specific goals of 1) describing the aims and scope of the model; 2) investigating its impacts for individuals, their families, and their communities; and 3) exploring challenges of integrated FASD service delivery in Alberta. We also identified gaps in the evidence to inform future directions for FASD research, practice, and policy.

#### **Materials and Methods**

We drew on strategies proposed by Arksey and O'Malley (2005) for conducting scoping reviews, and our reporting was guided by the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) extension for Scoping Reviews (Tricco et al., 2018). Our scope of inquiry included any documents available in the academic or grey literature that provided evidence about the Alberta FASD Service Network model. Documents were considered for review only if they were written in English. Both qualitative and quantitative evidence was included. Commentaries and editorials were excluded.

#### **Information Sources and Search Terms**

Our study was conducted between May and December 2020. We reviewed documents from 2007 to present to align with the commencement of the 10-Year Strategic Plan. For the academic literature review, the first author (KF) searched Web of Science, PubMed, PsycINFO, and MEDLINE (via Ovid), compiled all search results, and removed duplicates. For the grey literature review, two researchers (KF, AW) independently conducted a general Google search, as well as targeted searches of the Alberta government websites, other organizations involved in the implementation and evaluation of the model (e.g., PolicyWise for Children and Families, Canada FASD Research Network, various regional FASD Service Networks), and relevant conference archives. We also screened reference lists and contacted government and regional Service Network stakeholders for relevant reports that were not widely available. Our search terms for the academic literature included: ["Fetal Alcohol Spectrum Disorder" OR "FASD" OR "Foetal Alcohol Spectrum Disorder"] AND ["Alberta"], and for the grey literature search, we added ["Service Network" OR "Strategic Plan"] to refine the results. Results from the academic and grey literature searches were combined, and a preliminary screen of record titles was conducted by the first author (KF) to remove any irrelevant records (e.g., those that did not mention FASD or the Alberta FASD Service Network Model). Relevant abstracts were then screened independently by two authors (KF, AW) to identify full texts for review. Discrepancies about inclusion at any stage were resolved through discussion until consensus was reached, and additional authors were consulted if necessary.

# **Data Charting and Synthesis**

A form was developed for charting the data, which included the document type, description, and key content or findings (see Table 1). Two researchers (KF, AW) independently charted data for the first five documents to ensure consistency. The first author then charted data for the remaining articles. Given the wide variety of documents reviewed and the exploratory nature of this study, a critical appraisal of evidence was not conducted.

Data synthesis was primarily descriptive, based on the approach laid out by Braun and Clark (2006) for thematic analysis to code, organize, and describe patterns in the data. The first step of data synthesis involved broadly coding the content of each document in terms of our three research goals (i.e., model scope, impacts, and challenges). We then organized documents according to the primary emphasis of their content. Many documents included overlapping or repetitive content, thus in categorizing the data, we selected key records that provided the most comprehensive, up-to-date, or unique evidence within a given category. When appropriate, we listed documents in multiple categories. Findings were also sub-grouped based on the five pillars of the 10-Year Strategic plan (i.e., FASD awareness, prevention, assessment and diagnosis, support services, and learning organization). Once records were categorized, two authors (KF, AW) collaboratively reviewed findings to identify common patterns as they pertained to each of our research goals.

Table 1. Details of records included.

Do	cument	Туре	Description	Ke	y Content/Findings
Mo	odel Aims and Scope				
1.	Alberta FASD Service Networks (2018)	Infographic	Highlights of SN model impacts	-	Brief overview of the SN model, and highlight of key successes, achievements, challenges, and new initiatives
2.	Government of Alberta (2008)	Government report	Overview of the 10-Year Strategic Plan	-	Description of the context, guiding principles, and pillars of the 10-Year Plan
3.	Government of Alberta (2010a)	Government report	FASD-Cross Ministry Committee annual report	-	Overview of the SN model background, initiatives, and key accomplishments
4.	Government of Alberta (2011a)	Government report	FASD-Cross Ministry Committee annual report	-	Synopsis of key activities and results from SN programs and other provincial and ministry initiatives
5.	Government of Alberta (2012a)	Government report	FASD-Cross Ministry Committee annual report	-	Update on key activities and results from SN programs and other provincial and ministry initiatives
6.	Government of Alberta (2012b)	Government report	Snapshot of SN program data	-	Summary of client demographics, presenting issues, and outcome status, as well as trends in service access from 2008 to 2012
7.	Government of Alberta (2019)	Government report	Report on the SN operating grant policies	-	Description of policies related to SN operating grants, program administration, and operation requirements
8.	Government of Alberta (2020b)	Government report	Overview and key findings from Year 10 evaluation	-	Brief history of the 10-Year Plan, service and activity areas, social return on investment, and updated key findings and recommendations
9.	KPMG (2012)	Evaluation report	Findings from a targeted evaluation of the Edmonton Fetal Alcohol Network at Year 5	-	Findings from a targeted evaluation of one of the longest-standing SNs (the Edmonton Fetal Alcohol Network), with both summative and formative questions related to governance and management, program enhancement, evaluation and research activity, training and education, program implementation support, program guidelines, and short-term outcomes; including recommendations for advancing the Network
10.	Milne et al. (2011)	Book chapter	Description of the Alberta cross-ministry approach to FASD	-	A brief history of the FASD-CMC, overview of the 10-Year Plan, and description of ministry initiatives related to each strategic pillar
11.	Milne et al. (2013)	Conference presentation	Overview of 10-Year Strategic plan and summary of Year 5 evaluation findings	-	History of the FASD-CMC, principles and strategic pillars of the 10-Year Plan, description the SN model, overview of the purpose, key findings, and recommendations of the Year 5 evaluation
12.	Stonehocker (2012)	Evaluation report	Findings from a targeted evaluation of the Lakeland FASD Network	-	Findings from the expanded evaluation of the Lakeland FASD Network, including a governance case study outlining the history and current structure and impacts of the SN, as well as a description and evaluation of non-FASD-CMC funded services

Impacts of the Model  Overall Impacts				
13. ACCFCR (2013)	Evaluation report	Full report from Year 5 evaluation of 10-Year Plan	<ul> <li>Fulsome description of the history of the 10-Year Plan and 5-Year evaluation framework, the service and activity areas; includes detailed reports of the evaluation method, findings, and recommendations for each of nine outcome areas</li> </ul>	
14. Government of Alberta (2013) 15. Government of	Government report	Overview and key findings from Year 5 evaluation	- Brief history of the 10-Year Plan, service and activity areas, social return on investment, and summary of key findings and recommendations	
Alberta (2017a)	Government report	Overview and key findings from Year 7 evaluation	<ul> <li>Brief history of the 10-Year Plan, service and activity areas, social return on investment, and updated key findings and recommendations</li> </ul>	
16. Poth et al. (2016)	Peer-reviewed article	Description of the Strategic Plan evaluation and associated challenges	<ul> <li>Practice note providing information pertaining to the context and goals of the 10-Year Plan evaluation, the resources available for the evaluatio and the major challenges and resulting responses</li> </ul>	
17. Wirzba (2013)	Conference presentation	Overview of the SN evaluation framework	<ul> <li>Report on the approach used to develop the SN evaluation framework, overview of deliverables, mid-term evaluation findings, and recommendations for the evaluation framework moving forward</li> </ul>	
18. Wirzba & Cameron (2014)	Evaluation report	Year 7 evaluation findings specific to the Edmonton Fetal Alcohol Network	<ul> <li>Description of the development of the Year 7 SN evaluation framework updates on developments within EFAN, and summary of evaluation findings and recommendations specific to EFAN in each strategic pillar</li> </ul>	
		vernment of Alberta, 2020b		
Impacts Related to Awar 19. Bukutu et al. (2016)	Meta data	Survey of general FASD knowledge and attitudes	Data from a 2011 computer-assisted telephone survey of 1200 adults in Alberta; focused on general knowledge and personal experiences related to FASD, as well as attitudes around FASD prevention	
20. Choate et al. (2019)	Peer-reviewed article	Review of Alberta awareness and prevention programming	<ul> <li>Secondary data analysis of the 2011 and 2017 Alberta FASD surveys related to public awareness of FASD; revealed positive trends in increased awareness and basic knowledge of FASD</li> </ul>	
21. Government of Alberta (2011b)	Government newsletter	FASD Cross-Ministry Committee newsletter	<ul> <li>Profile on the Corrections and Connections to the Community project; description of participants and program components, and discussion of program challenges and positive impacts</li> <li>Profile of FASD awareness activities in one rural SN</li> </ul>	
22. Hanson et al. (2018)	Meta data	Survey of general FASD knowledge and attitudes	<ul> <li>Data from a 2017 computer-assisted telephone survey of 1200 adults in Alberta; focused on general knowledge and personal experiences relate to FASD, as well as attitudes around FASD prevention</li> </ul>	

Impacts Related to Prevent	ion		
23. Denys et al. (2011)	Peer-reviewed article	Study of the effectiveness of the Step by Step mentorship program	<ul> <li>Review of 24 client files from a PCAP-based mentorship program adapted for clients with FASD; results indicated significant reduction in client needs and increase in client goals from pre- to post-program</li> </ul>
24. Government of Alberta (2010b)	Government newsletter	FASD-Cross Ministry Committee newsletter	<ul> <li>Spotlight on the Alberta PCAP program, including discussion of achievements and challenges</li> </ul>
25. Government of Alberta (2020c)	Government report	Overview and key findings related to PCAP from Year 10 evaluation	- Brief overview of the history and expansion of the PCAP program and positive program outcomes
26. Job et al. (2014)	Peer-reviewed article	Study of the experiences and perspectives of PCAP service providers	<ul> <li>An innovative study using the multi-method approach of a quilting activity and focus groups to capture PCAP service provider perspectives; findings highlighted the importance of relationships, reflection, and research</li> </ul>
27. Mitchell et al. (2013)	Conference presentation	Overview of the Prevention Conversation program	<ul> <li>Description of the background, strategies, and objectives of the Prevention Conversation Initiative, as well as evaluation questions, progress to date, and future steps</li> </ul>
28. Pei et al. (2019)	Peer-reviewed article	Study of the contributions and suitability of prevention initiatives in Indigenous communities	<ul> <li>A participatory study to examine the implementation of PCAP services in First Nations communities; gathered PCAP mentor perspectives and found that the model has positive impacts and is well-suited to use within Indigenous communities</li> </ul>
29. Pelech et al. (2013)	Conference presentation	Overview of PCAP evaluation findings	- Description of the PCAP approach, theoretical underpinnings, evaluation methodology, challenges, and preliminary findings related to client demographics and outcome
30. Rasmussen et al. (2012)	Peer-reviewed article	Study of the effectiveness of the First Steps mentorship program	- Retrospective analysis of data from 70 clients who completed a PCAP- based mentorship program; results indicated significant reduction in client needs and increase in client goals from pre- to post-program
		overnment of Alberta, 2010a, 2	2011a, 2012a, 2013, 2017a, 2020b; KPMG, 2012; Stonehocker, 2012
31. Brintnell et al. (2019)	Peer-reviewed article	Study of the Corrections and Connections to the Community project	<ul> <li>Overview of program goals: to develop FASD diagnostic services, correctional programming, and post-release transition support for adult males who are justice-involved</li> <li>Description of the complex clinical challenges, offending histories, and functional needs of the study population; findings focused on recidivism rates, risk factors for re-offending, post-release connection with transition advocates, self-reported benefits of the program, and post-release support needs</li> </ul>

32. Burns (2017)	Network report	Results from survey on clinic waitlists	-	Summary of Alberta-wide survey on 2013 FASD clinic waitlists; specific findings related to size, composition, and different 'levels' of waitlists (i.e., referral received, active files, clinic-ready) Follow up survey conducted in 2016 to explore size, composition, and types of waitlists, as well as approaches for waitlist management
33. Burns (2019)	Network report	Report from focus group on clinic waitlist management	-	Information gathered from multi-disciplinary focus group to discuss tools and approaches for clinic waitlist management; recommendations around team communication strategies, resource and capacity-building, adopting of consistent terminology, and reasonable timelines
34. Coons-Harding et al. (2019)	Peer-reviewed article	Pilot study of assessment measures used in Alberta FASD diagnostic clinics	-	Province-wide survey of tools used at FASD clinics to assess brain function; results revealed consistency in assessment practice across Alberta, alignment with the Canadian Diagnostic Guideline's recommended assessment tools, as well as areas for improvement
35. FASD-CMC (2009)	Discussion paper	Report on an expert forum to discuss FASD assessment and diagnosis for adults	-	Discussed the availability of adult diagnostic service across the province as well as key features and challenges of adult FASD assessment
36. Flannigan et al. (2018)	Peer-reviewed article	Study of the perspectives of service providers working in a multidisciplinary justice- related FASD program	-	Focus groups with justice and clinical service providers involved in a program providing FASD assessment services for justice-involved adults in an Alberta First Nations community; findings revealed several important positive perceived impacts, as well as barriers to overcome in moving forward
37. Flannigan et al. (2020)	Peer-reviewed article	Survey of assessment measures used across Canadian diagnostic clinics	-	National survey of tools used at FASD clinics to assess brain function; building on the Alberta pilot (Coons-Harding et al., 2019), results revealed consistency in assessment practice across the country, alignment with the Canadian Guideline recommendations, as well as several areas for improved FASD practice
38. Government of Alberta (2017b)	Government report	FASD-Cross Ministry Committee strategic and operational plan	-	Updated strategic and operational plan, including accomplishments to date, as well as detailed action items, goals, commitments, and priorities for beyond the 10-Year Plan
39. McFarlane (2011)	Peer-reviewed article	Overview of a community- based model for adult FASD assessment and diagnosis	-	Description of one SN's community-based model and process of adult FASD assessment and diagnosis, including a summary of clinical observations, as well as strengths and challenges of the model
40. McFarlane & Rajani (2007)	Peer-reviewed article	Description of a rural model for assessment and diagnosis	-	Overview of the history of one rural SN's FASD diagnostic service delivery model, clinic process, adaptations made for rural service delivery, challenges, and critical factors for success

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41. Métis Settlements	Network	Update on the Métis	- Description of the directions and goals of the Métis Settlements FASD		
General Council	newsletter	Settlement FASD Network	Network, as well as the scope of services offered		
(2015)					
Additional relevant records described above: Government of Alberta, 2010a, 2011a, 2011b, 2012a, 2013, 2017a, 2020b; KPMG, 2012; Stonehocker, 2012					
Impacts Related to Support	t Services				
Relevant records described above: Government of Alberta, 2008, 2010a, 2012a, 2013, 2017a, 2020b; KPMG, 2012; Wirzba & Cameron, 2014					
Impacts Related to the Lea	rning Organization				
42. Abells et al. (2018)	Conference	Overview of the FASD	- Description of the Alberta's FASD learning organization, critical		
	presentation	learning organization	components for success, and discussion of achievements and innovations		
			from the 10-Year Plan		
Additional relevant records	s described above: Gov	vernment of Alberta, 2010a, 2	013, 2017a		
Economic Impacts					
43. Thanh et al. (2013)	Peer-reviewed	Cost-benefit study of the	- Provides an estimation of the break-even effectiveness of the SN model		
	article	Service Network model	in terms of preventing FASD-related adverse outcomes, such as justice-		
			involvement, homelessness, mental health challenges, and school and		
			employment challenges; break-even effectiveness was estimated to be		
			28%		
44. Thanh et al. (2015)	Peer-reviewed	Economic evaluation of	- Using a decision analytic modeling approach, the Alberta PCAP cost-		
,	article	PCAP	effectiveness ratio and net monetary benefit were estimated; findings		
			revealed that the program is cost-effective		
45. Poitras & Argaez	Rapid response	CADTH report on the cost-	- Review of the current evidence related to FASD diagnostic testing tools,		
(2017)	report	effectiveness of FASD	clinical utility of diagnosis, clinical effectiveness of treatment, cost-		
( - /		assessment and diagnosis	effectiveness of diagnosis/assessment and treatment, and guidelines for		
		l l l l l l l l l l l l l l l l l l l	assessment and diagnosis		
Challenges of Integrated FASD Service Delivery					
Relevant records described above: Burns et al., 2017, 2019; Choate et al., 2019; Government of Alberta, 2012a, 2013, 2017a, 2020b					
neievant records described above. Burns et al., 2017, 2013, choate et al., 2013, Government of Alberta, 2012a, 2017a, 2020b					

ACCFCR = Alberta Centre for Child, Family, and Community Research; CADTH = Canadian Agency for Drugs and Technology; EFAN = Edmonton Fetal Alcohol Network; FASD = Fetal Alcohol Spectrum Disorder; FASD-CMC = Fetal Alcohol Spectrum Disorder Cross-Ministry Committee; PCAP = Parent-Child Assistance Program; SN = Service Network.

#### **Results**

Our search yielded a total of 455 records, and 45 were included in the final review (see Figure 1 for a complete PRISMA flowchart). We identified 14 peer-reviewed articles, 13 government reports or newsletters, five conference presentations, four evaluation reports, four Network reports or other documents, two meta-data sets, one book chapter, one discussion paper, and one rapid-response report. Overall, findings highlighted the integrated, collaborative, flexible, and cross-sectoral nature of services delivered by regional Networks across the pillars of FASD awareness, prevention, assessment and diagnosis, and lifespan support services. Regional Networks adapted responsively to the needs of their specific communities, and the services they provided led to substantial impacts for individuals with FASD, their families, and broader communities. The scope, impacts, and challenges of integrated FASD service delivery in Alberta are described in detail below.

# **Model Aims and Scope**

The overarching aims of the Alberta FASD Service Network model were to enhance service delivery in the areas of FASD awareness, prevention, assessment and diagnosis, and support for individuals and their families across the lifespan (Government of Alberta, 2008). Twelve regional Service Networks, comprised of government and community agencies, were established to provide coordinated services to individuals with FASD and their families in urban, rural, remote, and Indigenous communities across Alberta (Milne et al., 2011). The model was described as distinctly flexible, proactive, collaborative, culturally informed, and community-based, enabling each regional Network to tailor their focus to meet the unique needs of Albertans in their designated areas (Alberta FASD Service Networks, 2018; Milne et al., 2013). Each year, Networks served thousands of clients presenting with many complex needs, including behavioural challenges, mental health and substance use issues, and instability (Government of Alberta, 2012b). Networks were reported to be client-centred which allowed for responsive, comprehensive, and coordinated service delivery (Alberta Service Networks, 2018; Government of Alberta, 2010a, 2011a, 2012a, 2020b).

As mechanisms of integrated FASD service delivery, regional Networks offered cross-disciplinary and cross-sectoral programming and supports in all four service delivery pillars of the Strategic Plan (i.e., FASD awareness, prevention, assessment and diagnosis, support services). To promote FASD awareness in their communities, Networks used many proactive and creative ways to tailor their messages to their communities, such as organizing media campaigns, printing FASD messages on candy wrappers and water bottles, hosting "mocktail" competitions, sponsoring events with local sports teams, presenting to high school classes, and organizing "flash mobs" (Government of Alberta, 2011a, 2011b, 2012a; Stonehocker, 2012).

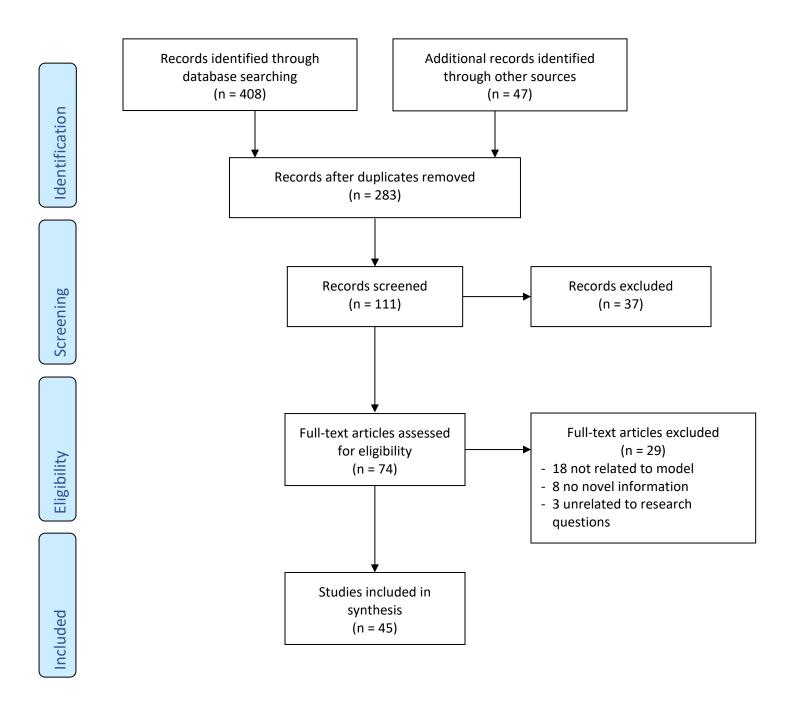


Figure 1. PRISMA diagram of article selection and reasons for exclusion.

Based largely on the Public Health Agency of Canada's 4-Level Model of FASD Prevention<sup>1</sup> (Poole, 2008), Networks engaged in a range of prevention initiatives by facilitating information-sharing and education related to the harms of alcohol use during pregnancy, healthy pregnancies, and the impacts of FASD (Government of Alberta, 2010a, 2011a, 2012a). These initiatives included many Level 2, 3, and 4 programs such as the Level 2 Prevention Conversation (PC) program, where Network facilitators travelled across Alberta to share targeted prevention messages with youth, women of child-bearing age, their partners and families, service providers, and the broader community (Government of Alberta, 2017a; Mitchell et al., 2013). The PC is also designed to help primary care professionals to develop the skills necessary for non-judgmental and empathic conversations with women about alcohol use (Mitchell et al., 2013). Another major program within the prevention pillar is the Parent-Child Assistance Program (PCAP), an evidence-based long-term supportive mentorship model for women at risk of having alcohol-exposed pregnancies (Grant et al., 1997).

Service delivery Pillar 3, FASD assessment and diagnosis, was implemented in every region of Alberta with Networks providing multi-disciplinary assessment and diagnostic services following standardized Canadian diagnostic guidelines (Chudley et al., 2005; Cook et al., 2015; Government of Alberta, 2017a, 2020b). Significant efforts were made during the 10-Year Plan to advance diagnostic practice across the lifespan, with a special focus on building capacity to assess and diagnose adults (FASD-CMC, 2009; Government of Alberta 2012a). Like awareness and prevention initiatives, FASD assessment and diagnostic activity increased steadily over the 10-Year Plan, with regional Networks providing services to hundreds of Albertans with suspected FASD each year (Government of Alberta, 2010a, 2011a, 2012a, 2013, 2017a).

Supports for individuals with FASD and their families accounted for the largest proportion of client service utilization across pillars (Government of Alberta, 2010a). Networks all over the province provided strengths-based, individually tailored, lifespan services to thousands of Albertans each year (Government of Alberta, 2013). Support service activities were focused on promoting and maintaining client health and safety, supporting basic needs (including supportive housing), assisting with service navigation, increasing advocacy, offering case management and mentorship, delivering life skills programs and support groups, developing collaborative intervention and follow-up plans, and promoting overall wellbeing (Government of Alberta, 2008, 2010a, 2020b; KPMG, 2012). Many regional Networks also engaged with individuals who were suspected of having FASD (but not formally diagnosed) to reduce some of the eligibilityrelated barriers that may prevent individuals from receiving critical supports. In a case study conducted as part of the Year 10 evaluation, Networks reported that their processes and support services evolved substantially over time, and that they adapted their intake procedures to incorporate a new tiered approach for more effectively addressing the spectrum of needs experienced by clients (Government of Alberta, 2020b). With this approach, services have been triaged into 1) rapid, 2) light-touch, and 3) longer-term responses based on individualized client needs (Government of Alberta, 2020b). Services were offered through a variety of methods, such as one-on-one, in-home, and outreach approaches, as well as respite care and group

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<sup>&</sup>lt;sup>1</sup> The 4-level model includes: broad strategies to engage stakeholders at the community level (Level 1); conversations about alcohol use and related risks with those who are in their child-bearing years (Level 2); targeted recovery supports for parents who struggle with alcohol use and other social or health problems (Level 3); and postpartum support for new parents to achieve or sustain healthy changes and support child development (Level 4).

programming (Government of Alberta, 2012a), and they often involved coordination of multiple supports (KPMG, 2012).

Lastly, although the learning organization pillar is not a primary focus of service delivery, regional Networks nonetheless engage in ongoing collaboration with local agencies and stakeholders which allowed for the assessment of community needs and for Networks to become the "eyes and ears" of the community (Abells et al., 2018; Government of Alberta 2010a). This collaboration enabled Networks to exchange information to guide business planning and resource allocation in their designated regions. Many regional Networks also participated in research projects and used research findings to guide their practice (Government of Alberta, 2017a).

# **Impacts of Alberta FASD Service Networks**

Findings related to Network programs and services were primarily derived from results of formal evaluations that were conducted by the Alberta government at Years 5, 7, and 10 of the Strategic Plan (Alberta Centre for Child, Family, and Community Research [ACCFCR], 2013; Government of Alberta, 2013, 2017a, 2020b; Poth et al., 2016; Wirzba, 2013; Wirzba & Cameron, 2014). Through these evaluations, data was collected from clients, caregivers, and other stakeholders to capture a diverse range of perspectives. In addition to these evaluation initiatives, several research groups have conducted studies on the impacts of certain programs delivered by regional Networks. Findings pertaining to Network impacts are organized around the four service delivery pillars (i.e., awareness, prevention, assessment and diagnosis, and support services). In addition, several studies were identified that focused on the economic impacts of Network activities and programs.

#### Impacts of FASD Awareness Initiatives (Pillar 1)

Large-scale surveys conducted after FASD awareness events indicated high rates of success in terms of sharing messages about the cause of FASD, that there is no known safe amount of alcohol to consume during pregnancy, and information about the needs of people with FASD (Government of Alberta, 2017a). Several documents indicated a notable growth in FASD awareness among Albertans over the span of the 10-Year Plan. At the Year 10 evaluation time point, results from a survey of more than 1,100 Albertans indicated that 90% had heard of FASD (Choate et al., 2019; Government of Alberta, 2020b; Hanson, 2018). This represented a 4% increase from a similar survey conducted in 2011 (Bukutu, 2016). Detailed questions were included in the survey to assess public understanding of FASD, and findings revealed that 99% of respondents knew alcohol use during pregnancy can lead to life-long harms, and 72.3% correctly answered all four questions about FASD understanding (Government of Alberta, 2020b; Hanson, 2018). These findings were especially encouraging when examined by age group, where researchers found a 16% increase in awareness of FASD in young adults aged 18 to 24 years (Choate et al., 2019).

#### Impacts of FASD Prevention Initiatives (Pillar 2)

By Year 10 of the Plan, over 14,000 participants had attended 755 PC training events, including member of the public, service providers, and post-secondary students across sectors (Government of Alberta, 2020b). Evaluation findings revealed that professionals who received

PC training had greater comfort and confidence in delivering messages about FASD prevention; improved their knowledge of FASD and relevant strategies, resources, and community services; and planned to incorporate this new knowledge into practice (Government of Alberta, 2020b). Additionally, almost all women (94%) who completed the PC indicated their intention to reduce or abstain from substance use during their current or subsequent pregnancies (Government of Alberta, 2017a). Similar positive feedback related to improved FASD awareness, knowledge, and attitudes was provided by members of the public who completed the training (Government of Alberta, 2020b).

The Alberta PCAP program grew steadily over the 10-Year Plan and by the final year, there were 28 active sites, and all regional Networks were following the PCAP model, including several specifically designed to meet the needs of Indigenous communities (Government of Alberta, 2010a, 2010b, 2011a, 2012a, 2013, 2017a, 2020b, 2020c). Early evaluation data suggested that PCAP sites were being implemented with strong fidelity to the original model (Pelech et al., 2013), while still allowing for flexibility to respond to the unique geographic, cultural, social, and other factors in each community (Government of Alberta, 2020b). Beyond program fidelity, additional information was collected from PCAP service providers related to effective practices as well as challenges and barriers to the successful implementation of PCAP programs. Using an innovative research methodology of combining focus groups with a creative quilting activity, researchers identified several themes that captured the experiences of prevention specialists (Job et al., 2014). Participants spoke to the pivotal role of the client-mentor relationship, the importance of which has been noted in other documents (Government of Alberta, 2010b). Relatedly, prevention specialists highlighted the need for improved understanding of individuals with FASD and their advocates, as well as the evolving process of client recovery and growth of the FASD prevention field (Job et al., 2014). Mentors also emphasized the unique advantages and challenges associated with working in urban versus rural locations (Government of Alberta, 2010b), and the critical link between research and practice (Job et al., 2014). For prevention specialists working with Indigenous communities, researchers have underscored the importance of participatory, collaborative, relational, community-based, and trauma-informed services, delivered in culturally responsive and respectful ways (Pei et al., 2019). Cultural sensitivity is a key priority for Alberta PCAP programs (Government of Alberta, 2020c), with many regional Networks collaborating with Indigenous communities and adapting programs to enhance service delivery in these areas (Government of Alberta, 2020b; KPMG, 2012).

With respect to PCAP client experiences and outcomes, many clients were reported to have complex needs, including mental health comorbidity, substance use problems, childhood trauma, and child welfare involvement; and many were diagnosed with FASD themselves (Government of Alberta, 2020b, 2020c). Evaluation data revealed that PCAP mentors were effective at helping to address these complex needs. Many clients reported improved wellbeing, reduced or discontinued substance use, increased use of contraception, better participation in educational programs, stronger connection to services, increased employment, stabilized housing, decreased welfare utilization, improved parenting and advocacy skills, and many women resumed care of their children (Government of Alberta, 2012a, 2013, 2017a, 2020b, 2020c; KPMG, 2012; Pelech et al., 2013; Stonehocker, 2012). Research data confirmed that PCAP services have had a positive impact by significantly reducing needs and increasing goal achievement among clients (Denys et al., 2011; Rasmussen et al., 2012). Importantly, clients experienced high levels of

satisfaction with the PCAP program (KPMG, 2012) as well as an increased sense of self-worth and confidence (Stonehocker, 2012).

In addition to the PC and PCAP programs, regional Service Networks implemented numerous other Level 3 and 4 prevention initiatives, such as the 2<sup>nd</sup> Floor Women's Recovery Centre, an inpatient substance use treatment program for women who are or may become pregnant (Stonehocker, 2012). By the end of the 10-Year Strategic Plan, more than 120 clients had been served by this program, many of whom reported notable positive impacts such as being referred for FASD assessments, maintaining extended periods of abstinence from substance use following discharge, and securing safe housing post-discharge (Government of Alberta, 2020b).

# Impacts of FASD Assessment and Diagnosis (Pillar 3)

According to government reports, assessment and diagnostic services helped clients and families to better understand how FASD affects the individual diagnosed, acquire more knowledge about available supports and resources, connect to these services (Government of Alberta, 2013, 2017a, 2020b), and feel more prepared to provide care for their family member with FASD (KPMG, 2012). Network stakeholders also reported that assessment and diagnostic services facilitated access to school and community-based supports that would not otherwise have occurred (Government of Alberta, 2011a), and decreased the need for more costly and reactive interventions, such as hospitalization or incarceration (Government of Alberta, 2012a). Crosssectoral connections were forged and strengthened through assessment and diagnostic services. with increased referrals for FASD assessment initiated through schools and primary care networks (Government of Alberta 2011a). In a study of one cross-sectoral collaboration, a partnership was created between a provincial correctional institution and the local Service Network assessment and diagnostic team, which provided FASD assessment, life skills training, group therapy, post-incarceration transition support, and follow-up to adult males with suspected FASD (Brintnell et al., 2019). Participants in this program experienced complex difficulties, such as cognitive impairments compounded by mental health and substance use issues, and challenges associated with adjusting their social networks upon release (Brintnell et al., 2019; Government of Alberta, 2011b). They also reported benefits of the program, including improved anger management and coping skills, reduced feelings of aggression, increased self-awareness and insight, stronger self-esteem, improved interpersonal relationships, and some increased healthpromoting behaviours (Brintnell et al., 2019).

According to Network stakeholders, one critical element of the Network model that has allowed for the positive impacts of FASD assessment and diagnostic services is that services are organized in a way that reflects the resources and needs of the community. For example, Networks in rural or isolated regions partner with other health care agencies to capitalize on the services of visiting providers who are available only sporadically. Some assessment and diagnostic clinics offer mobile services, where clinicians travel and provide services to multiple regions in the province, and some Networks have satellite offices in multiple communities to increase access to services in remote areas (Government of Alberta, 2012a; McFarlane, 2011; McFarlane & Rajani, 2007; Stonehocker, 2012). Continual investment from the FASD-CMC has enabled Networks and their affiliated agencies to provide ongoing training and education to clinical staff working in Alberta FASD diagnostic clinics (Government of Alberta, 2011a, 2013, 2017b), which is offered in various formats across the province such as on-site, online, or through telehealth (Burns, 2017). Researchers have reported that there is strong consistency in

FASD assessment practice across Alberta (Coons-Harding et al., 2019) and Canada (Flannigan et al., 2020), which may be supported by this consistent and standardized clinical training.

Partnerships between regional Service Network diagnostic clinics and Indigenous communities also grew over the course of the 10-Year Plan (Government of Alberta, 2011a, 2012a; KPMG, 2012). By 2009/2010, all eight Métis settlements in Alberta had access to FASD diagnostic services (Government of Alberta, 2011a) through a specialized Service Network that incorporates the Métis way of life (Métis Settlements General Council, 2015). In one recent study, researchers explored a partnership between a First Nations restorative justice program and the regional Service Network, established to increase access to FASD clinical services for justice-involved adults in the community (Flannigan et al., 2018; Government of Alberta, 2017a). Justice and clinical service providers working in the program reported that it built capacity at the professional, service, and community levels; humanized clients by treating them as people; and created bridges across professions and between service providers and the community (Flannigan et al., 2018).

# Impacts of FASD Support Services (Pillar 4)

Overall, clients of FASD support services reported high levels of satisfaction and a range of other positive impacts (Government of Alberta, 2017a). Notable impacts for individuals with FASD included better interpersonal relationships; improvements at school; increased self-care; improved life skills; and day-to-day support with money management, housing, income, and employment (Government of Alberta, 2017a, 2020b; Wirzba & Cameron, 2014). They also reported a reduced need to access other systems such as health and justice (Government of Alberta, 2020b). For caregivers, support services led to an improved understanding of FASD; a stronger sense of caregiving competence; improvements in family life; reduced levels of stress; better access to community resources; stronger personal support networks (Government of Alberta, 2017a, 2020b; Wirzba & Cameron, 2014); and increased recognition of individual strengths (KPMG, 2012).

#### Economic Impacts

In addition to these pillar-specific impacts, preliminary data was identified related to the cost-effectiveness of Service Network activities and programs. In one study, researchers estimated the overall cost-savings attributable to Network activities reducing adverse experiences of individuals with FASD, such as justice-involvement, homelessness, mental health concerns, and school and employment problems, and reported a break-even effectiveness of 28% (Thanh et al., 2013). Although this is a promising finding, the study model was based on the literature rather than effectiveness studies, with assumptions that may lack validity (Poitras & Argaez, 2017). In 2015, the same group of researchers studied the Alberta PCAP and developed a predictive model that estimated a 36% reduction in new FASD cases over a three-year period, translating to a net monetary benefit of \$22 million (Thanh et al., 2015).

# **Challenges with Integrated FASD Service Delivery**

Alongside the reported positive impacts of Alberta FASD Service Network activities and programs, we also identified numerous challenges with integrated FASD service delivery across all five strategic pillars.

# Challenges Related to Awareness

Although awareness of FASD in Alberta reportedly increased, the prevalence of FASD did not decrease, suggesting that awareness alone may not lead to behavioural change (Choate et al., 2019; Government of Alberta, 2020b). Moreover, because of increased FASD awareness and identification of individuals with FASD in Alberta, there has been a subsequent increase in demand for FASD services, but regional Networks have experienced difficulties meeting this demand (Government of Alberta, 2020b). Additionally, permissive messages from professionals about the risks of alcohol use during pregnancy prevail, highlighting the need to disseminate accurate FASD knowledge and information across sectors.

# Challenges Related to Prevention

Several prevention-related challenges were also identified. First, regional Network service providers reported challenges working in rural and remote communities, including meeting the high demand for services; barriers with travel, transportation, and service access; as well as difficulty finding qualified professionals in these areas (Government of Alberta, 2020b). With respect to the PC program specifically, Network service providers noted ongoing difficulty engaging with medical professionals, and a need for tailored messages for new audiences (Government of Alberta 2020b). For PCAP professionals, challenges included bridging research evidence to practice; balancing heavy caseloads with administrative and data collection responsibilities; and finding appropriate and specialized supports to meet the complex needs of their clients (Government of Alberta, 2013, 2017a, 2020b).

#### Challenges Related to Assessment and Diagnosis

Specific challenges related to FASD assessment and diagnostic service delivery included the high demand and cost of assessments; lack of sustainable funding; lack of professionals trained in FASD assessment; and relatively limited assessment opportunities for transition-aged youth and adults, particularly in remote regions (Government of Alberta, 2013, 2017a, 2020b). Long wait lists were also significant concerns for many diagnostic clinics across the province (Burns, 2017; Government of Alberta, 2013, 2017a), though there have been some notable efforts to develop recommendations for managing wait times (Burns, 2019). With the FASD assessment process itself, there are ongoing challenges with obtaining confirmation of prenatal alcohol exposure. Systems-level challenges include limited availability of post-assessment support; challenges with inter-agency coordination; and difficulty accessing information related to research and best practice (Government of Alberta, 2013).

# Challenges with Support Services

Network stakeholders reported several challenges related to FASD support services. At the systems-level, challenges include limited awareness of FASD among service providers; poor

coordination between agencies; a lack of FASD-informed services in the health sector (especially mental health and substance use); a scarcity of FASD resources in the school system; and difficulties navigating the court system (Government of Alberta, 2012a, 2017a, 2020b). Additional challenges with support services include transportation for clients in rural communities; limited respite for caregivers; few services for individuals facing housing challenges; lack of supports for youth transitioning to adulthood; and limited knowledge of how best to support seniors with FASD (Government of Alberta, 2017a, 2020b). There is also a lack of data on the link between assessment recommendations and access to services (Government of Alberta, 2017a, 2020b), though some evidence is emerging in this area (Pei et al., 2017b).

## Challenges with the FASD Learning Organization

Few challenges were identified specific to regional Networks' participation in the learning organization pillar, however some Network service providers reported difficulties with accessing training opportunities and information about FASD best practice, especially in rural or isolated regions (Government of Alberta, 2013).

# **Broad Challenges**

Several additional challenges were identified that apply across pillars and Network initiatives. First, reorganization in government priorities over time have made it difficult to hold FASD at the forefront of government attention (Government of Alberta, 2020b). Funding and resource limitations amidst rapidly increasing demands were also identified as primary concerns (Government of Alberta, 2020b). Addressing systemic issues such as stigma, poverty, intergenerational trauma, and disparities associated with FASD continues to pose a challenge for Networks, especially in isolated and Indigenous communities. All these challenges present ethical concerns for Network service providers when they feel unable to adequately meet the needs of their clients. Despite these challenges, Network stakeholders continue to advocate for impactful and meaningful services for Albertans with FASD and their families and communities.

#### **Discussion**

Individuals with FASD can experience a wide range of complex needs, necessitating supports from across disciplines and sectors (Brownell et al., 2013; Huculak & McLennan, 2009; Thanh & Jonsson, 2009). Despite the diverse service needs and utilization patterns among individuals with FASD, there is currently a lack of research on integrated services delivery approaches for this population (Pei et al., 2021). The Alberta FASD Service Network model is a unique example of integrated service delivery, as a coordinated system of Networks, programs, supports, and resources aimed at addressing the needs of individuals with suspected or diagnosed FASD across the lifespan. The purpose of this study was to review and synthesize the published evidence related to the Alberta FASD Service Network model. Specifically, our goals were to describe the aims and scope of the Network model; investigate impacts of Network activities and programs; and explore challenges with integrated FASD service delivery in Alberta. We identified a total of 45 publications pertaining to the Service Network model, most of which were peer-reviewed academic articles or government reports.

Alberta FASD Service Network programs and activities are characteristically integrated, collaborative, flexible, cross-sectoral, and responsive, and have contributed to numerous positive impacts for individuals, families, and communities. At the individual level, Network programs promoted clients' stability; self-understanding; self-worth; access to services in the community; and overall health, wellbeing, and quality of life. A client-centered approach is one of the core features of integrated care models (Crocker et al., 2020; Hazarika & Purdy, 2015) and may play a key role in the individualized and impactful services and supports provided by regional Networks. The positive impacts of Networks' FASD service delivery extend beyond the individual, with caregivers and families reporting improved understanding of FASD; increased sense of competency for caring for someone with FASD; and better access to services and supports in the community. At the community level, Network efforts increased awareness of FASD in Alberta's general population and facilitated the widespread sharing of prevention messages. For service providers in the community, Network training initiatives have led to improved knowledge of FASD and relevant resources; increased capacity to engage in FASDspecific practice; stronger inter-disciplinary connections; and increased consistency in FASD clinical practice. In addition, the Network model has had positive economic impacts, owing to its role in mitigating adverse life experiences of individuals with FASD, and in reducing the likelihood of alcohol-exposed pregnancies.

The positive impacts of the Alberta FASD Service Network model reflect many of the benefits reported in previous research on integrated care for other populations and settings, such as improved access to services; continuity and quality of care; greater client and service provider satisfaction; reduced service costs; and improved client health and quality of life (Crocker et al., 2020; Hazarika & Purdy, 2015; Menear et al., 2017). Our study also builds upon preliminary research suggesting that integrated service delivery in health care settings for individuals with FASD may promote a range of positive outcomes, including improved service provider capacity; greater satisfaction; and enhanced quality of life for individuals with FASD and their systems of support (Masotti et al., 2015; Turchi et al., 2018). The Alberta FASD Service Network model expands on this integrated approach to primary health care by combining and coordinating programs and interventions from across disciplines and sectors to provide impactful services across the lifespan for individuals with FASD, their families, and communities.

Despite the many positive impacts of the Network model, integrated FASD service delivery in Alberta has not been without challenges. In particular, Network stakeholders have reported challenges with limited funding and resources; difficulties meeting service demands; unique barriers to service provision in rural and isolated communities; lack of FASD-informed professionals; inconsistent or limited inter-agency engagement and coordination; challenges with bridging research to practice; as well as systemic problems such as racism and poverty. Many of these challenges are consistent with previous research on barriers to integrated health care (Baker et al., 2016; Kozlowska et al., 2018). In addition, FASD service gaps were revealed for certain subpopulations including individuals with FASD who are in transitional life stages; older adults with FASD; as well as those navigating particularly complex experiences such as homelessness, criminal justice involvement, and mental health and substance use challenges.

# **Moving Forward**

To build on the emerging evidence on integrated FASD service delivery in Alberta and elsewhere, there remains an ongoing need to conduct more research (Government of Alberta,

2020b). Specifically, more studies are needed to assess the longitudinal impacts of the Alberta FASD Service Network model, which would ideally include control groups to examine impacts that are uniquely attributable to integrated FASD service delivery. To continue to monitor regional Networks' progress and performance, standardized tools and evidence-based approaches developed from previous research and evaluation initiatives should be leveraged (Government of Alberta, 2020b). There is also a need to explore ways in which research evidence in all strategic pillars may be translated into approaches that can be applied to improve practice in day-to-day contexts. Additional research and policy efforts are needed to better engage with and train professionals to increase FASD capacity and meet the growing demands for FASD services. Efforts are also needed to improve the quality of and access to supports in the service gaps identified in this review. Although the Alberta FASD Service Network model incorporates many aspects of an integrated care approach, there is nonetheless an ongoing need to enhance the coordination and integration of services across communities and systems (Government of Alberta, 2017b). Together, these priority areas provide clear guidance for the continual advancement of FASD service delivery in Alberta and elsewhere.

Many of the priorities for future work that were identified in this study align with those noted by other researchers (Pei et al., 2021; Masotti et al., 2015). Previous literature also sheds light on potential ways in which integrated FASD service delivery may be enhanced. For example, researchers in integrated health care have suggested that establishing clearly defined and evidence-based models of care; engaging leadership that supports collaboration; securing additional resources; increasing communication and shared goals across the care system; promoting enthusiasm for collaboration; and monitoring the quality of services delivery are all facilitators to integrated care (Kozlowska et al., 2018). In the FASD field specifically, researchers have proposed a comprehensive guiding framework for integrated service delivery for individuals with complex needs, such as those with FASD, with recommended principles and practices aimed at policymakers, organizations, and service providers (Pei et al., 2021). The Alberta FASD Service Network models aligns in many ways with the recommendations in this framework, particularly around collaboration, responsiveness, and proactivity at the policy level; as well as early diagnosis and intervention; strength-based and client-centered approaches; and emphasis on services to support caregiver wellbeing (Pei et al., 2021).

#### Conclusion

The Alberta FASD Service Network model facilitates a continuum of integrated services for some of the most complex individuals and families in the province. Regional Networks' scopes of service are diverse, and although Networks are separate entities, they comprise a cross-disciplinary collective and draw on the expertise and capacity of one another. There is a unique structural flexibility and responsiveness within the model that enables Networks to provide meaningful services to clients and families in each region, supported by ongoing community collaboration and engagement. A substantial body of evidence indicates the positive impacts of this model, as well as important challenges that will need to be addressed as the model continue to evolve. We identified valuable evidence related to the scope, impacts, and challenges of the Alberta FASD Service Network model, and identified critical areas for future work. This knowledge is important to share as a key example of integrated FASD service delivery, which may be replicated and built upon in other parts of Canada and the world.

# **Key Messages**

**People with Disabilities**: Better awareness of FASD, access to assessment and diagnosis, and life-long supports for individuals, caregivers, and families all have important impacts on long-term wellbeing for people with FASD. Tangible benefits include increased safety, stability, and health; improved self-understanding and self-worth; greater autonomy; and stronger community engagement.

**Professionals**: Increased awareness and understanding of FASD, as well as cross-disciplinary networking and collaboration, improve capacity for effective service provision and supports for individuals with FASD, their caregivers, and their families. Service provider knowledge, confidence, and competence in working with individuals with FASD can be improved through targeted FASD training initiatives.

**Policy Makers**: The Alberta FASD Service Network model has led to notable individual, community-, and societal-level impacts, and may be adapted inter-provincially and/or nationally with the potential for cost-savings and more effective supports for individuals with FASD, their caregivers, and families. Federal policy makers should consider the promising evidence identified in this review and build upon the successes in Alberta by developing a coordinated national FASD strategy for all Canadians.

# Messages clés de cet article

**Personnes ayant une incapacité**: Une meilleure conscientisation au TSAF, l'accès à l'évaluation et au diagnostic ainsi que du soutien tout au long de la vie pour les personnes, les donneurs de soin et les familles ont un impact important sur le bien-être à long terme des personnes ayant un TSAF. Des bénéfices tangibles incluent une sécurité et une stabilité accrues, une meilleure santé ; une amélioration de la compréhension et de l'estime de soi ; une plus grande autonomie ; et un engagement communautaire plus fort.

**Professionnels**: Une meilleure conscientisation et compréhension du TSAF, ainsi que le réseautage et la collaboration interdisciplinaires, améliorent la capacité de prestation de services et de soutien efficace pour les personnes ayant un TSAF, leurs aidants et leurs familles. Les connaissances, la confiance et la compétence des dispensateurs de services à travailler avec des personnes ayant un TSAF peuvent être améliorées grâce à des initiatives de formation ciblées sur le TSAF.

**Décideurs**: Le modèle de réseau de services pour le TSAF de l'Alberta a eu des répercussions notables aux niveaux individuel, communautaire et sociétal, et peut être adapté à l'échelle interprovinciale et/ou nationale avec le potentiel de réaliser des économies et des soutiens plus efficaces pour les personnes ayant un TSAF, leurs donneurs de soins et leurs

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