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Canadian clinical capacity for fetal alcohol spectrum disorder assessment, diagnosis, disclosure and support to children and adolescents: a cross-sectional study

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ABSTRACT

Objective Canadian fetal alcohol spectrum disorder (FASD) guidelines encourage an age-specific interdisciplinary diagnostic approach. However, there is currently no standard-of-care regarding FASD diagnosis disclosure and few studies document Canadian FASD clinical capacity. Our objectives were to describe clinical capacity (defined as skills and resources) for FASD assessment, diagnosis, disclosure and support in Canada.

Design, setting and participants Data were drawn from the CanDiD study, a cross-sectional investigation of Canadian FASD clinical capacity. Forty-one clinics participated in the study. Data were collected in 2021 on the number and types of health professionals included in the assessment and diagnostic teams, the presence (or absence) of a minor patient when the FASD diagnosis is disclosed to parents/guardians, who is responsible for the diagnosis disclosure, the use of explanatory tools, and the types of support/counselling services available. The proportion of clinics that follow the Canadian interdisciplinary diagnostic guidelines by age group is described among participating clinics.

Results Overall, 21, 13 and 7 specialised FASD clinics were in Western/Northern, Central and Atlantic Canada, respectively. The number of referrals per year surpassed the number of diagnostic assessments completed in all regions. Approximately, 60% of clinics who diagnosed FASD in infants and preschool children (n=4/7 and 15/25, respectively) followed the interdisciplinary guidelines compared with 80% (n=32/40) in clinics who diagnosed school-aged children/adolescents. Diagnostic reporting practices were heterogeneous, but most used an explanatory tool with children/adolescents (67%), offered support/counselling (90–95%) and used case-by-case approach (80%) when deciding who would disclose the diagnosis to the child/adolescent and when.

Conclusions Limited diagnostic capacity and lack of FASD resources across Canada highlights a critical need for continued FASD support. This study identifies gaps in assessment, diagnosis and reporting practices for FASD in children/adolescents across Canada.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This is the first study that aims to describe Canadian clinical capacity for assessment, diagnosis, disclosure and support of fetal alcohol spectrum disorder (FASD) in children and adolescents.
⇒ This study used an extensive search to identify eligible clinics including membership in the Canadian FASD Research Network (CanFASD) and through an exhaustive Internet search using purposive sampling (ie, snowball or network sampling).
⇒ Quantitative data of Canadian specialty clinics who engage in FASD diagnostic assessment of children and adolescent<18 years were collected cross-sectionally via a telephone/videoconference survey.
⇒ Surveys included questions pertaining to: (1) general clinic information (e.g., location, source(s) of funding, services offered); (2) number of referrals and assessments done per year; (3) interdisciplinary team composition for FASD diagnosis by age group; (4) current diagnosis reporting practices for children/adolescents and (5) support and counselling following the diagnosis disclosure.
⇒ Clinical capacity data could not be collected from non-participating clinics, therefore, results from this study may not be generalisable to all Canadian clinics.

INTRODUCTION

Fetal alcohol spectrum disorder (FASD), which results from prenatal alcohol exposure (PAE),[1] is one of the most frequent neurodevelopmental disorders in North America.[2] A recent meta-analysis reported that 8% of children exposed to PAE are diagnosed with FASD and that North America has the second highest FASD prevalence after Europe.[3] Children exposed to PAE are at high risk of developing FASD regardless of the frequency or amount of alcohol consumed.[4] Globally, current FASD prevalence estimates in the general population is approximately 1% with

most countries in North America, Europe and the Western Pacific regions ranging between 1% and 3%.[3] However, experts believe that FASD is widely underdiagnosed worldwide because it is often overshadowed by other diagnoses (due to the high level of comorbidity) and because of limited expertise and/or resources available.[5–7]

Canadian FASD evidence-based diagnostic guidelines (first published by the Public Health Agency of Canada in 2005),[7] and most recently updated by the Canadian FASD Research Network (CanFASD) in 2016[1 8] include recommendations on key components for FASD assessment including screening, referral and support; medical assessment; sentinel facial features; neurodevelopmental assessments; nomenclature and diagnostic criteria and management and follow-up.[8] In fact, Canada is the only country that has developed and adopted a uniform diagnostic capacity for FASD through the harmonisation of two American FASD guidelines, namely, the 1996 Institute of Medicine (for the diagnosis of Fetal Alcohol Syndrome (FAS), partial FAS, alcohol-related birth defects and alcohol-related neurodevelopmental disorder) and the 4-Digit Code approach (which measures growth, facial features, central nervous system impairments and PAE).[7 9–11] Importantly, the Canadian guidelines require an age-specific interdisciplinary diagnostic team approach.[8] Specifically, they recommend that the diagnostic team for infants (<18 months) should include a paediatrician/physician and a child development specialist able to conduct physical and functional assessments (ie, speech-language pathologist, physiotherapist, occupational therapist or clinical psychologist) and that the diagnostic team for preschoolers (18 months to 5 years) and school-aged children (6–18 years) should include a physician, psychologist, speech-language pathologist, and an occupational therapist.[8] The Canadian guidelines have demonstrated significant promise for setting the bar for FASD recognition and service development nationally and internationally. When used in population studies in Europe, Africa and North America, the Canadian guidelines were shown to be a key source for health professionals.[9] For example, the Scottish Intercollegiate Guidelines Network and Healthcare Improvement Scotland have adapted their FASD clinical guidelines from Canada[12 13] and Australia recently reviewed their guidelines and adopted several concepts from the Canadian FASD guidelines.[14]

Because FASD guidelines require an age-specific interdisciplinary diagnostic team approach, FASD clinical capacity, defined herein as skills and resources to assess, diagnose, disclose and support FASD, remains challenging and complex in many jurisdictions and is further exacerbated due to the current healthcare workforce shortage.[15] A previous study reviewed Canadian FASD clinical practices in seven provinces and reported that only 46% of Canadian clinics had a complete multidisciplinary team on-site, but 90% used a team approach for diagnosis and treatment plan.[16] However, the authors did not specify which health professional participated in the diagnostic assessments by age group.[16] There are no empirical data on the Canadian clinical capacity for interdisciplinary diagnostic assessment since the guidelines were updated in 2016.

Skilful diagnosis disclosure and psychological support following a medical diagnosis to children and adolescents is extremely important to limit psychological trauma,[17] increase adherence to treatment plans,[18] and generally improve quality of life. While Canadian FASD guidelines recommend that individuals with FASD and their caregivers have access to resources to improve diagnostic outcomes,[8] there are currently no specific recommendations regarding the presence of a minor patient (≤18 years) when the FASD diagnosis is disclosed to parents/guardians and, to the best of our knowledge, no known studies describing clinical practices for FASD diagnosis disclosure to children—who should make the diagnosis disclosure, under which circumstances (e.g., favourable environment), and how (e.g., the use of explanatory tools).

These knowledge gaps compel a research agenda that aims to describe FASD clinical capacity to inform clinical and diagnostic protocols to children and adolescents.[12–14] Specific objectives of this study were to describe (i) diagnostic interdisciplinary team composition (<18 months; ≥18 months to ≤5 years; ≥6–18 years) and the number of clinics who follow the Canadian interdisciplinary diagnostic team guidelines by age group; (ii) FASD assessment and diagnosis reporting practices for children and adolescents including if the minor patient is present during the diagnosis disclosure, who discloses the diagnosis to the child/adolescent patient and the use of explanatory tools to facilitate the FASD diagnosis disclosure and (iii) FASD support and counselling provided to patients and families during the diagnosis disclosure and in the 3-month period following the diagnosis. Because Canada is one of the key leaders in FASD research and policy, exposing gaps in Canadian clinical capacity may have great relevance internationally when developing clinical guidelines.

METHODS

Data were drawn from the Canadian Interdisciplinary Clinical Capacity to Diagnose FASD (CanDiD) study—a cross-sectional survey-based study developed by clinicians and researchers at Vitalité Health Network in 2021. CanDiD is the first investigation that aims to describe Canadian clinical capacity for assessment, diagnosis, disclosure and support of FASD in children and adolescents. Quantitative data were collected via a telephone/videoconference survey (available in French and English) of Canadian specialty clinics who engage in FASD diagnostic assessment of children and adolescent <18 years. Clinics were identified through membership in the Canadian FASD Research Network (CanFASD), and through an exhaustive Internet search using purposive sampling (i.e., snowball or network sampling). Introductory recruitment emails were sent to all identified clinics in spring 2021, followed by a phone call 1 week later to

schedule an interview. To increase response proportion, up to three follow-up emails (or phone calls) were sent. Semistructured 20 min surveys were completed with a key respondent in each clinic identified by the clinic manager or lead paediatrician who is most knowledgeable with clinical capacity. A copy of the questionnaire was sent to respondents prior to survey completion to allow preparation and consultation with clinic staff.

Study variables

Questionnaire items were developed de novo or adapted from the literature.[8] All items were translated in French by two Francophone health professionals and back translated (by Anglophone health professionals) to ensure accurateness of the translation. Questionnaires were then extensively pilot-tested in both French and English with healthcare professionals who work closely with children and families affected by FASD for readability and ease of comprehension. Variables measured included questions pertaining to: (1) general information on the clinic (e.g., location, source(s) of funding and services offered); (ii) number of referrals and assessments done per year (used to calculate diagnostic capacity, defined as the proportion of assessment completed in a year among the number of referrals received); (iii) interdisciplinary team composition for FASD diagnosis by age group; (iv) current diagnosis reporting practices for children/adolescents and use of explanatory tools and (v) immediate and postdiagnosis support and counselling following the diagnosis disclosure. Online supplemental table 1 describes each variable investigated including the item used in the survey, response options and recoding of response options for analysis.

Data analysis

Of 78 clinics identified, 18 were excluded (i.e., did not diagnose FASD in children ≤18 years, or had permanently closed), 6 refused to participate and 13 did not return our recruitment efforts. Forty-one clinics completed the study questionnaire (68% of eligible clinics (41/60)).

To protect the clinics confidentiality, select characteristics were compared in three provincial groupings: *Western and Northern Canada* included clinics located in British Columbia, Alberta, Saskatchewan, Manitoba, and Yukon; *Central Canada* included clinics located in Ontario and Quebec; and *Atlantic Canada* included clinics located in New Brunswick, Nova Scotia, Prince Edward Island, and Newfoundland. Because of the small sample size, FASD clinical capacity characteristics were reported by age group for all clinics. Means for continuous variables and frequency distributions for categorical variables were compared. Analyses were performed using SPSS, V.26.0 (IBM Corp. Released 2012. IBM SPSS Statistics for Windows, V.25.0. Armonk, NY: IBM Corp.).

PATIENT AND PUBLIC INVOLVEMENT

Patients or the public were not involved in this study.

RESULTS

In this study, more than half of respondents were clinic administrators (56%, n=23), 15% (n=6) were physicians/paediatricians, and 29% (n=12) were other health professionals.

Sociodemographic and clinic characteristics

Half of the FASD clinics were in Western/Northern Canada (n=21), and 13 and 7 clinics were in Central and Atlantic Canada, respectively (compared with n=11, 7 and 1 of non-participating clinics (n=19), respectively). Western/Northern Canada had the highest proportion of clinics that were operational before 2006 (including the oldest clinic in the sample (i.e., operational since 1999)) and Atlantic Canada had the highest proportion of clinics that were operational in the last decade (table 1). No clinic located in Central or Atlantic Canada was operational before 2005.

Most regions received provincial funding (85%–95%). Proportion of in-kind donations and private funding were highest in Central (46%) and Atlantic Canada (57%). Atlantic clinics reported the highest proportion of federal funding (43%), while Central and Western/Northern clinics reported receiving non-governmental organisation (NGO) funding (15% and 33%, respectively; Atlantic clinics reported no NGO funding) (table 1).

Among participating clinics, approximately 2537 referrals are received every year and only 1797 assessments are completed (diagnostic capacity: 71%). Western/Northern clinics received the highest number of FASD referrals per year (mean (SD): 84(111); total of 1503/2537 (59%)) and their diagnostic capacity was highest (83%) (table 1). Diagnostic capacity in Central and Atlantic clinics was approximately 50% (55% in Central and 43% in Atlantic Canada).

All participating clinics offered diagnosis services (i.e., inclusion criteria for the CanDiD study). Approximately one-third of Canadian clinics were involved in prevention efforts (34%), 43%–69% of regions were involved in FASD screening, almost two-thirds of clinics offered FASD training for health professionals (63%), and most offered support to families (88%) (table 1).

Assessment and diagnosis by age group

Requirement of the confirmation of PAE or the presence of three sentinel facial features for FASD diagnosis assessment was variable among regions: 67% (n=14), 77% (n=10) and 43% (n=3) of clinics located in Western/Northern, Central and Atlantic regions required this confirmation, respectively.

Only 17% (n=7/41) of clinics diagnosed FASD in infants <18 months; among these seven clinics, 4 followed the Canadian interdisciplinary team guidelines (figure 1). Similarly, 60% (n=15/25) of clinics who diagnosed FASD in preschool children aged 18 months to 5 years followed the interdisciplinary team guidelines. Most clinics (n=40/41) diagnosed FASD in school-aged children (ie, ≥6–18 years), of which 80% (n=32/40) followed the Canadian guidelines (figure 1).

Table 1 Clinical characteristics of Canadian clinics offering FASD diagnosis to children ≤18: CanDiD study, 2021 (n=41)

	FASD clinics in Canada			
	Western and Northern Canada	Central Canada	Atlantic Canada	Total (all clinics)
Number of clinics, n	21	13	7	41
Year clinic became operational, n				
≤2005	8	3	1	12
2006–2011	8	5	2	15
≥2012	4	4	3	11
Do not know	1	1	1	3
Number of referrals per year				
Total	1503	780	254	2537
mean (SD)	84 (111)	65 (74)	36 (39)	69 (90)
Number of assessments per year				
Total	1257	430	110	1797
Mean (SD)	63 (64)	36 (33)	16 (13)	46 (52)
Source of funding for clinic services, % (n)				
Federal funding	5 (1)	15 (2)	43 (3)	15 (6)
Provincial funding	95 (20)	85 (11)	86 (6)	90 (37)
Research grant	14 (3)	0	14 (1)	10 (4)
Non-governmental organisation	33 (7)	15 (2)	0	22 (9)
Other (donations, private funding)	14 (3)	46 (6)	57 (4)	32 (13)
Services offered, % (n)				
Prevention	38 (8)	31 (4)	29 (2)	34 (14)
Screening	43 (9)	69 (9)	57 (4)	54 (22)
Diagnosis	100 (21)*	100 (13)*	100 (7)*	100 (41)*
Support to families	86 (18)	100 (13)	71 (5)	88 (36)
Specialised FASD training for health professionals	71 (15)	54 (7)	57 (4)	63 (26)

*Participating clinics were selected because they engaged in FASD diagnostic assessment of children/adolescent <18 years (ie, inclusion criteria).
FASD, fetal alcohol spectrum disorder.

Diagnosis disclosure

Designated individuals in charge of the FASD diagnosis disclosure to children/adolescents varied considerably across clinics. In 41% of clinics (n=17/41), paediatricians/physicians were responsible for the disclosure. Other health professionals and clinic administrators were responsible for diagnosis disclosure in 15% (n=6/41) and 5% of clinics (n=2/41), respectively. One quarter of clinics used a multidisciplinary team for the disclosure (20% (n=8/41) used more than one professional including a physician and 5% (n=2/41) used more than one professional excluding a physician). Finally, in 15% of clinics (n=6/41), the person responsible for the disclosure varied and often included parents in the diagnosis delivery.

Only 5% of clinics (n=2/41) always disclose the diagnosis to children/adolescents at the same time as the parents/guardian disclosure, 15% (n=6/41) never included children when first disclosing the diagnosis to parents/guardian and 80% (n=33/41) included the child sometimes, depending on certain factors. Most frequently cited determining factors included parents/guardian request, child developmental age, child chronological age, clinical judgement and clinic's policy.

Most clinics reported using at least one type of explanatory tools when announcing the diagnosis with parents/guardian (85%) or children/adolescents (67%) (table 2). In both parents and children, visual tools (pictures, graphs) or communication tools (analogies) were used most often (table 2).

Immediate and postdiagnosis support/counseling following diagnosis disclosure

Almost all clinics offered support and counselling to parents/guardian at the time of disclosure (95%) and in the 3-month period following the disclosure (90%). Seventy-one per cent and 76% of clinics offered support and counselling to children when announcing the diagnosis

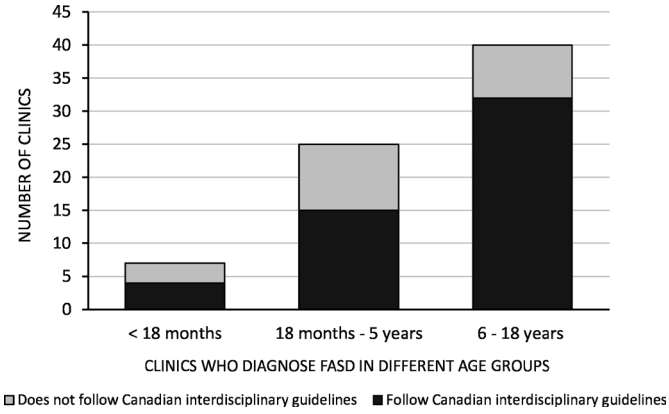

Figure 1 Canadian FASD diagnostic guidelines recommend that the diagnostic team for infants (<18 months) be composed of a paediatrician/physician and a child development specialist able to conduct physical and functional assessments (ie, speech-language pathologist, physiotherapist, occupational therapist or clinical psychologist). Recommendations for the diagnostic core team for preschoolers (18 months to 5 years) and school-aged children (6–18 years) include a physician, psychologist, a speech-language pathologist and an occupational therapist. FASD, fetal alcohol spectrum disorder.

and in the 3-month following the disclosure, respectively. While only one-third of clinics offered support/counselling to other family members (i.e., siblings, other close family members) at the time of FASD diagnosis disclosure, 65% offered them support/counselling in the 3-month period following the disclosure.

All clinics provided information to families in need postdiagnosis. The information requested most often included information on financial aid programmes, mental health programmes outside the clinic, support group programmes and information pertaining to Jordan's principal Implementation Act (i.e., ensures equality in health, social and educational services to all First Nations children).

Table 2 Description of explanatory tools used when announcing the FASD diagnosis to parents/guardian and children/adolescents: CanDiD study, 2021 (n=41)

	Parent/guardian	Child*
Use of tools when announcing the FASD diagnosis, % (n)		
Visual tools (pictures, graphs)	73 (30)	53 (20)
Electronic tools (ipads, computers)	17 (7)	13 (5)
Communication tools (analogies)	63 (26)	53 (20)
Use at least one tool	85 (35)	67 (27)

*Among 38 clinics who disclose the FASD diagnostic to child.
FASD, fetal alcohol spectrum disorder.

DISCUSSION

Principal findings

Although the majority (53%) of specialised FASD clinics were located in Western Canada, this region deserved the largest population of youth <19 years (i.e., approximately 4.9 million compared with 2.7 million in Central Canada and 467K in Atlantic Canada).[19] Consequently, 59% of total requests for FASD consultations were received in Western Canadian clinics. While it is important to note that their diagnostic capacity was higher than eastern and central clinics, clinics in all jurisdictions were not able to meet FASD referral demands highlighting a critical lack of resources.

Our results show that few clinics assessed and diagnosed FASD in infants and preschool-aged children. Although FASD can be diagnosed at various ages, it is commonly diagnosed when children enter the school-system (>5 years) and fail to attain behavioural and developmental milestones (e.g., motor skills, social skills, and language development).[20 21] Most clinics followed the Canadian interdisciplinary guidelines for infants, preschool, and school age children and adolescents (57% (n=4/7), 60% (n=15/25) and 80% (n=32/40), respectively).

Diagnostic reporting practices were heterogeneous across Canada with the exception that most used some type of explanatory tool when announcing the diagnosis to both parents/caregivers and patients. While physicians were involved in diagnosis disclosure to minor patients in most clinics (60%), approximately one-fifth of clinics entrusted other health professionals with the disclosure, and remaining clinics used administrators, parents or a variable approach depending on the clinical judgement of the healthcare team. Most clinics (80%) did not systematically include or exclude children/adolescents when announcing the diagnosis to parents/caregivers and used a case-by-case approach when delivering the diagnosis.

Finally, our results indicate that most Canadian clinics supported families during and after the diagnosis disclosure. This is of utmost importance as receiving a life-altering diagnosis can be traumatising for patients and families.[18] Prompt and easy access to counselling following a medical diagnosis can impact adherence to treatment plans[17] and, in turn, impact FASD-related outcomes.

Limitations of this study include that self-report data are subject to misclassification. Although key respondents were appointed by clinic managers or lead paediatricians and represented the person 'most knowledgeable about the clinic's clinical capacities', data were provided by a single person and may not adequately reflect clinical capacities of each clinic. To protect each clinic's confidentiality, it was impossible to describe interprovincial differences. Finally, because we had no clinical capacity data for non-participating clinics, results may not be generalisable to all clinics in Canada.

Despite these limitations, CanDiD is the first study that aims to better understand national clinical capacity for FASD assessment, diagnosis, disclosure and support in children and adolescents providing important evidence

of available FASD resources—or lack thereof—for policymakers, clinicians, and researchers. Only one previous research team aimed to determine FASD clinical capacity in Canada. However, their studies precede the 2016 updated FASD guidelines and only report FASD clinical programmes in selected Canadian territories and provinces.[16 22]

Clinical and policy implications, and future directions

Our work highlights the imminent need for a National FASD Strategy to ensure that all individuals with FASD and their families have access to services they need. Results from this study demonstrate that although progress has been made in FASD advocacy, monitoring and training, diagnostic capacity remains an important public health issue.[16] Our study mirrors findings from Clarren *et al* highlighting a critical need for increased diagnostic capacity.[16] If FASD prevalence rates are underestimated in Canada as well as in other jurisdictions worldwide, and current resources do not meet demand, policy-makers and clinicians need to mobilise efforts to find solutions to offer healthcare services to all individuals with FASD. Equality and equity in health services access is essential to improve health condition, support youth and families, and improve quality of life of individuals with FASD. Future studies should investigate FASD prevention and potential FASD health inequality in Canada.

Early diagnosis, diagnostic treatment planning, skilful treatment delivery and support of patients and families experiencing FASD is of utmost importance to improve child development[23] and mitigate negative factors associated with its neurodevelopmental impairments including academic failure, substance abuse, poor mental health, problems with law enforcement, and maintaining employment.[23–26] In a recent viewpoint article, Nunn[27] stated that medical news delivery should be age-appropriate, and in most cases, interaction and delivery is more important than the information itself. Because a child's chronological age does not necessarily correspond to their developmental age, when and how a diagnosis should be disclosed is also unclear.[18] Other factors such as cognitive impairments or maturity levels may represent additional barriers when delivering a neurodevelopmental diagnosis.[18] While existing medical news delivery protocols such as BREAKS[28] or SPIKES[29] can offer some guidance, they are not specific to neurodevelopment disorders and do not offer insight for medical news delivery to minors. Although recommendations on reporting practices of neurodevelopmental disorders cannot take a one-size-fits all approach, high heterogeneity in Canadian reporting practices highlight the need for more research to better understand which tools should be used and which health professionals should make the disclosure to improve clinical and diagnostic delivery protocols for children/adolescents.

It is noteworthy that following the survey completion, most clinics who did not have a complete interdisciplinary diagnostic team acknowledged that they did not meet the Canadian guidelines because of limited human and/or financial resources—they were simply doing the 'best they could'. Specialised multidisciplinary FASD clinics have the potential to (i) develop and implement prevention programmes to reduce alcohol consumption in pregnant women and in women of childbearing age; (ii) offer timely resources to individuals and families afflicted by FASD; (iii) provide continued training to healthcare professionals to ensure proper screening and diagnoses and (iv) improve healthcare utilisation (and indirectly improve justice and education services) by providing early accurate diagnoses. Consequently, continued national support for FASD clinical capacity including funding for development, training, and maintenance of interdisciplinary teams is imperative to improve health services for children living with this life-long difficult condition.[7]

Because FASD is a lifelong-multifaceted medical diagnosis associated with a heavy individual, clinical, public health, and economic burden, experts highlight the urgent need for increased capacity to recognise, diagnose, and monitor the full range of FASD.[5 6] Lange *et al* recommended the development of a universal screening protocol as well as other strategies such as education and support to decrease FASD.[3] We hope that findings from this study may increase understanding that FASD is a critical public health problem and that continued monitoring, healthcare services increase, training for health professionals, as well as the development of clinical tools and guidelines are prioritised nationally and internationally.

CONCLUSION

The CanDiD study provides evidence-base data that identifies outstanding knowledge gaps in FASD clinical capacity. Specifically, results from this study indicate that a lack of resources appears to be a serious impediment to healthcare for youth with FASD highlighting a need for continued FASD support.

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Contributors ED, DB and NL developed the survey instruments and contributed to conceptualisation of the study. DB conducted the interviews. ED and NL supervised the data collection. DB and LL entered the data. ED conducted data analysis. ED, MP and NB coordinated drafting the article. All authors reviewed the literature, contributed to the design of the analysis and interpretation of data, drafted sections of the article, reviewed the article critically, approved the final version and are responsible for the reported research. ED was the guarantor of this work.

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Patient consent for publication Not required.

Ethics approval This study involves human participants. The study was approved by the ethics committee of Vitalité Health Network. #101241; approved on 12 April

2021. Participants gave informed consent to participate in the study before taking part.

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Data availability statement Data are available upon reasonable request. All data relevant to the study are included in the article or uploaded as supplementary information.

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