

# A CASE FOR COLLABORATIVE PRACTICE: A LONGITUDINAL LOOK AT PROVINCIAL SUPPORT SERVICES FOR CHILDREN (3 TO 12 YEARS) WITH FETAL ALCOHOL SPECTRUM DISORDERS IN ALBERTA OVER SIX YEARS

### THE CHILD AND YOUTH DATA LABORATORY (CYDL) LONGITUDINAL PROJECT

April 6, 2018

# PURPOSE

There are estimated to be more than 48,800 individuals with Fetal Alcohol Spectrum Disorder (FASD) in Alberta<sup>1,2</sup>. To improve the wellbeing of children with FASD in Alberta, it is important to understand the kinds of provincial supports and services they access so that opportunities for collaborative and integrated service delivery can be identified. Data from the Child and Youth Data Laboratory's Longitudinal Project is particularly well suited for analyses that require cross-ministerial consideration of service delivery.

# HIGHLIGHTS

This report highlights patterns of service delivery for provincial support services between 2005/06 and 2010/11 experienced by the 1,055 children who were aged 3 to 12 years in 2005/06, and who were assigned a diagnostic code of FASD for administrative purposes by a health service at any point in the study period. Results from this report point to a need for collaborative programming, resourcing, and planning, particularly between Child Intervention and other support services to enhance service delivery to children with FASD in Alberta.

Of note is the clear picture that emerges of the vulnerability many children with FASD face. Of the **1,055 children with FASD that are the focus of this report**, over the six years:

- 49% received services from Child Intervention (CI) and at least one additional service that provides disability supports (special education and/or Family Support for Children with Disabilities [FSCD]) and another 8% received services from Child Intervention only (p. 4).
- Across Alberta, the overall pattern of service delivery for provincial disability supports was similar within each region. In Calgary/South 41% of children with FASD received services from CI and at least one additional service, compared to 55% in Edmonton/Central, and 50% in Northern Alberta (p.5).
- A clear need for collaborative, integrated services for children with FASD that involves services from Education, Children's Services, and Community Social Services is evident to support both mental health (p. 6) and education (p.7).

This report is part of the Longitudinal Project by the CYDL in collaboration with Alberta partnering government ministries. Please see the last page for a brief description of the project and go to https://policywise.com/initiatives/cydl/p2 to access other deliverables.

# BACKGROUND

**Fetal Alcohol Spectrum Disorder (FASD)** is a diagnostic term that describes the range of effects that can occur in an individual who was prenatally exposed to alcohol <sup>3,4</sup>. Individuals with FASD may experience a wide range of disabilities and challenges including birth defects, growth problems, cognitive delay, and speech and language difficulties as well as a range of other health challenges<sup>3,4</sup>. As a result, the neurocognitive, behavioural, and physical challenges that emerge from prenatal alcohol exposure are lifelong and vary considerably for each individual.

The focus of this report is children with FASD aged 3 to 12 years in 2005/06 and describes their experiences with disability services and CI between 2005/06 and 2010/11. Using individually linked administrative data, this report characterizes categories of service delivery for provincial supports across three ministries: Education, Community and Social Services, and Children's Services. The specific provincial services considered were those whose mandate includes supporting children with disabilities, special education, and Family Support for Children with Disabilities (FSCD), as well as Child Intervention (CI). The inclusion of CI is important because the dynamics of families of children with FASD are often complex and marked by trauma. That is, the majority (but not all) of those diagnosed with FASD come from families whose stories include histories of addiction, mental health issues, abuse, and trauma. As well, these families can face immense social vulnerability<sup>5</sup>. For example, one study found that of 80 women who had at least one child with an FASD diagnosis, 95% had experienced physical or sexual abuse, nearly 60% were living below the poverty line, and more than 95% had mental health problems<sup>6,7</sup>. Because the mandate of Child Intervention is to intervene when there are concerns that a child or youth is being neglected or abused by their parent or guardian, families with such social vulnerability may receive support from CI. Additionally, when a child is placed in care, the supports that otherwise may be provided to a family through for example, FSCD, are provided by CI.

Whether children with FASD received services from special education, FSCD and/or CI was assessed using administrative data. First, children identified with mild, moderate, or severe disabilities, as well as those who were gifted and talented, are eligible for special education services. Each child identified as having special education needs must have an individualized plan to help teachers and parents coordinate, implement, and evaluate a student's progress. In this report, only special education codes for disabilities are included in the analyses. Second, FSCD provides a range of supports and services to families of children with disabilities based on each child and family's assessed needs. FSCD services are meant to strengthen families' abilities to promote their child's healthy development, and encourage participation in activities at home and in the community. Third, any involvement with CI over the six years was considered as "having received services". The nature and duration of the services are not considered in this report.

This report explores the constellations of provincial and support services including special education, FSCD and CI, that children with FASD may have accessed over six years in Alberta and how these categories of service delivery intersect with the use of other provincial areas of practice such as education and mental health in Alberta. Information from this report may be used to inform collaborative practice around programming, resourcing, and planning for enhanced service delivery to children with FASD in Alberta.

Categories of service delivery for provincial supports were defined based on whether a child was assigned a diagnostic code of FASD for administrative purposes by a health service during the six years, and then by whether they had ever received special education, FSCD, and/or CI, between 2005/06 and 2010/11. Children were considered to have FASD if they had a diagnostic code for: a) fetal alcohol spectrum (FAS) (ICD 10-CA Q86.0) or b) being a newborn affected by maternal use of alcohol (ICD 10-CA P04.3), at any point in the six-year period from a health service (emergency department, outpatient clinic visit, or a hospitalization).

Children with a diagnostic code of FASD were then categorized into one of five groups based on the services they received over six years (see Table 1):

- a) no use of disability or CI services, "No Disability/Child Intervention (CI) Services",
- b) only special education, "Special Ed Only",
- c) services from FSCD and special education, "FSCD & Special Ed",
- d) services only from CI, "CI Only", and finally,
- e) services from CI and special education and/or FSCD, "CI Plus Other".

Children who were 3 to 12 years in 2005/06 who did not have a diagnostic code for FASD from a health service during the six years of the study were categorized as "General Population".

#### TABLE 1: Categories of service delivery for provincial supports.

		Categori	es of Service	Delivery	
	No Support Services	Special Ed Only	FSCD & Special Ed	CI Only	CI Plus Other
FASD diagnostic code from health service	Yes	Yes	Yes	Yes	Yes
Special education accessed at some point	No	Yes	Yes*	No	Yes/No**
FSCD accessed at some point	No	No	Yes	No	Yes/No**
CI accessed at some point	No	No	No	Yes	Yes

\*There were fewer than 15 children with FASD who received only FSCD and they were included in this group.

\*\*These children received services from at least special education or FSCD, or both, as well as from CI.

### LIMITATIONS AND CONSIDERATIONS

In the following analyses there were 1,055 children between 3 and 12 years old in 2005/06 who had a diagnostic code of FASD from a health service between 2005/06 and 2010/2011 (see p. 17 for *Definitions and Notes*) and 391,829 who did not (General Population).

When interpreting results, readers should consider the following limitations of the study:

• This report underestimates the prevalence of FASD in Alberta as not all individuals with FASD can be identified. In this report, FASD has been defined based on whether, during the six-year study period, an individual was assigned a diagnostic code for administrative purposes by a health service for FAS or being a newborn affected by maternal use of alcohol. Children with FASD could be missed if they a) are undiagnosed, b) have been diagnosed with FASD but did not have a diagnostic code for FASD from a health service during the study period, or d) had a different diagnostic code, one related to but not specifically for FAS or being a newborn affected by maternal use of alcohol.

**Footnote:** Ninety-five percent confidence intervals were calculated to enable comparison of statistical differences between groups. The Cochran-Armitage trend test was used to test trends over time. Results of such statistical testing are included in supplementary tables. Policy-relevant and meaningful differences are discussed in the report. *See https://visualization.policywise.com/P2dashboard/FASD3to12yearsStat.xlsx* 

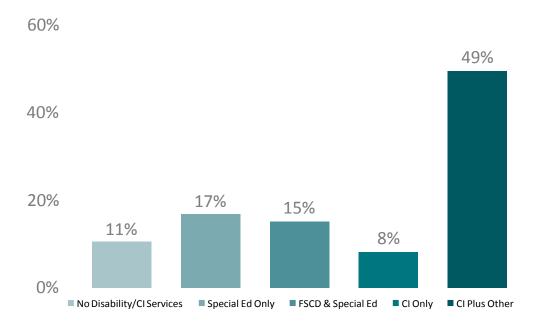
### LIMITATIONS AND CONSIDERATIONS cont.

When interpreting results, readers should also consider:

- Children and youth who moved in or out of Alberta during the study period would be missed. Because inclusion in the study population is based on enrolment in AHCIP for at least one full year, results cannot be generalized to youth who did not meet this criterion. In the analyses of service delivery categories across the six years, this report is restricted to children who were residing in Alberta for the six years as indicated by their having accessed at least one provincial service in each study year such as attending school, going to the hospital, or receiving supports from, for example, programs administered by Children's Services or Community and Social Services. In total 17.5% of children were excluded but only 64 individuals or 5.7% of children with FASD were in the study cohort. Nevertheless, results from the analyses cannot be generalized to them.
- Other provincial disability supports for children that are FASD-specific, and community-based supports for disabilities and FASD, are not included. For example, not captured in this report are use of provincial supports such as school-based FASD-specific programs, or community-based disability supports and programming such as those from Catholic Social Services.

### A CASE FOR COLLABORATIVE PRACTICE (Tables 2, 3, and 4; pp. 9-11):

Of the **1,055 children with FASD**\* that are the focus of this report, over the six years, **49% (521 children) received** services from both CI and at least one additional service that provides disability supports (special education or FSCD) (CI Plus Other).



Percentage of those Albertans aged 3 to 12 years in 2005/06 with a diagnostic code for FASD from a health service in each of the **five disability service delivery** *categories* between 2005/06 and 2010/11. See Table 2.

\*Children with FASD refers to those children assigned a diagnostic code of FASD for administrative purposes by a health service (see Definitions and Notes, p. 17) between 2005/06 and 2010/11.

A closer look at the demographics of these groups reveals that, consistent with the literature<sup>8</sup> there were fewer females with FASD (404 females and 651 males; 38% females and 62% males). The proportion of females and males varied as a function of the category of service delivery (see Table 4 for details). In particular, in the CI Plus Other category, males were slightly over-represented (64%). An examination of the age distributions for each service category (see Table 3 on p. 10) illustrates that children are more likely to receive multiple support services such as CI *and* a disability service like special education as they age into the education system. As noted, this report does not identify all children with FASD or suspected FASD. It's possible as well, that being involved in CI increases the likelihood of being assessed and referred for diagnosis and so, were the true incidence and prevalence of FASD known, the proportion of those children served by CI at some point may be different.

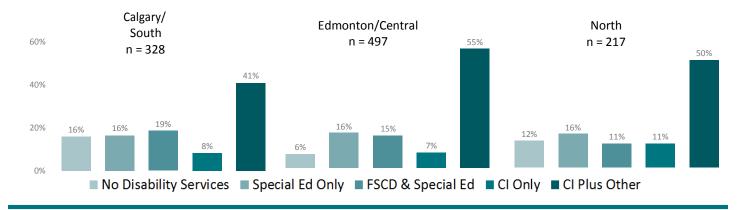
What stands out in this analysis is the vulnerability of more than half of the children (58%) with FASD as evidenced by their need to receive support at some point during the study period from CI. As well nearly half of the children in this group received services from CI and at least one other additional support service such as FSCD and/or special education.

This finding points to the importance of working toward collaborative, integrated service delivery especially for those children with FASD who not only face the challenges of living with a complex diagnosis, but also the challenges that come with complex family environments often affected by addiction, trauma, and instability.

### A CASE FOR COLLABORATIVE PRACTICE ACROSS ALBERTA (Table 5; p. 12):

Across Alberta, the overall pattern of service delivery for provincial supports was **similar such that all regions had between 41% to 55% of children with FASD in the CI Plus Other category**.

Alberta's seven Children's Services and Community and Social Services delivery regions were collapsed into three regions: a) Calgary and South, b) Edmonton and Central, and c) North Central, Northwest, and Northeast. For all analyses involving region, 13 children with FASD\* (~1%) were excluded because their region couldn't be identified.



Percentage of Albertans aged 3 to 12 years in 2005/06 with a diagnostic code for FASD from a health service between 2005/06 and 2010/11 by region and by service delivery category. See Table 5.

\*Children with FASD refers to those children assigned a diagnostic code of FASD for administrative purposes by a health service (see Definitions and Notes, p. 17) between 2005/06 and 2010/11.

### A CASE FOR COLLABORATIVE PRACTICE: CHILDREN WITH FASD

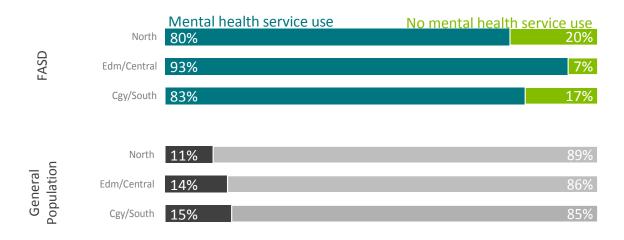
#### COLLABORATIVE PRACTICE TO SUPPORT MENTAL HEALTH (Table 6; p.13):

Research has shown that children exposed to alcohol prenatally often face mental health challenges<sup>9</sup>. To ascertain the extent to which mental health challenges might affect children and youth with FASD in Alberta, use of mental health services over the six years was assessed. See *Definitions and Notes* on p. 16 for details of which diagnostic codes were included to capture mental health services.

In Alberta, a greater percentage of children and youth with FASD\* accessed mental health services compared with the general population of children and youth. Moreover, there were regional differences in mental health service use over six years. Compared to the general population (in grey) most children with FASD (in colour) used mental health services in the six-year study period with the highest proportion in central Alberta and the lowest proportion in northern Alberta.

To support children with FASD across the province, service delivery that is not only collaborative and integrated, but also takes into account the mental health needs of children with FASD is needed.

Percentage of Albertans aged 3 to 12 years in 2005/06 with and without a diagnostic code of FASD from a health service between 2005/06 and 2010/11 **by region and mental health service use** (right panel). See Table 6.



<sup>\*</sup>Children with FASD refers to those children assigned a diagnostic code of FASD for administrative purposes by a health service (see Definitions and Notes, p. 17) between 2005/06 and 2010/11.

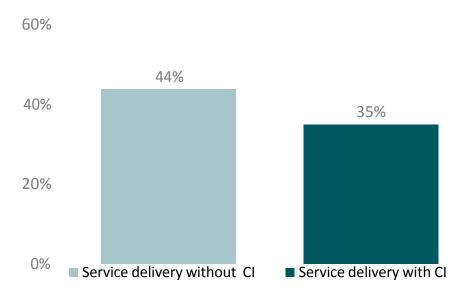
## COLLABORATIVE PRACTICE TO SUPPORT EDUCATION (Table 7; p. 14):

For children aged 3-12 years in 2005/06 with FASD, differences among the service delivery categories emerged in terms of the positive outcome captured by educational achievement at Grade 6. Educational achievement was computed by Alberta Education using age, grade, school type, special education codes, provincial achievement test scores, and home education status (see *Definitions and Notes* on p. 15 for more details).

Of the 1,055 children between 3 and 12 years in 2005/06 with FASD, 536 had data available on their educational achievement at Grade 6. Of those 536 children, 39% were meeting or exceeding educational expectations. For the matching cohort without a known diagnosis of FASD, 86% were meeting or achieving educational expectations at Grade 6.

Because there were too few children to consider the five categories of service delivery separately, the two service delivery categories were combined into those receiving CI (CI Only and CI Plus Other), and those that did not (No Disability/CI Services, Special Ed Only and FSCD & Spec Ed). Of children with FASD\* who were not receiving CI, 44% were meeting or exceeding educational expectations at Grade 6. Of those children with FASD who received services from CI, 35% were meeting or exceeding educational expectations at Grade 6.

These results illustrate the importance of working collaboratively across practice services to ensure that children with FASD are receiving coordinated, integrated supports from both education and other service touchpoints they may encounter such as FSCD or CI.



Percentage of Albertans with a diagnostic code for FASD by a health service, who were **meeting or exceeding educational expectations at Grade 6** by whether CI was part of their service delivery over six years. See Table 7.

\**Children with FASD* refers to those children assigned a diagnostic code of FASD for administrative purposes by a health service (see *Definitions and Notes*, p. 17) between 2005/06 and 2010/11.

#### SUMMARY

One group in particular stands out in this report: Children with FASD who received a complex constellation of services that included CI and other disability services over the six years (CI Plus Other). This group stands out, in part, because almost half of the children identified with FASD between 3 and 12 years old in 2005/06 were in this category of service delivery. This finding shines a light on the immense vulnerability of these children. As a result, these children in particular would **benefit from collaborative and integrative practices**, as well as system navigators, to support their well-being and reap the full benefits of the provincial services and programs they may access over time.

There are some important caveats to this study. In addition to the limitations and considerations on pages 3 and 4, it is important to consider:

- No data for severity of FASD are included in these analyses. As a result, those children in the No Disability/CI Services category may have been less severely affected by FASD and/or may have community-based or natural supports in place from which to draw upon.
- Children receiving support from CI may be assessed and evaluated frequently and thus may receive more health services. As a result, these children could have more opportunities to receive a diagnostic code for FASD over the six years compared to children in the other service delivery categories.
- Data from Alberta's seven FASD Service Networks are not included in this report. Therefore there may have been children who were categorized as receiving No Disability/CI Services who received supports.
- This report does not reveal how children with FASD "move through the system" of provincial disability services and the relation between receiving a diagnosis and subsequent services.
- The regional differences that emerged are almost certainly confounded or augmented by multiple social determinates of health that may intersect with these results in important ways. For example, sex, socio-economic status, First Nations status, newcomer status, gender, mental illness and other comorbidities, as well as access to services may all intersect to create varying influences that contribute to poor or better outcomes.
- The vulnerability and trauma experienced in particular by Indigenous peoples and the subsequent prevalence of FASD in those communities can be traced back to a history of communal and intergenerational trauma<sup>5</sup>. The importance of understanding FASD and services received in those communities is being explored using principles of Ownership, Control, Access and Possession (OCAP<sup>™</sup>) in collaboration with, and with guidance from, the Alberta First Nations Information Governance Centre and communities.

# **INFORMING POLICY**

The results of this report may inform policy by prompting consideration of:

- How might programs and services work collaboratively to create integrated service delivery across programs to improve the wellbeing of children with FASD?
- Is the definition of educational achievement used (p. 15 of *Definitions and Notes*) appropriate for children with FASD or others with other disabilities? Could it be supplemented or augmented by other outcome measures to paint a more robust picture of success?
- Some of the regional differences may look similar but may be the result of different root causes. For example, both northern and southern Alberta had proportionally fewer children with FASD who used mental health services compared to central Alberta. In the case of northern Alberta this may be an issue of access whereas in southern Alberta, this may be the result of other kinds of services and supports offered as alternatives to provincial disability services creating a different profile as compared to central Alberta. Exploring these regional differences may help to tailor and inform services to different regions.

TABLE 2: Number and percentage of individuals with and without FASD aged 3 to 12 years in 2005/06 and by service delivery category across six years.

Number of individuals	Across Six Years
General Population	391,829
Total With FASD	1,055
Total N	392,884
Percentage of individuals	Across Six Years
General Population	99.73
Total With FASD	0.27
Total %	100
Number of individuals with FASD only	Across Six Years
No Disability/CI Services	111
Special Ed Only	178
FSCD & Special Ed	159
CI Only	86
CI Plus Other	521
Total N	1,055
Percent of individuals with FASD only	Across Six Years
No Disability/Cl Services	10.52
Special Ed Only	16.87
FSCD & Special Ed	15.07
CI Only	8.15
CI Plus Other	49.38
Total %	100

Fetal Alcohol Spectrum Disorder (FASD)

Family Support for Children with Disabilities (FSCD) Child Intervention (Cl)

TABLE 3: Number and percentage of individuals with and without FASD based on their age 2005/06 by service delivery category.

Number of individuals	3 to 4 years	5 to 6 years	7 to 8 years	0 to 10 years	11 to 12 years
	72,512	,	,	,	
General Population	,	,	77811	81526	85040
Total With FASD	164	223	213	231	224
Total N	72,676	75,163	78,024	81,757	85,264
Percentage of individuals					
General Population	99.77	99.70	99.73	99.72	99.74
Total With FASD	0.23	0.30	0.27	0.28	0.26
Total %	100	100	100	100	100
Number of individuals with FASD only					
No Disability/CI Services	25	20	18	27	21
Special Ed Only	25	50	36	37	30
FSCD & Special Ed	19	38	38	33	31
CI Only	18	24	18	10	16
CI Plus Other	77	91	103	124	126
Total N	164	223	213	231	224
Percent of individuals with FASD only					
No Disability/CI Services	15.24	8.97	8.45	11.69	9.38
Special Ed Only	15.24	22.42	16.90	16.02	13.39
FSCD & Special Ed	11.59	17.04	17.84	14.29	13.84
CI Only	10.98	10.76	8.45	4.33	7.14
CI Plus Other	46.95	40.81	48.36	53.68	56.25
Total %	100	100	100	100	100

Fetal Alcohol Spectrum Disorder (FASD)

Family Support for Children with Disabilities (FSCD) Child Intervention (CI)

#### TABLE 4: Number and percentage of individuals with and without FASD aged 3 to 12 years in 2005/06 and by service delivery category and by sex across six years.

Number of individuals	Sex	Across Six Years
General Population	Female	190,740
Concruit i opulation	Male	201,089
	Total	391,829
Percentage of individuals	Sex	Across Six Years
General Population	Female	48.68
	Male	51.32
	Total %	100
Number of individuals	Sex	Across Six Years
Total With FASD	Female	404
	Male	651
	Total	1,055
Percentage of individuals	Sex	Across Six Years
Total With FASD	Female	38.29
	Male	61.71
	Total %	100
Number of individuals with FASD only	Sex	Across Six Years
No Disability/Cl Services	Female	55
No Disability/er scritters	Male	56
	Total	111
Special Ed Only	Female	72
· · · · · · · · · · · · · · · · · · ·	Male	106
	Total	178
FSCD & Special Ed	Female	55
	Male	104
	Total	159
CI Only	Female	36
	Male	50
	Total	86
CI Plus Other	Female	186
	Male	335
	Total	521
Descente of individuals with FACD and	6	
Percentage of individuals with FASD only	Sex	Across Six Years
No Disability/CI Services	Female Male	49.55 50.45
	Total %	100
Special Ed Only	Female	40.45
Special Lu Only	Male	59.55
	Total %	100
FSCD & Special Ed	Female	34.59
	Male	65.41
	Total %	100
CI Only	Female	41.86
•	Male	58.14
	Total %	100
CI Plus Other	Female	35.70
	Male	64.30
	Total %	100

Fetal Alcohol Spectrum Disorder (FASD)

Family Support for Children with Disabilities (FSCD)

Child Intervention (CI)

TABLE 5: Number and percentage of individuals with FASD aged 3 to 12 years in 2005/06 by region by service delivery category across six years.

	Service Delivery		
Number of individuals with FASD only by region	Category	Across Six Years	
Calgary/South	No Disability/CI Services	52	
• <i>1</i> .	Special Ed Only	54	
	FSCD & Special Ed	61	
	CI Only	27	
	CI Plus Other	134	
Total <i>n</i> Calgary/South		328	
Edmonton/Central	No Disability/Cl Services	32	
	Special Ed Only	81	
	FSCD & Special Ed	74	
	CI Only	35	
	CI Plus Other	275	
Total n Edmonton/Central		497	
North	No Disability/Cl Services	27	
	Special Ed Only	34	
	FSCD & Special Ed	24	
	CI Only	24	
	CI Plus Other	108	
Total n North		217	
Percent of individuals with FASD only by region	Service Delivery		
Percent of individuals with FASD only by region	Category	Across Six Years	
Percent of individuals with FASD only by region Calgary/South	Category No Disability/CI Services	15.85	
	Category No Disability/Cl Services Special Ed Only	15.85 16.46	
	Category No Disability/Cl Services Special Ed Only FSCD & Special Ed	15.85 16.46 18.60	
	Category No Disability/Cl Services Special Ed Only FSCD & Special Ed Cl Only	15.85 16.46 18.60 8.23	
Calgary/South	Category No Disability/Cl Services Special Ed Only FSCD & Special Ed	15.85 16.46 18.60 8.23 40.85	
Calgary/South Total n Calgary/South	Category No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only CI Plus Other	15.85 16.46 18.60 8.23 40.85 100	
Calgary/South	Category No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only CI Plus Other No Disability/CI Services	15.85 16.46 18.60 8.23 40.85 100 6.44	
Calgary/South Total n Calgary/South	Category No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only CI Plus Other No Disability/CI Services Special Ed Only	15.85 16.46 18.60 8.23 40.85 100 6.44 16.30	
Calgary/South Total n Calgary/South	Category No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only CI Plus Other No Disability/CI Services Special Ed Only FSCD & Special Ed	15.85 16.46 18.60 8.23 40.85 100 6.44 16.30 14.89	
Calgary/South Total n Calgary/South	Category No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only CI Plus Other No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only	15.85 16.46 18.60 8.23 40.85 100 6.44 16.30 14.89 7.04	
Calgary/South Total n Calgary/South Edmonton/Central	Category No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only CI Plus Other No Disability/CI Services Special Ed Only FSCD & Special Ed	15.85 16.46 18.60 8.23 40.85 100 6.44 16.30 14.89 7.04 55.33	
Calgary/South Total n Calgary/South Edmonton/Central Total n Edmonton/Central	Category No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only CI Plus Other No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only CI Plus Other	15.85 16.46 18.60 8.23 40.85 100 6.44 16.30 14.89 7.04 55.33 100	
Calgary/South Total n Calgary/South Edmonton/Central	Category No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only CI Plus Other No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only CI Plus Other No Disability/CI Services	15.85 16.46 18.60 8.23 40.85 100 6.44 16.30 14.30 14.30 14.30 55.33 100 12.44	
Calgary/South Total n Calgary/South Edmonton/Central Total n Edmonton/Central	Category No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only CI Plus Other No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only CI Plus Other No Disability/CI Services Special Ed Only	15.85 16.46 18.60 8.23 40.85 100 6.44 16.30 14.89 7.04 55.33 100 12.44 15.67	
Calgary/South Total n Calgary/South Edmonton/Central Total n Edmonton/Central	Category No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only CI Plus Other No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only CI Plus Other No Disability/CI Services Special Ed Only FSCD & Special Ed	15.85 16.46 18.60 8.23 40.85 100 6.44 16.30 14.89 7.04 55.33 100 12.44	
Calgary/South Total n Calgary/South Edmonton/Central Total n Edmonton/Central	Category No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only CI Plus Other No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only CI Plus Other No Disability/CI Services Special Ed Only	15.85 16.46 18.60 8.23 40.85 100 6.44 16.30 14.89 7.04 55.33 100 12.44 15.67 11.06	
Calgary/South Total n Calgary/South Edmonton/Central Total n Edmonton/Central	Category No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only CI Plus Other No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only CI Plus Other No Disability/CI Services Special Ed Only FSCD & Special Ed CI Only	15.85 16.46 18.60 8.23 40.85 100 6.44 16.30 14.89 7.04 55.33 100 12.44 15.67 11.06 11.06	

Fetal Alcohol Spectrum Disorder (FASD)

Family Support for Children with Disabilities (FSCD)

Child Intervention (CI)

TABLE 6: Number and percentage of individuals with and without FASD aged 3 to 12 years in 2005/06 by region who ever used mental health services between 2005/06 and 2010/11.

Number of individuals with FASD	Region	Across Six Years
Mental health service use	Calgary/South	273
	Edmonton/Central	463
	North	173
	Total	909
No mental health service use	Calgary/South	55
	Edmonton/Central	34
	North	44
	Total	133
Total Population with FASD	Calgary/South	328
· · ·	Edmonton/Central	497
	North	217
	Total	1,042
Percent of individuals with FASD	Region	Across Six Years
Mental health service use	Calgary/South	83.23
	Edmonton/Central	93.16
	North	79.72
Number of individuals General Population		79.72 Across Six Years
Number of individuals General Population Mental health service use	North Region Calgary/South	
	Region	Across Six Years
	Region Calgary/South	Across Six Years 25,581
	Region Calgary/South Edmonton/Central	Across Six Years 25,581 23,924
	Region Calgary/South Edmonton/Central North	Across Six Years 25,581 23,924 6,356
Mental health service use	Region Calgary/South Edmonton/Central North Total	Across Six Years 25,581 23,924 6,356 <b>55,861</b>
Mental health service use	Region Calgary/South Edmonton/Central North Total Calgary/South	Across Six Years 25,581 23,924 6,356 55,861 141,265
Mental health service use	Region Calgary/South Edmonton/Central North Total Calgary/South Edmonton/Central	Across Six Years 25,581 23,924 6,356 55,861 141,265 142,383
Mental health service use	Region Calgary/South Edmonton/Central North Total Calgary/South Edmonton/Central North	Across Six Years 25,581 23,924 6,356 55,861 141,265 142,383 51,152
Mental health service use	Region Calgary/South Edmonton/Central North Total Calgary/South Edmonton/Central North Total	Across Six Years 25,581 23,924 6,356 55,861 141,265 142,383 51,152 334,800
Mental health service use	Region Calgary/South Edmonton/Central North Total Calgary/South Edmonton/Central North Total Calgary/South	Across Six Years 25,581 23,924 6,356 55,861 141,265 142,383 51,152 334,800 166,846
Mental health service use	Region Calgary/South Edmonton/Central North Total Calgary/South Edmonton/Central North Total Calgary/South Edmonton/Central	Across Six Years 25,581 23,924 6,356 55,861 141,265 142,383 51,152 334,800 166,846 166,307
Mental health service use No mental health service use Total General Population	Region Calgary/South Edmonton/Central North Total Calgary/South Edmonton/Central North Total Calgary/South Edmonton/Central North	Across Six Years 25,581 23,924 6,356 55,861 141,265 142,383 51,152 334,800 166,846 166,307 57,508 390,661
Mental health service use No mental health service use Total General Population Percent of individuals General Population	Region Calgary/South Edmonton/Central North Total Calgary/South Edmonton/Central North Total Calgary/South Edmonton/Central North Total Region	Across Six Years 25,581 23,924 6,356 55,861 141,265 142,383 51,152 334,800 166,846 166,846 166,307 57,508 390,661 Across Six Years
Mental health service use No mental health service use Total General Population	Region Calgary/South Edmonton/Central North Total Calgary/South Edmonton/Central North Total Calgary/South Edmonton/Central North	Across Six Years 25,581 23,924 6,356 55,861 141,265 142,383 51,152 334,800 166,846 166,307 57,508 390,661

Fetal Alcohol Spectrum Disorder (FASD)

TABLE 7: Number and percentage of individuals with FASD aged 3 to 12 years in 2005/06 who were meeting or exceeding educational expectations at Grade 6 by whether their service delivery included CI.

Number of individuals with FASD only	Meeting or Exceeding		Across Six Years
	Expectations at Grade 6	Yes	
Service Delivery with Cl		Tes	109
		No	203
		Total	312
Service Delivery without Cl		Yes	98
		No	126
		Total	224
Percent of individuals with FASD only	Meeting or Exceeding	A	Across Six
Fercent of individuals with FASD only	Expectations at Grade 6	Y	'ears
Service Delivery with Cl		Yes	34.94
		No	65.06
		Total	100
Service Delivery without Cl		Yes	43.75
		No	56.25
		Total	100

Fetal Alcohol Spectrum Disorder (FASD)

Child Intervention (CI)

## **DEFINITIONS AND NOTES**

- Age, sex, and postal code (translated into Statistics Canada dissemination areas) were provided for each individual by each participating program. In the case of discrepancies between programs, the most common value for an indicator was chosen. In the event of two or more most common values, the value for the indicator was chosen randomly from the most common values.
- Child Intervention services are focused on meeting the safety and well-being of children and helping families and communities to meet these needs. The Child Intervention Program provides services to children and youth between the ages of 0 and 17 years who are or may be at risk of being abused, neglected or otherwise in need of intervention. As well, young adults (18-22 years of age) may also be eligible for post-intervention supports through the use of Support and Financial Assistance Agreements to help them transition to adulthood.
- Children's Services (CS) and Community and Social Services (CSS) service delivery regions were used for regional analyses. Dissemination areas from the 2006 Statistics Canada Census were used to determine region. Those with missing dissemination areas are excluded from analyses. There are seven regions (Northwest, Northeast, North Central, Edmonton, Central, Calgary, South); the boundaries for these regions are shown on the map. In this report, the Northwest, Northeast and North Central regions were combined into "North", the Edmonton and Central regions were combined into "Edmonton/Central", and the Calgary and South regions were combined into "Calgary/South".
- Cross-ministry analyses included only study participants who were linked across the relevant programs. This means that not all participants in the project were represented in every analysis. As well, only participants with a value for a given indicator were included in analyses involving that indicator (i.e., missing values were excluded).



- Educational achievement was computed by Alberta Education using age, grade, school type, special education codes, provincial achievement test scores, and home education status. Educational achievement was categorized as above, meeting, or below expectations for a student's age and grade.
- Fetal Alcohol Spectrum Disorders (FASD) were defined based on whether an individual was assigned a diagnostic code of: a) fetal alcohol spectrum (FAS) (ICD 10-CA Q86.0) or b) being a newborn affected by maternal use of alcohol (ICD 10-CA P04.3), for administrative purposes by a health service (emergency department, outpatient clinic visit, or a hospitalization) at any point between 2005/06 and 2010/11.

#### **DEFINITIONS AND NOTES** (continued)

- The Family Support for Children with Disabilities (FSCD) program provides a wide range of child- and familycentered supports and services to children and youth (aged 0 to 17 years) with a disability.
- Mental health service use was defined by the presence or absence of mental health diagnosis codes (Two or more ICD-9: 290-309.9, 311-314.9, 316, or a single ICD-10CA: F00-F06.9, F09-F69, F84-F99, G31.2, G44.2, R41.0) in Alberta Health and Wellness' databases (Inpatient—Discharge Abstract Database, Ambulatory Care, and Practitioner Payments), or in the Family Support for Children with Disabilities (FSCD) or the Assured Income for the Severely Handicapped (AISH) information systems. Only Albertans who were registered with the Alberta Health Care Insurance Plan for the full fiscal year or who had a mental health service with FSCD or AISH were included. Mental health service use is a proxy for presence of a mental health condition; some youth with mental health conditions may not have accessed mental health services in Alberta during the year, and some mental health service use may have occurred for youth who did not in fact have mental health conditions.
- **Study population:** The study CYDL Longitudinal Project included individuals with a date of birth between April 1, 1980 and March 31, 2011 and who were registered in the Alberta Health Care Insurance Plan (AHCIP) full-time for at least one year between April 1, 2005 and March 31, 2011. The youngest study participants were those born in the last study year. The oldest study participants were 25 years old at the end of the first study year and consequently 30 years old at the end of the last study year.

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# A CASE FOR COLLABORATIVE PRACTICE: CHILDREN WITH FASD

NOTES

# THE CHILD AND YOUTH DATA LABORATORY

**The Child and Youth Data Laboratory's** (CYDL's) Longitudinal Project (*Experiences of Albertan Children and Youth over Time, 2005/06 to 2010/11*) is a joint initiative between PolicyWise for Children & Families and participating ministries in the Government of Alberta. The mandate of the CYDL is to link and analyse administrative data from Government ministries, to provide evidence for policy and program development.

The CYDL is managed by **PolicyWise for Children & Families**. PolicyWise is a not-for-profit organization whose mission is to develop and integrate evidence to inform, identify and promote effective public policy and service delivery to improve the well-being of children, families and communities in Alberta, Canada and internationally.

### THIS PROJECT

**The CYDL Longitudinal Project,** focuses on understanding the experiences of Albertan children and youth as they develop. The focus is service use within and across ministries, as it is related to key indicators and to the passage of time. Studying experiences over several years of development adds a valuable level of richness to an already ground-breaking initiative, providing detailed insight into the factors that help to shape our children and youth as they develop.

### SUGGESTED CITATION

Child and Youth Data Laboratory (2018). A case for collaborative practice: a longitudinal look at provincial disability services and outcomes for children (3 to 12 years) with Fetal Alcohol Spectrum Disorders in Alberta over six years. Edmonton: PolicyWise for Children & Families.

#### **OUR PARTNERS**

This project was carried out on behalf of six ministries of the Government of Alberta. Each ministry collaborated extensively with the CYDL on this project, and their dedication to the project is gratefully acknowledged:

Children's Services Community and Social Services Advanced Education Health Education Justice and Solicitor General

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This study is based in part on data provided by the Government of Alberta. The interpretation and conclusions contained herein are those of the researchers and do not necessarily represent the views of the Government of Alberta. The Government of Alberta does not express any opinion in relation to this study.

