A Tri-Province Initiative to Expand Understanding of Costs, Services & Prevention of a Public Health Issue: *Fetal Alcohol Spectrum Disorder & Children/Youth In Care [2010-2014]:*

Inventory of Canadian FASD Services & Resources: *Regional analysis*

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1.0 BACKGROUND ~ Tri-Province Project: Canadian FASD Services

The goal of the (2011-2014) Tri-Province Initiative is to expand understanding of the costs, services and prevention of fetal alcohol spectrum disorder (FASD), specifically as it relates to a vulnerable group: children and youth in care. One approach taken to meet that goal is the listing and analysis of the FASD services and resources within each province and territory. Project outcomes are FASD Service & Resource Inventories for each of the 10 provinces and one for the three territories: Yukon, Northwest and Nunavut coupled with a national analysis of the regional trends and service gaps.

There are limitations to this work. To create each Inventory, internet searches were done to gather the information on available resources in each province and across the various regions in each area. In many instances further phone calls and emails were initiated to further clarify contacts, agency mandates, and specific program offerings. The creation of the Inventories took place over a three year period (2011 – 2014). Although every attempt has been made to include the most up-to-date data, current contacts and relevant material, the challenging reality is that "current" is a relative term that relates to the moment in time each Inventory was completed. The reality is the agencies and services listed in the Inventories may no longer be in service, contact information may have changed, and additional services may have emerged that are not noted. In many instances, the description of the agency or service in the Inventory is taken directly from the agency's own website or other written material.

2.0 METHOD IN CONDUCTING PROVINCIAL/TERRITORIAL INVENTORIES OF FASD SERVICES

2.1 FASD in Canada

Detailing the type and availability of FASD resources within Canada that serve the children, youth, families and caregivers impacted by FASD is an important task. As Darwin aptly noted, the first goal of science is to describe. One of the most commonly cited statistics regarding the general prevalence of FASD in Canada is that that it affects 9.1 per every 1000 births (<1%) (PHAC, 2003). Other Canadian studies have looked at higher-risk populations, such as children in care, and higher prevalence rates are noted (e.g., 11% children living in foster care in Manitoba) (Gough & Fuchs, 2006). FASD is strongly correlated with a mental health diagnosis which is associated with other risk factors such as substance misuse; the dual FASD/mental health risk is detailed in Table 1 below (http://canada.justice.gc.ca/eng/rp-pr/csj-sjc/esc-cde/rr13_10/p2.html). It aptly underscores the critical importance of FASD services and resources to address the added social, health and economic costs associated with those who have FASD.

Table 1: Lifetime Prevalence of Mental Health Disorders in Specific Populations

Disorder	General adult population	Incarcerated adult males[3]	Adult males with FASD[4]	Adult females with FASD[4]
Depression	8%[1]	29.8%	40%	50%
Psychosis	1%[1]	10.4%	47%	30%
Anxiety	12%[1]	55.6%	0	50%
Antisocial personality disorder	6-9%[1]	74.9%	21%	14%
Substance abuse	15.9%[2]	52.9%	60%*	60%*
Alcohol abuse	46.6%[2]	69.8%	60%*	60%*

[1] Public Health Agency of Canada 2002; [2] Canadian Community Health Survey: Mental Health and Well-being 2002 in Tjepkema 2004; [3] Motiuk and Porporino 1992; [4] Famy et al. 1998; * Combined substance and alcohol abuse.

Children, youth and adults with FASD have varying special needs throughout their life spans, as do their families and caregivers. Not only do the primary disabilities adversely impact those with FASD (e.g., mental health, physical issues, social challenges), the secondary disabilities associated with FASD add further challenges (e.g., drug addiction, homelessness, alcohol misuse). Thus, FASD services must span different service options. In addition to information, services such as access to interventions related to diagnoses, treatment, and support for FASD are needed. FASD services must be available to various age groups (children, youth, adults, seniors), as FASD is a life span disorder. As well, given Canada's broad geographical expanse, FASD services need to be accessible to those living in all settings – rural and urban. Informed by Canada's diversity and responsibility to its Aboriginal peoples' (First Nations, Metis, Inuit) services need to be culturally sensitive and understanding of highly vulnerable groups, such as women who use or at risk of using substances throughout their pregnancies.

By examining the landscape of current FASD resources available in the regions across Canada this kind of cross-sectional analysis offers users, providers and funders of FASD services with a 'snap shot' of available resources within each province/territory. When knitted together it provides a Canadian portfolio on FASD services and resources. In addition to listing and collating all the services, we further analyzed the data by asking five key questions:

- **What types of FASD services are available?**
  Is it mostly information, diagnostic services or treatment offerings?

- **Who are the FASD services being offered to?**
  Who are the services aimed at – children and youth or adults or both?

- **Where are the FASD services located?**
  Are they only in urban centers or equally available to rural, urban and isolated communities?

- **Are the FASD services generalist or specialist?**
  Are the offered within a generalist setting (e.g. Health Centre, Community Agency) or are they specific (e.g., FASD-only agency)?

- **Is there cultural representation in the FASD services?**
  Do services reflect the population?

There is an old management adage - *"you can't manage what you don't measure."* Understanding starts with first describing the phenomenon – in this case – the what, where, who, and how questions related to FASD service provision in Canada. Description allows analysis, which can foster a more strategic approach to assessing service success, gaps and needs. This review is the first step of hopefully many that will build towards a more adequate, equitable and fulsome range of FASD services across Canada.

2.2 FASD Resources in the Provinces and Territories: A Portrait

The cross-Canada analysis of FASD resources was informed by the separate Inventories and the listings of the FASD services in each of Canada's provinces and territories. As noted above, to create the Inventories, internet searches were utilized to gather initial information on available resources in each region. In many instances further phone calls and emails were initiated to further clarify contacts, agency mandates, and specific program offerings. The creation of the Inventories took place over a three year period (2011 – 2014). Included in each Inventory are both 'brick and mortar' resources, where one can physically attend for information and/or services, as well as provincial/territorial-specific internet and written resources. For the cross-Canada analysis, internet resources were not included.

2.3 FASD Resources in Canada: A Portfolio

After the FASD Inventory for each province/territory was completed, the data were converted into an Excel document for each region. This was done so that the characteristics of each agency, within each region, within each province/territory, and finally within Canada, could be gathered for analysis across the five key question areas. See Table 2.

Table 2: Key Questions	Values
Q1. What types of FASD services are available?	a) information and resources, b) assessment and/or diagnostic service c) treatment, social support or intervention
Q2. Who are the FASD services being offered to?	a) 0-17 year olds (children/youth) b) 18 years and over (adults) c) both child/youth and adults d) does not service clients
Q3. Where are the FASD services located?	a)urban, b) rural, c) suburban, d) across two or more geographical locations),
Q4. Are the FASD services generalist or specialist?	a) agency/service FASD specific b) agency/service not FASD specific
Q5. Is there cultural representation in the FASD services?	a) Agency exclusively serves our Aboriginal peoples b) Agency does not exclusively serve our Aboriginal peoples

For the Canadian portion of the analyses, the 10 provinces and three territories were divided into five 'regions'. *Western* are the four most westerly provinces; *Eastern*, the four most easterly provinces; and *Northern* refers to Canada's three territories. *Ontario,* because it has the largest population and *Quebec*, due to its cultural uniqueness, were not grouped into a region, but for the purpose of this analysis, remained at the provincial level. While this approach is advantageous in providing a *regional* portrait, the limitation is that the provincial view is lost for eight provinces and the three territories. See Table 3.

Table 3: Regions	Provinces/ Territories	Total
Western Region	British Columbia, Alberta, Saskatchewan, Manitoba	**4**
Ontario Region	Ontario	**1**
Quebec Region	Quebec	**1**
Eastern Region	New Brunswick, Nova Scotia, Prince Edward Island, Newfoundland & Labrador	**4**
Northern Region	Yukon, Northwest, Nunavut	**3**

3.0 FINDINGS

3.1 Overview ~ Canadian FASD Services and Resources to Population

Across Canada, a total of 506 FASD resources were included in this analysis. Figure 1 depicts the number of FASD services and resources (not including internet resources) by the five regions. By far, the Western Region (n=223) exceeds the total number of resources (n=199) offered in Ontario, Quebec and the Eastern Region provinces. Figure 2 examines the percentage of FASD resources by region compared to the population of Canada by region, which offers a more fulsome picture of resources across Canada.

Figure 1: FASD Services/Resources by Region.

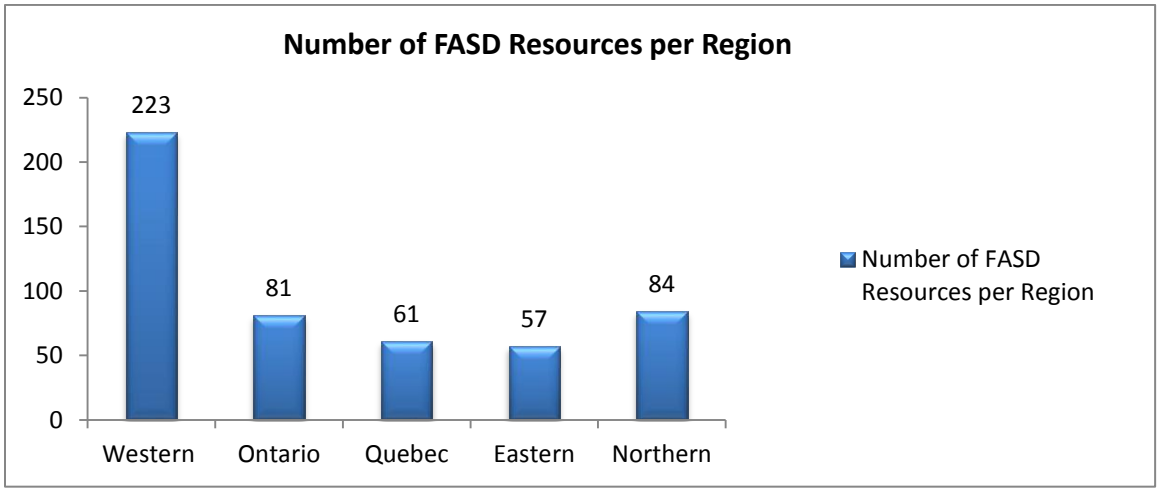
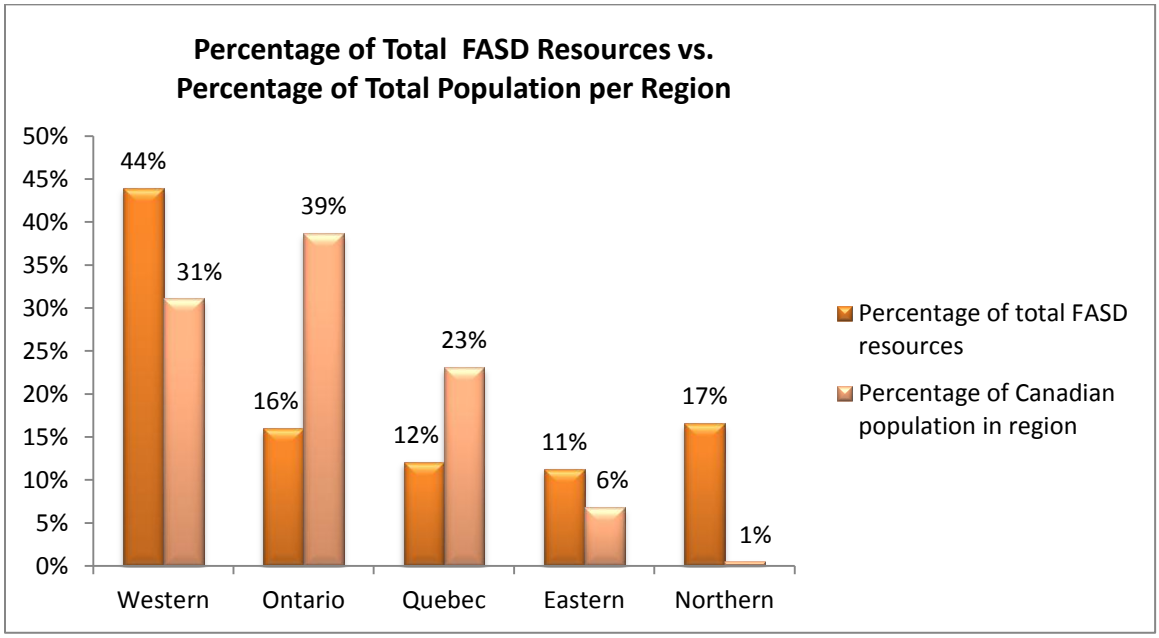


Figure 2: FASD Services/Resources by Region vs. Regional Population.



As is evident when viewing Figure 2, considerable variance exists across the five regions on the percentage of the population to the percentage of FASD resource availability. The *"percentage of FASD resources available exceeds population percentage"* in the Western, Eastern and Northern regions. The region's where *"population percentage exceeds percentage of FASD resources available*" is with Ontario and Quebec. The major limitation with this type of regional grouping analysis is provincial variance within the Western, Eastern and Northern regions is not depicted. (Population data source: *Retrieved online from Human Resources and Skills Development Canada website at* http://www4.hrsdc.gc.ca/.3nd.3c.1t.4r@-eng.jsp?iid=34)

3.2 Q1 – What Types of FASD Service Are Available?

All services and resources were categorized into four areas (see Table 4):

1) Information,

2) Treatment/Intervention,

3) Diagnosis/Assessment,

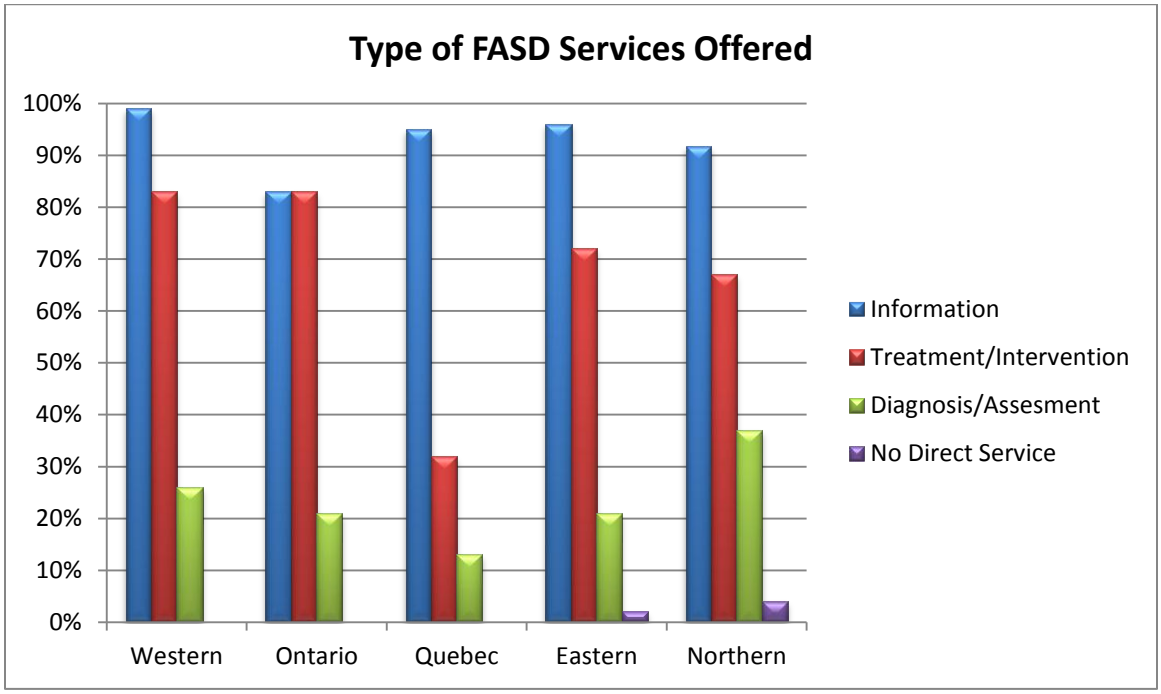
4) No Direct Service/Advocacy Only

The type of FASD service offered within a region is an important consideration when examining broader national issues such as equity, accessibility, and availability. Service type is also important when taking a more specific regional, provincial or local lens, such as with diagnostic capacity. For example, having resources that cater to those diagnosed with FASD and supports to their caregivers (e.g., respite) is essential in mitigating short and long-term risks associated with this disability (e.g., multiple placements). The importance of diagnostic services cannot be underestimated. To receive proper treatment, services, supports and funding throughout one's life, proper detection and diagnosis of FASD is required. Although there are diagnostic services in each region of Canada, a recent study found that as of 2011, Canada was greatly lacking in its ability to diagnose and assess all people who required these services (Clarren, Lutke, & Sherbuck, 2011). The ultimate goal is prevention of FASD, however, if rates are to diminish in the future, services for families at risk of having children afflicted with FASD are of the utmost importance. In short – the type of FASD service available matters.

Table 4: Service Type Category	Definition
Information	Service provides information on FASD
Treatment/Intervention	Service provides some type of treatment and/or intervention, such as therapeutic/educational groups, mentoring, counselling, or support
Diagnosis/Assessment	Service provides FASD diagnostic services and/ or child/adult FASD assessments
No Direct Service/Advocacy only	Service does not provide direct service or information, but may function as a coordination service or advocacy intervention

This review found, and it is important to note, that most FASD resources offer more than one type of service (i.e. one FASD service may offer information, assessment and treatment whereas another FASD service may offer only information sources). The percentage of each type of service, per region, is displayed in Figure 3.

Figure 3: Type of FASD Services by Region.



Information

Across all five regions, *information on FASD* is the dominant form of FASD service, with it being offered in at least 80% of the services within each region. In each geographical area there seems to be a variety of services that offer information on FASD to the general public. In fact most FASD resources offer some type of information on FASD. Note, most resources offer information in addition to other service types.

Treatment/Intervention

Across four of the five regions, *FASD treatment and intervention* services are available in over 60% of services offered (i.e., , Northern (~65%) Western and Ontario regions (~82%). Quebec is noticeably lower in this service area with only ~32% of the services offering treatment and intervention.

Diagnosis/Assessment

FASD diagnostic and assessment services were grouped together in this analysis. In some areas, diagnostic services may not be readily available but assessment services are and vice versa. Assessment can include completing an assessment regarding whether or not an individual should complete a further FASD diagnostic assessment. Overall, this area constitutes one-third or less of the FASD services across the regions. The range is a low ~13% in Quebec to a high of ~38% in the Northern region.

No Direct Service/Advocacy Only

In the Northern and Eastern regions, some services were categorized as offering *no direct service.* These types of resources mainly consisted of 'area coordination' services which worked to coordinate FASD services between various services or advocacy groups.

3.3 Q2 – Who Are The FASD Services Being Offered To?

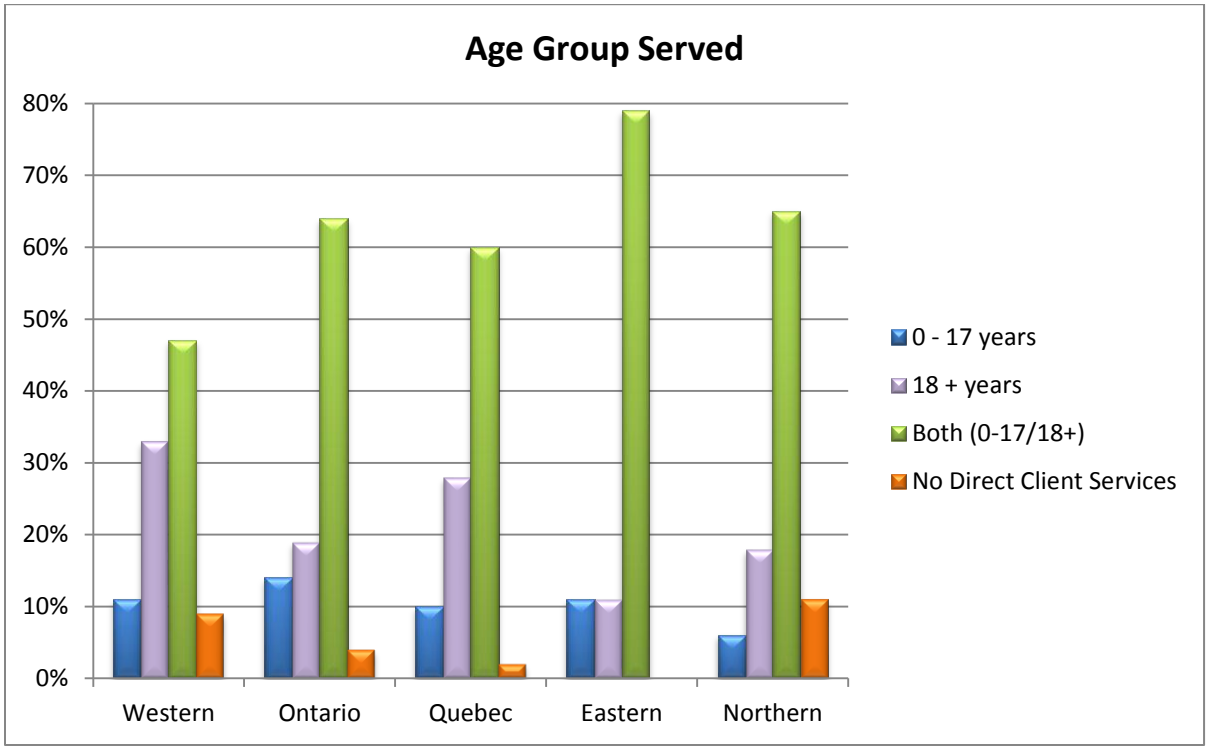
In regards to the age group served, the listed resources were separated into the following categories:

- *Ages zero to 17* [children/youth],
- *Ages 18 and over* [adult],
- Both *zero to 17* & *18 and over* [all ages],
- *No direct client services* [no direct].

Examples of how we categorized services (see Figure 4 for summary analysis):

- *Services for mothers at risk of having children affected by FASD* — Adult
- *Services that diagnosed FASD in young children AND offered support to parents,* — All Ages
- *Service is a coordinating network* — No Direct

Figure 4: Age group services aimed at



As is seen in the chart above, the majority of resources in each region are aimed at both *children/youth* and *adult populations*. Regional variability is greatest with services for *adults only,* which ranges from ~10% in the Eastern region to ~32% in the Western region. Services solely for *children/ youth* are evident every region with a narrower range difference between regions (e.g., ~6% Northern to ~14% in Ontario. The findings, albeit suggestive and not conclusive, do raise important questions that bear examining:

- Most resources serve both *children/youth* and *adults*. Is this the most effective service approach to impact prevention, mitigate risks and provide supports? Do targeted, specific interventions have more, less or the same impact as generalized services?

- Programs that focus on *children/youth* are known to be important in mitigating risk earlier and promoting resilience. Would increasing the offering of specific services to FASD youth improve short-term outcome and increase FASD prevention rates later in life?

3.4 Q3 – Where Are The FASD Services Located?

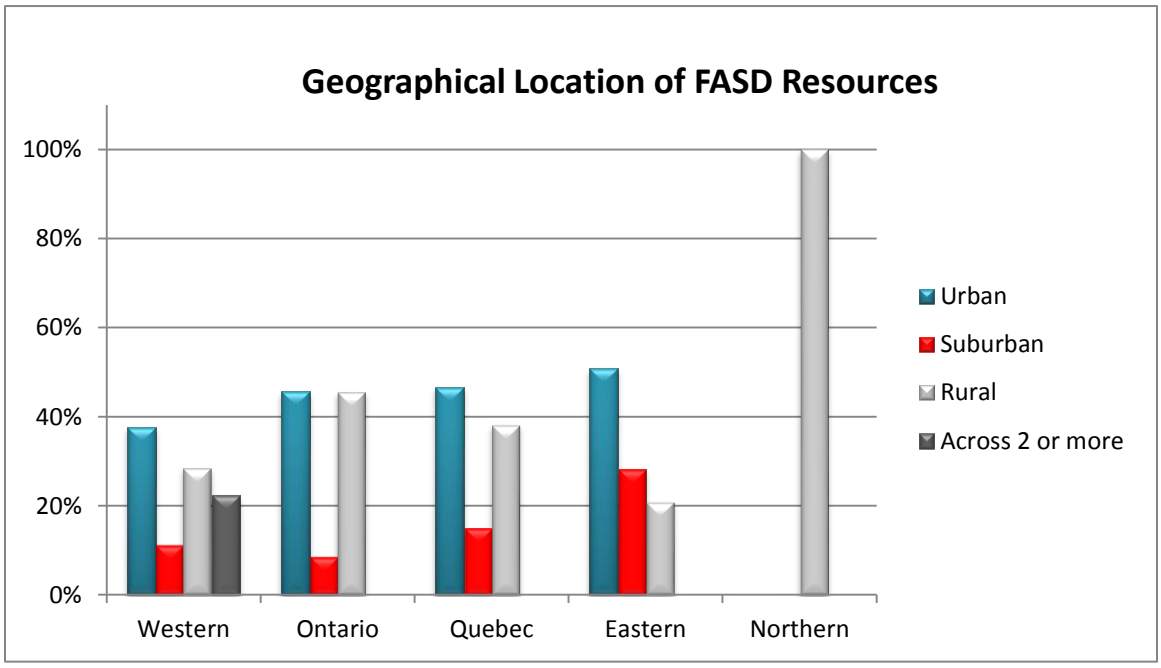
Across Canada, our geographical landscape varies widely from the east to west and the north to south borders. While 95% of Canada is classified as "rural", blanketed by forests and wilderness, the preponderance of Canada's population (70%) lives near urban settings, south of the 49th Parallel. Since FASD has no known cure, its impact is adversely experienced throughout one's life span, and most every community across Canada will have some members affected by it (diagnosed with it or caring for someone affected by it) it is important the FASD resources are readily available and accessible regardless of location (i.e., urban, suburban and rural). See Table 5 for the definitions employed in this analysis for "urban", "suburban" and "rural".

Table 5. Geographical regions.

Table 5: Location	Population of 100,000 or more
Rural	Population of less than 30,000
Suburban	Population of 30,000 – 99,999
Urban	Population of 100,000 or more
Mix of 2 or more	Resource offers services across two or more geographical locations

While the aim of this review is to be exact in the determination or categorization of the data in order to meet data integrity needs, this segment of the analysis faced a number of challenges. The examination was complicated because for the Eastern region, an agency's geographical region is determined based on the *county* the agency is located in - not the city. For the other four regions, geographical location of the FASD service is based on the city the agency is located in – not the county it is in.

Figure 5: Geographical region.



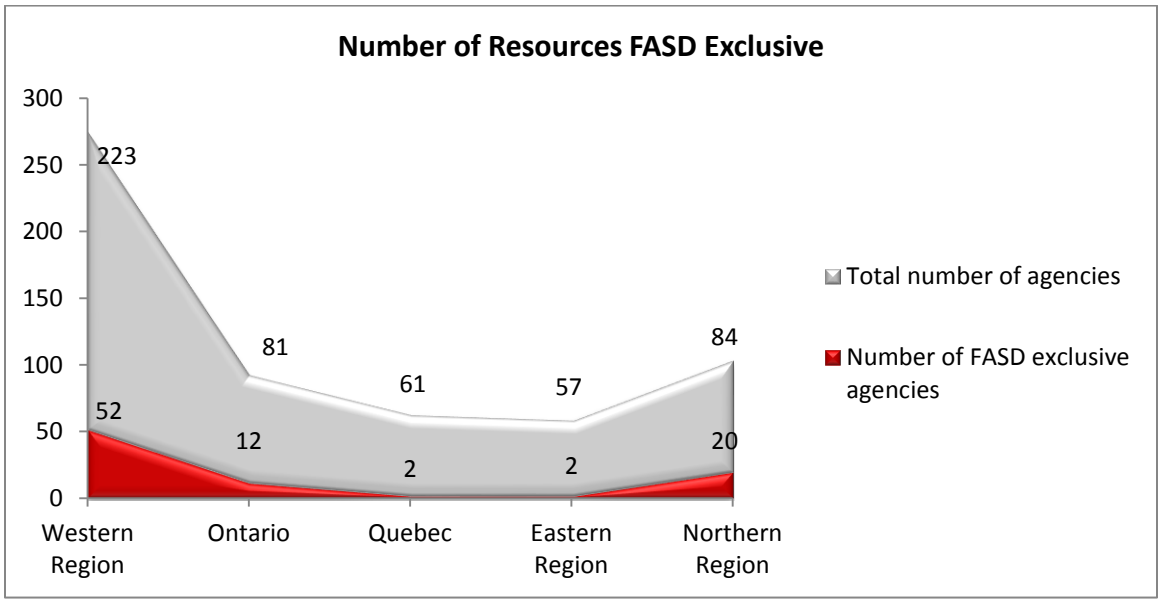
As of 2011, 81% of Canadians now live in an "urban" setting (http://www4.hrsdc.gc.ca/.3ndic.1t.4r@-eng.jsp?iid=34). The higher weighting of "urban" locations for most FASD services across all regions makes intuitive and logical sense (except the Northern region where "rural" dominates).

That said, the graph does raise questions on service or accessibility balance. For example, in the Western, Ontario and Quebec regions, where only one-in-five (~20%) Canadians live in a rural setting, yet over 28% (Western), 38% (Quebec) and 42% (Ontario) of the FASD services are classified as "rural".

3.5 Q4 – Are The FASD Services Generalist Or Specialist?

The fourth question area examined in the cross-Canada FASD service analysis is the issue of generalist service (i.e., FASD is among many services offered) vs. specialist (i.e. FASD service is exclusively offered). There is no commentary provided or research cited on the benefit or value of one service type over the other – the intent is simply to describe the type of service agency offering the FASD services. Future research will help understand if benefits accrue differently by service model. See Figure 6 for the percentage of services in each region rated as *"FASD exclusive".*

Figure 6: FASD exclusive resources.

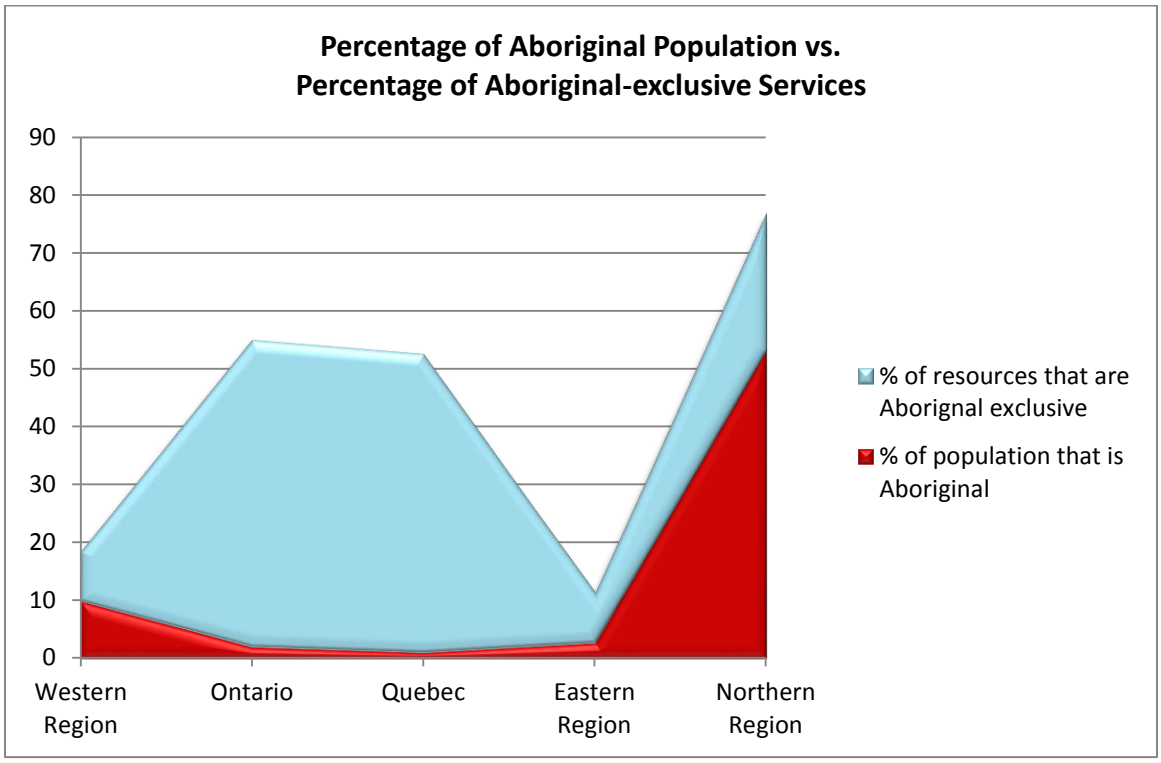


Analysis of the 506 total FASD services across Canada by region by the number of FASD exclusive agencies in each region finds considerable variance. For example, Western (52 exclusive of 223; 23%); Ontario (12 exclusive of 81; 15%); Quebec (2 exclusive of 61; 3%); Eastern (2 exclusive of 57; 3.5%); and Northern (20 exclusive of 84; 24%). This analysis simply points to more questions. How does receiving service from an exclusive FASD service vs. a more generalist service agency impact service users? Are service users more likely or less likely to seek FASD services if it is a generalist agency offering it vs. an exclusive FASD agency? Does having FASD exclusive agencies positively or negatively raise the profile of FASD within a community? Again, another area that would benefit from a more sustained inquiry.

3.6 Q5 – Is There Cultural Representation In The FASD services?

FASD is a concern across all populations, genders, SES cohorts and geographical locations. Notwithstanding the growing recognition that the prevalence of FASD is more often associated with a set of social circumstances (e.g., poverty, high alcohol consumption, binge drinking), particular groups, like children in care or some Aboriginal communities, have been found to be higher risk for FASD (Burnside et al., 2011). Therefore, how FASD services are culturally experienced, more specifically, how they are available to our First Nations people and their communities across Canada is important to understand. For that reason, we examined how the provinces and territories address the issue of FASD services within the Aboriginal population. See Figure 7 for Aboriginal specific FASD services vs. resources are available to both Aboriginal and non-Aboriginal people.

Figure 7. Aboriginal-exclusive FASD resources.



**Aboriginal population data course: Retrieved online from Statistics Canada website at http://www12.statcan.ca/census-recensement/2006/as-sa/97-558/figures/c1-eng.cfm*

Confusing findings emerge from the analysis. Considerable variance across regions is evident when the Aboriginal population in each region is compared to the percentage of regional Aboriginal-exclusive services. What is not a surprise, is the Northern region, with the highest percentage of Aboriginal people (relative to the non-Aboriginal population), also has the highest percentage of Aboriginal-exclusive resources. What is a surprise, is in both Ontario and Quebec, over half (50%) of all FASD resources are tagged as "Aboriginal-exclusive" resources, yet both provinces have the two lowest Aboriginal populations. Furthermore, the Western region, with the second highest Aboriginal population (10%) after the Northern region, has less than 20% of its FASD resources as "Aboriginal exclusive". The limits with this analysis is it is descriptive, not explanatory, where queries can be raised but not answered.

4.0 STUDY STRENGTHS AND LIMITATIONS

The advantages of a descriptive study is that the quantitative and/or qualitative data can be used to find data and depict the characteristics of the phenomenon being studied. For this examination it is the number and pattern of FASD services and resources across Canadian regions that are examined. The strengths of this review and methodology is that it afforded the first scientific "toe in the water" on the examination of the provincial, regional and national FASD services across a number of domains. It is to the point of first measuring a service for trends and patterns in order to understand those trends, with the ultimate goal being to improve the service. In this study, for example, we examined service type, location of services, and target age served. One can't begin a discussion about whether the availability of services is adequate if you don't first understand what the availability is. Data completeness is at the heart of data integrity – many attempts were made over time to ensure all relevant data were included.

Study limitations with descriptive inquiries are not insignificant, as is the case with this analysis. More specifically, one limitation with this review is there are possible errors regarding the completeness of the data collected. As well, the cross-sectional, point-in-time nature of the study means the currency of the data has a short-shelf life. And finally, while findings are intriguing, they are suggestive and no inferences can be drawn about associations, causal or otherwise.

5.0 CONCLUSION

This analysis offers a first glimpse of the breadth and depth and type of FASD services across Canada. What we know for sure is the range of services (e.g., information, diagnostic, and intervention) are offered in each region. We know there are diagnostic services for FASD in each province and territory. It appears that across Canada, an inclusive view to FASD service delivery is taken, where service tends to be offered to all ages vs. a specialist approach. It is also evident that the landscape is quite uneven regarding FASD services. Depending on where you live in Canada services for FASD may look and be experienced very differently.

When examining services across geographical location, there appears to be a somewhat equitable balance between urban and rural services. Whether there should be is a question. Further analysis is also required to assess whether there are adequate resources for the specific rural populations like the Far North. Additional analysis is needed to assess whether FASD resources are available to the most remote communities.

This review identified that in the area of FASD-exclusive resources, all regions across Canada have limited capability. The potential with FASD-exclusive resources is they tend to increase the visibility of FASD within a community or region, which may aid in reducing stigmatization or it may increase it. Further study will be important to determine the advantage or risk.

Finally, FASD services do exist that are specific to serving our Aboriginal people. While this is important to ensure that culturally sensitive services are offered, further research needs to be completed with other vulnerable, high risk cohorts, such as: those living in poverty in urban centers, women who use or are at risk of using substances, children and families within the child welfare system, and new comers to Canada. In short, this is the start line not the finish line in examining Canada's portfolio of FASD services.

6.0 REFERENCES

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