A profile of young Albertans with Fetal Alcohol Spectrum Disorder

Child and Youth Data Laboratory (CYDL)

Key findings

This report is an overview of the experiences of young Albertans (0 to 25 years) with Fetal Alcohol Spectrum Disorder (FASD) from 2005/06 to 2010/11.

- 3,025 individuals were identified as having FASD. Most were diagnosed in the health system during the study; others were diagnosed and were clients of Family Support for Children with Disabilities.
- Just under 0.1% of young Albertans had an FASD diagnosis in any given study year. Over six years, a total of 0.2% individuals were diagnosed.
- The proportion of individuals who were male or First Nations was higher among individuals who received an FASD diagnosis than the rest of the population.
- A higher proportion of young Albertans living in the Northwest and North Central regions had FASD than in other Alberta regions.
- Although individuals with FASD lived in a range of socioeconomic status neighbourhoods, they were overrepresented in the lowest socio-economic areas.
- Almost 40% of individuals with FASD were meeting or exceeding educational expectations, compared to 80% of those without an FASD diagnosis.
- Individuals with FASD had higher proportions of high service use, diagnoses of asthma or diabetes, mental health conditions, and high-cost health service use.
- Disability support services (Family Support for Children with Disabilities, Special Education, Assured Income for the Severely Handicapped, and Persons with Developmental Disabilities) were accessed by individuals with FASD proportionally more than those without an FASD diagnosis.
- Other services with a higher percentage use by individuals with FASD were Child Intervention, Income Support and Justice system involvement.
- 10% of individuals with FASD were enrolled in postsecondary education at some point in the study period compared to 34% of those without an FASD diagnosis.

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.



Contents

Key findings and Context	1 to 2
Data analyses	.3 to 10
Tables	11 to 25
Definitions and Notes	25 to 27
Data sources	28
References	29
About CYDL	30

Report context

- The CYDL's innovative data linkage process has revealed new information about Albertans with FASD.
- This report is one of a set of profiles completed by the CYDL as part of the Longitudinal project. See *The project* (p. 2) for a description.
- A larger FASD report, coming out in the next year, will further clarify the relationships shown in this profile.
- The number of individuals with FASD (3,025) is substantially lower than those with no FASD (1,592,906), so consider numbers for context.

Context

Fetal Alcohol Spectrum Disorder (FASD) is a complex and preventable disorder caused by alcohol exposure during pregnancy. It is a lifelong disorder and has consequences throughout the lifespan. To be diagnosed with FASD, a patient must be severely impaired on at least three of eleven specified domains of functioning and there must be evidence of perinatal alcohol exposure. There is no common pattern of impairments across the domains amongst individuals with FASD. This means individuals with FASD have a wide range of impairments, requiring the use of different types of supports.

The FASD Service Networks in Alberta provide a range of supports and interventions including youth transition programs, workshops for individuals with FASD and their caregivers, employment supports, support groups, housing, and more (http://fasd.alberta.ca/). Diagnosis and other information from the 12 networks is submitted to, and stored in, a central location, the Online Reporting System (ORS). Some diagnoses also occur in the health system and are required in order to receive certain FASD services such as those provided by Family Support for Children with Disabilities. The FASD 10-year strategy started in 2007/08. Since then, there has been an increase in the number of diagnostic clinics, prevention services, and supports for individuals and caregivers. Linkage to Online Reporting System and other FASD-specific services would provide a better estimate of the true prevalence of FASD in Alberta.

The prevalence of FASD in Canada has been estimated to be 1%³. Males are diagnosed with FASD more often than females.² Indigenous children and youth are also overrepresented among FASD clients.⁴ This is often attributed to histories of trauma increasing the risk of alcohol misuse during pregnancy.⁴

Individuals with FASD are known to be over-represented in child intervention systems and in the justice system.^{5,6} Poor impulse control and challenging family environments are likely factors.⁶ Some health problems, such as asthma and mental health conditions, are more prevalent among individuals with FASD than the rest of the population.^{7,8}

A comprehensive picture of the sociodemographic characteristics and experiences of individuals with FASD is currently lacking. This report demonstrates the vitality of individual-level linkage of population data. The use of all available datasets would further enrich our understanding of this vulnerable population.

The project

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.

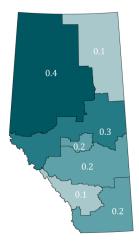
Ninety-five percent confidence intervals were calculated to enable comparison of statistical differences between groups. The Cochran-Armitage trend test was used to test trends over time. Only effects that apply to a meaningful proportion of the population were noted in the text. See https://visualization.policywise.com/P2dashboard/FASDProfileStat.xlsx

Number breakdown (Table 1; p.11)

All analyses in this report consider Albertans (aged 0 to 25 years in each study year, unless otherwise specified) who were registered with Alberta Health or had a Family Support for Children with Disabilities (FSCD) service between 2005/06 to 2010/11. See *Definitions and Notes* (p. 27).

- There were 3,025 unique individuals aged 0 to 25 receiving services for FASD across the six study years.
- FASD diagnoses were determined from diagnostic codes from emergency department visits (535), other ambulatory care visits (1,186), and hospitalizations (1,074), as well as FSCD service use (882). Some individuals with FASD received a diagnosis from the health system and had an FASD-related service from FSCD.
- Time trends refer to the indicator, which can change over years, but "FASD" is considered if a service was received for FASD at any point in the study. Some individuals with "no FASD" in our study will have received a diagnosis prior to the study or had not been diagnosed. See *Definition and Notes* (p. 26).
- Refer to tables (p. 11 to 24) for sample sizes, which vary across FASD diagnosis and analyses.

Percentage of Albertans aged 0 to 25 with FASD by CS/CSS service delivery regions



CS/CSS service delivery regions - 2005/06 to 2010/11 combined (Table 2; p. 12)

Regions include Children's Services (CS) and Community and Social Services (CSS) service delivery regions. For information on regional analyses and a legend, see *Definitions and Notes* (p. 25).

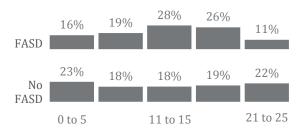
- The Northwest and North Central regions had the highest proportions of individuals receiving services for FASD in most study years.
- The lowest proportions were found in the Northeast and Calgary regions of Alberta.
- Both the underlying prevalence and availability of diagnostic services impact regional proportions.

Gender- 2005/06 to 2010/11 combined (Table 3; p. 13)

 The proportion of males was higher among individuals diagnosed with FASD (58%), in comparison to those with no diagnosis (51%). Percentage of Albertans aged 0 to 25 by gender



Percentage of young Albertans by age group in 2010/11



Age in 2010/11 (Table 4; p. 14)

Age is shown in a single year (2010/11). The age distribution varied by year (see Table 4 for age distribution in each study year).

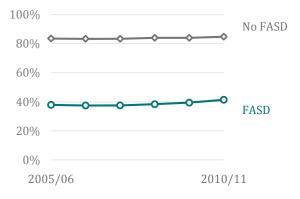
 Individuals diagnosed with FASD were most often between 11 and 20 years of age in 2010/11, but services occurred across the entire age range.

Educational achievement by study year (Table 5; p. 15)

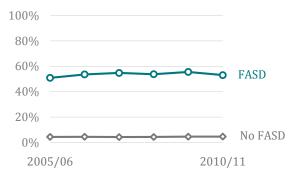
This analysis considers individuals in grades 3 to 12 who were registered in the Alberta education system. See *Definitions and Notes* (p. 26).

- 38 to 41% of individuals diagnosed with FASD were meeting or exceeding educational expectations within a given study year.
- The proportion of individuals with no FASD diagnosis meeting educational expectations was twice as high (83 to 85% per year).

Percentage of Albertans in grades 3 to 12 meeting or exceeding educational expectations over time



Percentage of Albertans aged 0 to 25 with high service use over time



High service use by study year (Table 6; p. 15)

High service users were defined as receiving two or more select government services. See *Definitions* and *Notes* (p. 26).

- Just over half of individuals with FASD were high service users within each study year (51 to 56% per year), compared to 4 to 5% (per year) of those without an FASD diagnosis.
- 78% of young Albertans diagnosed with FASD were high service users at some point in the study period, compared to 11% of those without an FASD diagnosis.

Asthma- 2005/06 to 2010/11 combined (Table 7; p. 16)

Asthma was defined using diagnostic codes from health services. See *Definitions and Notes* (p. 25).

 The proportion of individuals with an FASD diagnosis who had asthma services during the study was twice that of those with no FASD diagnosis. Percentage of Albertans aged 0 to 25 with asthma



Diabetes- 2005/06 to 2010/11 combined (Table 7; p. 16)

Percentage of Albertans aged 0 to 25 with diabetes



Diabetes was defined using diagnostic codes from health services. See *Definitions and Notes* (p. 25).

- Diabetes was rare among young Albertans.
- The percentage of individuals with diabetes was twice as high among individuals diagnosed with FASD than those without an FASD diagnosis.

Cancer- 2005/06 to 2010/11 combined (Table 7; p. 16)

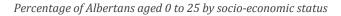
Cancer was defined using diagnostic codes from health services. See *Definitions and Notes* (p. 25).

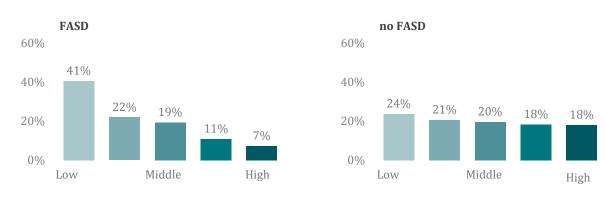
- Fewer than 2% of young Albertans had a cancer service between 2005/06 and 2010/11.
- There was little difference in cancer percentages between those with or without an FASD diagnosis.

Percentage of Albertans aged 0 to 25 with cancer



Socio-economic status- 2005/06 to 2010/11 combined (Table 8; p. 17)

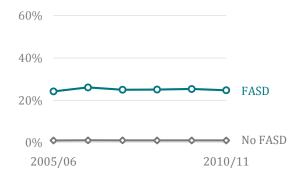




Socio-economic status captures the social and material environments in which individuals live. See *Definitions and Notes* (p. 27).

- Individuals with FASD lived in neighbourhoods in every socio-economic quintile but were disproportionately overrepresented in the lowest and underrepresented in the highest socio-economic neighbourhoods, compared to those with no FASD diagnosis.
- Socio-economic status was relatively evenly distributed across individuals with no FASD diagnosis.
- This effect was stable across study years.

Percentage of Albertans aged 0 to 17 accessing Family Support for Children with Disabilities (FSCD) services over time



Family Support for Children with Disabilities (FSCD) by study year (Table 9; p. 18)

This analysis considers Albertans (aged 0 to 17 years in any given study year) who received FSCD services. See *Definitions and Notes* (p. 26).

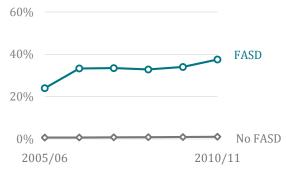
- 24 to 26% of individuals with FASD accessed FSCD services each study year, compared to 1% of those without an FASD diagnosis.
- 37% of age-eligible individuals with FASD received FSCD services at some point across the entire study period. FSCD services are often received across multiple years.

Assured Income for the Severely Handicapped (AISH) by study year (Table 10; p. 18)

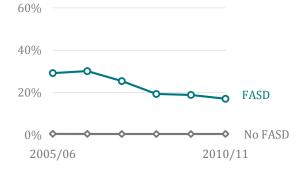
This analysis considers Albertans (aged 18 to 25 years) receiving AISH services. See *Definitions and Notes* (p. 25).

- A substantially higher proportion of individuals with FASD accessed AISH services than those without FASD.
- The proportion of individuals receiving AISH supports doubled across the study period regardless of FASD diagnostic status.
- 42% of individuals with FASD received AISH services at some point in the study period.

Percentage of Albertans aged 18 to 25 accessing Assured Income for the Severely Handicapped (AISH) services over time



Percentage of Albertans aged 18 to 25 accessing Persons with Developmental Disabilities (PDD) services over time



Persons with Developmental Disabilities (PDD) by study year (Table 11; p. 19)

This analysis considers Albertans (aged 18 to 25 years) receiving PDD services. See *Definitions and Notes* (p. 27).

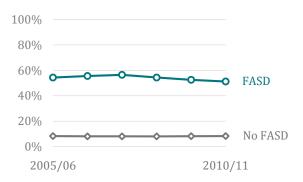
- Between 17 and 30% of individuals with FASD received PDD services per year, compared to 0.4 to 0.5% of those with no FASD diagnosis.
- A higher number of individuals with FASD received PDD supports in each year but the proportion of those not receiving services increased more. This is at least partially due to program eligibility.

Students with special needs by study year (Table 12; p. 19)

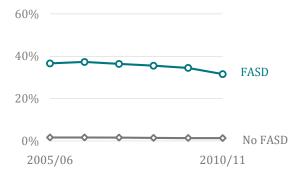
This analysis considers young Albertans (aged 2.5 to 19 years) who received a special education code. See *Definitions and Notes* (p. 27).

- 51 to 56% of individuals with FASD had been students with special needs in each study year, compared to 8% of individuals without FASD.
- 69% of students with FASD had special needs at some point across the six study years, compared to 13% of individuals with no FASD diagnosis.

Percentage of Albertan students aged 2.5 to 19 with special needs over time



Percentage of Albertans aged 0 to 22 accessing Child Intervention services over time



Child Intervention by study year (Table 13; p. 20)

This analysis considers Albertans (aged 0 to 22 years) receiving Child Intervention services. See *Definitions and Notes* (p. 25)

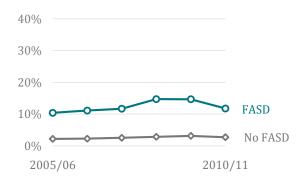
- Child Intervention services were accessed more by those with FASD (32 to 37% per year) than those with no diagnosis (1 to 2% per year).
- The proportion of those with and those without FASD in Child Intervention decreased slightly over time.
- 48% of individuals with FASD accessed Child Intervention services at some point across the six study years, compared to 3% of those without FASD.

Income support by study year (Table 14; p. 20)

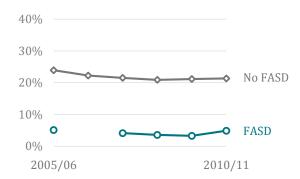
This analysis considers Albertans (aged 18 to 25 years) who received income support. See *Definitions and Notes* (p. 26).

- A higher percentage of young adults with FASD accessed income support (10 to 15% per year) than those without FASD (2 to 3% per year).
- 22% of those with FASD were on income support at some point in the study period, compared to 5% of those with no FASD.

Percentage of Albertans aged 18 to 25 accessing income support services over time



Percentage of Albertans aged 17 to 25 enrolled in post-secondary over time



Post-secondary enrolment by study year (Table 15; p. 21)

This analysis considers Albertans (aged 17 to 25 years) enrolled in post-secondary. See *Definitions and Notes* (p. 27).

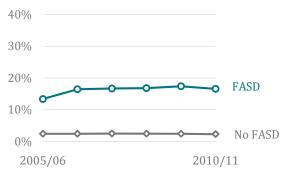
- 3 to 5% of individuals with FASD were enrolled in post-secondary per year, compared to 21 to 24% of those without FASD.
- 2007/08 was suppressed for individuals with FASD due to low sample size.
- 10% of young adults with FASD were enrolled at some point during the study, compared to 34% of those with no FASD diagnosis.

Criminal offences by study year (Table 16; p. 21)

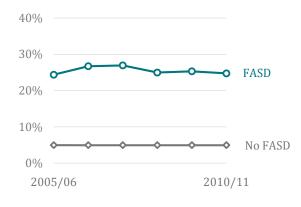
This analysis considers Albertans (aged 12 to 25 years) with criminal offences. See *Definitions and Notes* (p. 25).

- The proportion of individuals with FASD with criminal offences (13 to 17% per year) was higher than those with no FASD (2% per year).
- 31% of young Albertans with FASD had an offence at some point across the six study years, compared to 7% of those with no FASD diagnosis.

Percentage of Albertans aged 12 to 25 with criminal offences over time



Percentage of Albertans aged 0 to 25 with high cost health use over time



High cost health use by study year (Table 17; p. 22)

Albertans within the top 5% of health care costs per year were defined as high cost health users. See *Definitions and Notes* (p. 26).

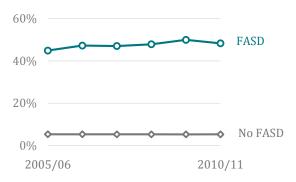
- Individuals with FASD had higher percentages of high cost health use (24 to 27% per year) than the rest of the population (5% per year), in a given study year.
- 64% of individuals with FASD had high cost health use at some point across the six study years, compared to 17% of individuals with no FASD diagnosis.

Mental health service by study year (Table 18; p. 22)

Mental health conditions are defined as receipt of services related to mental health conditions; that is, receipt of services is used here as a proxy for confirmed presence of a mental health condition. See *Definitions and Notes* (p. 26).

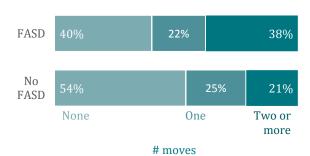
- 45 to 50% of Albertans with FASD had a mental health condition in a study year compared to 5% (per year) of those with no FASD.
- 74% of individuals with FASD had a mental health condition at some point across the six study years, compared to 14% of those with no FASD diagnosis.

Percentage of Albertans aged 0 to 25 with a mental health condition over time



Residential mobility (Table 19; p. 23)

Percentage of Albertans aged 0 to 25 by number of moves



Residential mobility was determined using number of unique postal codes in the Alberta Health registry. See *Definitions and Notes* (p. 27).

- FASD clients moved more often than the rest of the population.
- 38% of those with FASD had two or more moves across the six study years compared to 21% of those with no FASD diagnosis.

First Nations, treaty status- 2005/06 to 2010/11 combined (Table 20; p. 24)

This analysis considers young Albertans (aged 0 to 30 years). First Nations status was not available from Family Support for Children with Disabilities (FSCD), so those with an FASD service in FSCD only were excluded from this analysis. See *Definitions* and *Notes* (p. 26).

• Proportionally, more individuals who received an FASD diagnosis were First Nations (39%) than those with no FASD diagnosis (6%).

Percentage of Albertans aged 0 to 25 by First Nations status



 $\label{thm:continuous} \begin{tabular}{ll} \textbf{Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by source of diagnosis and study year, Albertans aged 0 to 25 years* \end{tabular}$

Study Year

FASD source	2006	2007	2008	2009	2010	2011	All years
Number							
Individuals with FASD- emergency room	81	97	93	103	120	128	535
Individuals with FASD- other ambulatory care	291	270	341	294	289	223	1,186
Individuals with FASD- hospitalization	219	185	195	198	216	211	1,074
Individuals with FASD- any health service	557	518	591	553	571	500	2,421
Individuals with FASD- FSCD service	463	501	487	488	481	449	882
Total number of individuals with FASD*	967	960	1,020	994	1,003	911	3,025
Individuals with no FASD	1,121,607	1,140,730	1,170,079	1,198,037	1,229,867	1,248,569	1,592,906
Total number	1,122,574	1,141,690	1,171,099	1,199,031	1,230,870	1,249,480	1,595,931
Percent of individuals with FASD							
Individuals with FASD- emergency room	8.38	10.10	9.12	10.36	11.96	14.05	17.69
Individuals with FASD- other ambulatory care	30.09	28.13	33.43	29.58	28.81	24.48	39.21
Individuals with FASD- hospitalization	22.65	19.27	19.12	19.92	21.54	23.16	35.50
Individuals with FASD- any health service	57.60	53.96	57.94	55.63	56.93	54.88	80.03
Individuals with FASD- FSCD service	47.88	52.19	47.75	49.09	47.96	49.29	29.16
Percent of entire study population							
Individuals with FASD	0.09	0.08	0.09	0.08	0.08	0.07	0.19

 $Year\ represents\ fiscal\ year\ and\ "All\ years\ combined"\ refers\ to\ service\ use\ in\ 2005/06\ to\ 2010/11\ in\ all\ tables, See\ Definitions\ and\ Notes\ (p.25).$

Family Support for Children with Disabilities (FSCD)

 $^{{\}it *Individuals could have received a diagnosis or FASD service from more than one source.}$

Tables

TABLE 2 Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by CS/CSS service delivery regions and study year, Albertans aged 0 to 25 years

		Study Year						
	CS/CSS service delivery regions	2006	2007	2008	2009	2010	2011	All years
Number of individuals with FASD	Calgary	643	673	679	677	697	705	758
	Central	337	358	364	348	346	341	374
	Edmonton	771	808	830	857	899	896	925
	North Central	249	250	240	242	238	232	258
	Northeast	31	33	33	32	32	35	40
	Northwest	261	290	307	305	309	311	358
	South	247	264	274	302	285	285	312
Number of individuals with no FASD	Calgary	405,641	424,997	435,979	446,684	453,983	449,009	566,896
	Central	146,834	152,235	154,660	155,946	156,394	154,077	192,157
	Edmonton	356,308	371,479	378,092	385,777	391,273	386,396	484,814
	North Central	68,739	70,276	71,225	71,746	71,740	70,858	88,491
	Northeast	20,910	22,253	23,566	24,735	26,012	25,383	33,222
	Northwest	74,413	77,400	78,587	79,305	79,622	78,709	98,848
	South	96,223	99,468	101,357	102,486	103,919	102,619	127,788
Total number	Calgary	406,284	425,670	436,658	447,361	454,680	449,714	567,654
	Central	147,171	152,593	155,024	156,294	156,740	154,418	192,531
	Edmonton	357,079	372,287	378,922	386,634	392,172	387,292	485,739
	North Central	68,988	70,526	71,465	71,988	71,978	71,090	88,749
	Northeast	20,941	22,286	23,599	24,767	26,044	25,418	33,262
	Northwest	74,674	77,690	78,894	79,610	79,931	79,020	99,206
	South	96,470	99,732	101,631	102,788	104,204	102,904	128,100
Percent of entire study population	Calgary	0.16	0.16	0.16	0.15	0.15	0.16	0.13
	Central	0.23	0.23	0.23	0.22	0.22	0.22	0.19
	Edmonton	0.22	0.22	0.22	0.22	0.23	0.23	0.19
	North Central	0.36	0.35	0.34	0.34	0.33	0.33	0.29
	Northeast	0.15	0.15	0.14	0.13	0.12	0.14	0.12
	Northwest	0.35	0.37	0.39	0.38	0.39	0.39	0.36
Children's Consises (CC) and Community of	South	0.26	0.26	0.27	0.29	0.27	0.28	0.24

Children's Services (CS) and Community and Social Services (CSS) service delivery regions.

TABLE 3

Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by gender, Albertans aged 0 to 25 years $\,$

	Gender	All years
Number of individuals with FASD	Female	1,257
	Male	1,768
	Total	3,025
Number of individuals with no FASD	Female	781,960
	Male	810,946
	Total	1,592,906
Percent of individuals with FASD	Female	41.55
	Male	58.45
Percent of individuals with no FASD	Female	49.09
	Male	50.91

TABLE 4

Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by age group and study year, Albertans aged 0 to 25 years $\,$

				Study	Year		
	Age group	2006	2007	2008	2009	2010	2011
Number of individuals with FASD	0 to 5	697	651	599	553	500	481
	6 to 10	817	789	737	681	639	557
	11 to 15	753	791	822	845	836	817
	16 to 20	323	405	507	585	682	753
	21 to 25	94	142	167	215	265	323
	Total	2,684	2,778	2,832	2,879	2,922	2,931
Number of individuals with no FASD	0 to 5	285,194	292,233	300,128	306,404	309,724	312,141
	6 to 10	237,876	234,229	232,014	232,062	233,106	234,906
	11 to 15	255,043	251,247	247,316	243,510	241,111	237,876
	16 to 20	288,354	278,938	271,168	265,623	260,321	255,043
	21 to 25	264,586	282,886	294,036	296,793	293,933	288,354
	Total	1,331,053	1,339,533	1,344,662	1,344,392	1,338,195	1,328,320
Percent of individuals with FASD	0 to 5	25.97	23.43	21.15	19.21	17.11	16.41
	6 to 10	30.44	28.40	26.02	23.65	21.87	19.00
	11 to 15	28.06	28.47	29.03	29.35	28.61	27.87
	16 to 20	12.03	14.58	17.90	20.32	23.34	25.69
	21 to 25	3.50	5.11	5.90	7.47	9.07	11.02
Percent of individuals with no FASD	0 to 5	21.43	21.82	22.32	22.79	23.14	23.50
	6 to 10	17.87	17.49	17.25	17.26	17.42	17.68
	11 to 15	19.16	18.76	18.39	18.11	18.02	17.91

21.66

19.88

20.82

21.12

20.17

21.87

19.76

22.08

19.45

21.96

19.20

21.71

16 to 20

21 to 25

TABLE 5 Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by educational achievement and study year, Albertans in grades 3 to 12

		Study Year							
	Educational Achievement	2006	2007	2008	2009	2010	2011	All years	
Number of individuals with FASD	Below expectations	702	745	777	793	783	738	1,122	
	Meeting or above expectations	429	447	467	494	510	522	695	
	Total	1,131	1,192	1,244	1,287	1,293	1,260	1,817	
Number of individuals with no FASD	Below expectations	60,373	61,912	61,912	59,933	60,923	57,877	102,635	
	Meeting or above expectations	307,655	310,281	311,336	316,249	321,430	323,730	497,544	
	Total	368,028	372,193	373,248	376,182	382,353	381,607	600,179	
Percent of individuals with FASD	Below expectations	62.07	62.50	62.46	61.62	60.56	58.57	61.75	
	Meeting or above expectations	37.93	37.50	37.54	38.38	39.44	41.43	38.25	
Percent of individuals with no FASD	Below expectations	16.40	16.63	16.59	15.93	15.93	15.17	17.10	
	Meeting or above expecations	83.60	83.37	83.41	84.07	84.07	84.83	82.90	

 $\label{thm:conditional} \begin{tabular}{ll} \textbf{Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by high service use and study year, Albertans aged 0 to 25 years \\ \end{tabular}$

		Study Year							
	High service user	2006	2007	2008	2009	2010	2011	All years	
Number of individuals with FASD	High service user	1,313	1,452	1,513	1,503	1,570	1,500	2,360	
	Not high service user	1,267	1,257	1,249	1,293	1,255	1,326	665	
	Total	2,580	2,709	2,762	2,796	2,825	2,826	3,025	
Number of individuals with no FASD	High service user	52,025	55,444	54,145	56,005	59,665	59,226	169,556	
	Not high service user	1,125,955	1,172,370	1,199,051	1,219,034	1,227,731	1,212,067	1,423,350	
	Total	1,177,980	1,227,814	1,253,196	1,275,039	1,287,396	1,271,293	1,592,906	
Percent of individuals with FASD	High service user	50.89	53.60	54.78	53.76	55.58	53.08	78.02	
	Not high service user	49.11	46.40	45.22	46.24	44.42	46.92	21.98	
Percent of individuals with no FASD	High service user	4.42	4.52	4.32	4.39	4.63	4.66	10.64	
	Not high service user	95.58	95.48	95.68	95.61	95.37	95.34	89.36	

TABLE 7

Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by chronic health condition type, Albertans aged 0 to 25 years

	Chronic health condition	All years
Number of individuals with FASD	Asthma	486
	No Asthma	2,465
	Diabetes	38
	No diabetes	2,913
	Cancer	52
	No Cancer	2,899
	Total	2,951
Number of individuals with no FASD	Asthma	131,436
	No Asthma	1,460,714
	Diabetes	7,934
	No diabetes	1,584,216
		0.1.10
	Cancer	24,185
	No Cancer	1,567,965
	Total	1,592,150
Percent of individuals with FASD	Asthma	16.47
	Diabetes	1.29
	Cancer	1.76
Percent of individuals with no FASD	Asthma	8.26
	Diabetes	0.50
	Cancer	1.52

 $\label{thm:conditional} \begin{tabular}{ll} \textbf{Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by socio-economic status and study year, Albertans aged 0 to 25 years \\ \end{tabular}$

	Study Year								
	Socioeconomic status	2006	2007	2008	2009	2010	2011	All years	
Number of individuals with FASD	Lowest SES	913	974	999	1,022	1,042		1,101	
	Low middle SES	527	536	557	554	557	591	595	
	Middle SES	427	457	466	469	451	458	521	
	High middle SES	250	247	252	254	266	281	293	
	Highest SES	169	181	177	181	206	221	199	
	Total	2,286	2,395	2,451	2,480	2,522	2,544	2,709	
Number of individuals with no FASD	Lowest SES	277,723	285,598	287,009	286,970	287,893	281,067	364,187	
	Low middle SES	239,692	245,968	247,064	248,596	248,665	242,795	314,590	
	Middle SES	211,856	221,686	228,065	233,064	236,601	232,998	298,938	
	High middle SES	198,255	209,109	216,954	224,359	229,499	229,192	278,988	
	Highest SES	195,981	208,416	216,781	225,109	231,336	232,904	274,487	
	Total	1,123,507	1,170,777	1,195,873	1,218,098	1,233,994	1,218,956	1,531,190	
Percent of individuals with FASD	Lowest SES	39.94	40.67	40.76	41.21	41.32	39.03	40.64	
	Low middle SES	23.05	22.38	22.73	22.34	22.09	23.23	21.96	
	Middle SES	18.68	19.08	19.01	18.91	17.88	18.00	19.23	
	High middle SES	10.94	10.31	10.28	10.24	10.55	11.05	10.82	
	Highest SES	7.39	7.56	7.22	7.30	8.17	8.69	7.35	
Percent of individuals with no FASD	Lowest SES	24.72	24.39	24.00	23.56	23.33	23.06	23.78	
	Low middle SES	21.33	21.01	20.66	20.41	20.15	19.92	20.55	
	Middle SES	18.86	18.93	19.07	19.13	19.17	19.11	19.52	
	High middle SES	17.65	17.86	18.14	18.42	18.60	18.80	18.22	
	Highest SES	17.44	17.80	18.13	18.48	18.75	19.11	17.93	

TABLE 9

Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by Family Support for Children with Disabilities (FSCD) program use and study year, Albertans aged 0 to 17

Study Year

	FSCD service	2006	2007	2008	2009	2010	2011	All years
Number of individuals with FASD	FSCD	579	642	617	610	596	557	1,045
	No FSCD	1,814	1,820	1,853	1,823	1,755	1,695	1,790
	Total	2,393	2,462	2,470	2,433	2,351	2,252	2,835
Number of individuals with no FASD	FSCD	8,552	9,345	9,380	9,332	9,319	9,331	16,470
	no FSCD	826,357	854,552	869,607	882,933	892,714	886,866	1,171,581
	Total	834,909	863,897	878,987	892,265	902,033	896,197	1,188,051
Percent of individuals with FASD	FSCD	24.20	26.08	24.98	25.07	25.35	24.73	36.86
	no FSCD	75.80	73.92	75.02	74.93	74.65	75.27	63.14
Percent of individuals with no FASD	FSCD	1.02	1.08	1.07	1.05	1.03	1.04	1.39
	no FSCD	98.98	98.92	98.93	98.95	98.97	98.96	98.61

ΓABLE 10

Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by Assured Income for the Severly Handicapped (AISH) program use and study year, Albertans aged 18 to 25

Study Year

	AISH service	2006	2007	2008	2009	2010	2011	All years
Number of individuals with FASD	AISH	60	105	129	163	209	268	351
	No AISH	190	210	256	333	405	446	476
	Total	250	315	385	496	614	714	827
Number of individuals with no FASD	AISH	2,771	3,023	3,491	3,758	4,144	4,510	8,656
	No AISH	387,934	410,440	422,155	429,851	431,847	419,699	696,100
	Total	390,705	413,463	425,646	433,609	435,991	424,209	704,756
Percent of individuals with FASD	AISH	24.00	33.33	33.51	32.86	34.04	37.54	42.44
	No AISH	76.00	66.67	66.49	67.14	65.96	62.46	57.56
Percent of individuals with no FASD	AISH	0.71	0.73	0.82	0.87	0.95	1.06	1.23
	No AISH	99.29	99.27	99.18	99.13	99.05	98.94	98.77

Percent of individuals with no FASD

TABLE 11

Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by Persons with Developmental Disabilities (PDD) program use and study year, Albertans aged 18 to 25

No PDD

No PDD

PDD

PDD service 2006 2007 2008 2009 2010 2011 All years Number of individuals with FASD 73 98 116 122 No PDD 177 220 287 400 498 592 629 Total 250 614 714 827 Number of individuals with no FASD 2,020 1,992 1,965 1,918 1,936 1,980 3,862 No PDD 388,685 411,471 423,681 431,691 434,055 422,229 700,894 390,705 413,463 425,646 433,609 435,991 424,209 Total 704,756 Percent of individuals with FASD PDD 29.20 30.16 25.45 19.35 18.89 17.09 23.94

70.80

0.52

99.48

69.84

0.48

99.52

74.55

0.46

99.54

80.65

0.44

99.56

81.11

0.44

99.56

82.91

0.47

99.53

76.06

0.55

99.45

 $^{\mbox{\scriptsize TABLE }12}$ Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by special needs service use and study year, Albertans aged 2.5 to 19

	Study Year							
	Special needs students	2006	2007	2008	2009	2010	2011	All years
Number of individuals with FASD	Special needs	1,181	1,255	1,291	1,273	1,232	1,179	1,875
	No special needs	992	1,002	994	1,067	1,111	1,121	842
	Total	2,173	2,257	2,285	2,340	2,343	2,300	2,717
Number of individuals with no FASD	Special needs	65,281	65,299	65,996	66,459	68,219	68,104	140,954
	No special needs	721,673	742,446	748,832	757,222	760,805	754,122	973,841
	Total	786,954	807,745	814,828	823,681	829,024	822,226	1,114,795
Percent of individuals with FASD	Special needs	54.35	55.60	56.50	54.40	52.58	51.26	69.01
	No special needs	45.65	44.40	43.50	45.60	47.42	48.74	30.99
Percent of individuals with no FASD	Special needs	8.30	8.08	8.10	8.07	8.23	8.28	12.64
	No special needs	91.70	91.92	91.90	91.93	91.77	91.72	87.36

TABLE 13

Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by child intervention service use and study year, Albertans aged 0 to 22

				5	tudy Ye	ar		
	Child intervention service	2006	2007	2008	2009	2010	2011	All years
Number of individuals with FASD	Child intervention	937	999	993	976	945	864	1,431
	No child intervention	1,621	1,677	1,736	1,768	1,794	1,871	1,572
	Total	2,558	2,676	2,729	2,744	2,739	2,735	3,003
Number of individuals with no FASD	Child intervention	17,783	18,407	18,080	16,810	16,013	15,527	41,497
	No child intervention	1,067,533	1,107,697	1,127,066	1,145,703	1,155,908	1,141,876	1,445,818
	Total	1,085,316	1,126,104	1,145,146	1,162,513	1,171,921	1,157,403	1,487,315
Percent of individuals with FASD	Child intervention	36.63	37.33	36.39	35.57	34.50	31.59	47.65
	No child intervention	63.37	62.67	63.61	64.43	65.50	68.41	52.35
Percent of individuals with no FASD	Child intervention	1.64	1.63	1.58	1.45	1.37	1.34	2.79
	No child intervention	98.36	98.37	98.42	98.55	98.63	98.66	97.21

TABLE 14

Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by receipt of income support and study year, Albertans aged 18 to 25

Study Year

					oudy 100	-		
	Income support	2006	2007	2008	2009	2010	2011	All years
Number of individuals with FASD	Income support	26	35	45	73	90	84	186
	No income support	224	280	340	423	524	630	641
	Total	250	315	385	496	614	714	827
Number of individuals with no FASD	Income support	8,552	9,418	10,833	12,377	13,707	11,552	38,691
	No income support	382,153	404,045	414,813	421,232	422,284	412,657	666,065
	Total	390,705	413,463	425,646	433,609	435,991	424,209	704,756
Percent of individuals with FASD	Income support	10.40	11.11	11.69	14.72	14.66	11.76	22.49
	No income support	89.60	88.89	88.31	85.28	85.34	88.24	77.51
Percent of individuals with no FASD	Income support	2.19	2.28	2.55	2.85	3.14	2.72	5.49
	No income support	97.81	97.72	97.45	97.15	96.86	97.28	94.51

TABLE 15
Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by post-secondary enrolment and study year, Albertans aged 17 to 25

				S	tudy Yea	r		
	Post-secondary students	2006	2007	2008	2009	2010	2011	All years
Number of individuals with FASD	Post-secondary	14	< 10	18	20	22	38	90
	No post-secondary	260	345	419	540	650	741	803
	Total	274		437	560	672	779	893
Number of individuals with no FASD	Post-secondary	98,297	96,847	96,236	95,130	96,761	94,962	250,240
	No post-secondary	312,560	338,260	351,055	360,036	360,758	350,228	476,024
	Total	410,857	435,107	447,291	455,166	457,519	445,190	726,264
Percent of individuals with FASD	Post-secondary	5.11		4.12	3.57	3.27	4.88	10.08
	No post-secondary	94.89		95.88	96.43	96.73	95.12	89.92
Percent of individuals with no FASD	Post-secondary	23.92	22.26	21.52	20.90	21.15	21.33	34.46
	No post-secondary	76.08	77.74	78.48	79.10	78.85	78.67	65.54

Numbers and percentages were replaced with "." if numerators were under 10.

 $\label{thm:conditional} \textbf{Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by criminal offences and study year, Albertans aged 12 to 25$

		Study Year						
	Criminal offences	2006	2007	2008	2009	2010	2011	All years
Number of individuals with FASD	Criminal offences	132	189	216	242	274	280	564
	No criminal offences	853	960	1,077	1,197	1,300	1,408	1,265
	Total	985	1,149	1,293	1,439	1,574	1,688	1,829
Number of individuals with no FASD	Criminal offences	16,342	17,025	17,756	17,776	17,524	16,341	70,677
	No criminal offences	657,748	685,126	695,928	703,206	703,324	687,606	923,258
	Total	674,090	702,151	713,684	720,982	720,848	703,947	993,935
Percent of individuals with FASD	Criminal offences	13.40	16.45	16.71	16.82	17.41	16.59	30.84
	No criminal offences	86.60	83.55	83.29	83.18	82.59	83.41	69.16
Percent of individuals with no FASD	Criminal offences	2.42	2.42	2.49	2.47	2.43	2.32	7.11
	No criminal offences	97.58	97.58	97.51	97.53	97.57	97.68	92.89

TABLE 17

Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by high cost health use and study year, Albertans aged 0 to 25

				S	tudy Yea	ar		
	High cost health use	2006	2007	2008	2009	2010	2011	All years
Number of individuals with FASD	High cost	589	680	703	661	683	669	1,903
	Not high cost	1,827	1,866	1,907	1,985	2,016	2,034	1,048
	Total	2,416	2,546	2,610	2,646	2,699	2,703	2,951
Number of individuals with no FASD	High cost	55,517	56,321	57,796	59,115	60,646	61,568	263,620
	Not high cost	1,064,004	1,082,121	1,110,085	1,136,728	1,167,079	1,184,786	1,328,530
	Total	1,119,521	1,138,442	1,167,881	1,195,843	1,227,725	1,246,354	1,592,150
Percent of individuals with FASD	High cost	24.38	26.71	26.93	24.98	25.31	24.75	64.49
	Not high cost	75.62	73.29	73.07	75.02	74.69	75.25	35.51
Percent of individuals with no FASD	High cost	4.96	4.95	4.95	4.94	4.94	4.94	16.56
	Not high cost	95.04	95.05	95.05	95.06	95.06	95.06	83.44

 $\label{thm:permutation} \textbf{Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by mental health service use and study year, Albertans aged 0 to 25$

				S	tudy Yea	ar		
	Mental health service	2006	2007	2008	2009	2010	2011	All years
Number of individuals with FASD	Any condition	1,112	1,232	1,256	1,295	1,373	1,334	2,235
	No condition	1,365	1,375	1,414	1,410	1,376	1,427	790
	Total	2,477	2,607	2,670	2,705	2,749	2,761	3,025
$\label{eq:number of individuals with no FASD} \\$	Any condition	60,111	61,023	62,288	63,798	65,256	66,474	227,952
	No condition	1,060,025	1,078,134	1,106,232	1,132,618	1,162,967	1,180,335	1,364,954
	Total	1,120,136	1,139,157	1,168,520	1,196,416	1,228,223	1,246,809	1,592,906
Percent of individuals with FASD	Any condition	44.89	47.26	47.04	47.87	49.95	48.32	73.88
	No condition	55.11	52.74	52.96	52.13	50.05	51.68	26.12
Percent of individuals with no FASD	Any condition	5.37	5.36	5.33	5.33	5.31	5.33	14.31
	No condition	94.63	94.64	94.67	94.67	94.69	94.67	85.69

 $\label{thm:condition} \textbf{Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by residential mobility and study year, Albertans aged 0 to 25$

				S	Study Ye	ar		
	Residential mobility	2006	2007	2008	2009	2010	2011	All years
Number of individuals with FASD	No moves	1,797	1,887	2,009	2,027	2,054	2,081	1,180
	One move	443	486	443	457	480	453	650
	Two or more moves	176	173	158	162	165	169	1,121
	Total	2,416	2,546	2,610	2,646	2,699	2,703	2,951
Number of individuals with no FASD	No moves	910.052	932.237	951.671	000 550	1,084,078	1 100 220	858,302
Number of marviagas with no FASD		,	, ,	, ,				•
	One move	174,899	174,974	,	168,739	124,539	127,238	392,618
	Two or more moves	34,567	31,226	32,610	27,549	19,103	18,780	341,222
	Total	1,119,518	1,138,437	1,167,876	1,195,838	1,227,720	1,246,346	1,592,142
Percent of individuals with FASD	No moves	74.38	74.12	76.97	76.61	76.10	76.99	39.99
	One move	18.34	19.09	16.97	17.27	17.78	16.76	22.03
	Two or more moves	7.28	6.79	6.05	6.12	6.11	6.25	37.99
Percent of individuals with no FASD	No moves	81.29	81.89	81.49	83.59	88.30	88.28	53.91
	One move	15.62	15.37	15.72	14.11	10.14	10.21	24.66
	Two or more moves	3.09	2.74	2.79	2.30	1.56	1.51	21.43

TABLE 20

Number and percent of individuals with Fetal Alcohol Spectrum Disorder (FASD) by First Nations status, Albertans aged 0 to $25\,$

	First Nations status*	All years
Number of individuals with FASD	First Nations	933
	Non First Nations	1,488
	Total	2,421
Number of individuals with no FASD	First Nations	88,502
	Non First Nations	1,504,178
	Total	1,592,680
Percent of individuals with FASD	First Nations	38.54
	Non First Nations	61.46
Percent of individuals with no FASD	First Nations	5.56
	Non First Nations	94.44

^{*} First Nations treaty status was defined in Health and only compared to those with an FASD code from health

Definitions and notes

- **Age**, **gender**, 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.
- **All years** refers to the indicator occurring at any point across the six study years unless otherwise specified.
- The **Assured Income for the Severely Handicapped (AISH)** program provides financial and health-related assistance to Albertan adults (aged 18 and older) who have a severe handicap that is permanent and substantially limits ability to earn a living.
- **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 Services/Community and Social Services 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.
- Three **chronic health** conditions were defined: asthma, diabetes, and cancer. **Asthma** was defined as having two or more physician visits at least 30 days apart and within two years, with an ICD-9 diagnostic code 293 in any field, or any ambulatory care visit or hospitalization with an ICD-10 diagnostic code J45 to J46 in any field. **Diabetes** was defined as having two or more physician visits at least one day apart and within two years, with an ICD-9 diagnostic code 250 in any field, or any ambulatory care visit or hospitalization with an ICD-10 diagnostic code E10 to E24 in any field, or from a medical code 12 from Assured Income for the
 - to E24 in any field, or from a medical code 12 from Assured Income for the Severely Handicapped (AISH) services. Gestational diabetes diagnoses were excluded and were defined as a diabetes code 120 days prior to or 180 day after a pregnancy code (ICD-9: 641 to 676.7, V27-V27.9 and ICD-10 CA: 010 to 016.9, 021 to 095.9, 098 to 099.9, Z37 to Z37.99). An individual was considered to have **cancer** if they received any cancer code (ICD-9: 140 to 208.92) from physician visits, or any ambulatory care visit or hospitalization with a diagnostic code (ICD-10: C00 to C97.9) in any field, or an AISH medical code 10. Only Albertans who were registered with the Alberta Health Care Insurance plan for the full fiscal year were included.
- Individuals with **criminal offences** include those (aged 12 or older) charged with offences under various federal statutes.
- 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).



Definitions and notes

- Educational achievement was computed by Alberta Education using age, grade, school type, special education codes, provincial achievement test scores, home education status, number of high school credits earned, number of higher level courses taken, average grade in higher level courses, possession of an Alberta Education certificate or diploma, and Alexander Rutherford scholarship eligibility. Educational achievement was categorized as above, meeting, or below expectations for a student's age and grade. An educational achievement rating was not available for youth in 'other' schools (accredited post-secondary institutions offering high school courses for credit to adults; most youth in these schools were between 18 and 20 years), for home-schooled high school youth with no credits, and for students in grades lower than 3. The single most common educational achievement status was used for All years.
- The **Family Support for Children with Disabilities (FSCD)** Program provides a wide range of child- and family-centred supports and services to children and youth (aged 0 to 17 years) with a disability.
- An individual was considered to have **Fetal Alcohol Spectrum Disorder (FASD)** if they received a diagnosis (ICD10-CA: Q86.0 or P04.3) in any of the six study years from Health (from an emergency room visit, ambulatory care visit, or hospitalization) or from Family Support for Children with Disabilities (FSCD). Those with "No FASD" include some individuals with FASD who had a diagnosis prior to our study or had not been diagnosed.
- Health identified individuals who had **First Nations treaty status** and thus were eligible for payment of Alberta Health Care Insurance Plan (AHCIP) premiums by the federal government. Health care premiums ceased to be collected on January 1st, 2009; First Nations treaty status in the registry has been updated less often since that time, reducing the accuracy of this indicator.
- **High cost health use:** Cost estimates per type of service across physician visits (general practitioner or specialist), ambulatory care visits (emergency or other ambulatory care), and hospitalizations (by type of service) were obtained from the Canadian Institute for Health Information. Estimated costs per visit were summed across all visits for each individual. High cost health users were those in the top 5% of estimated costs for their age groups and genders.
- **High service users** were individuals who fell into two or more of the following categories within a given study year: high cost health users, English as a Second Language students, special education students, individuals charged with offences, individuals with corrections involvement, or clients of Persons with Developmental Disabilities, Family Support for Children with Disabilities, Assured Income for the Severely Handicapped, Child Intervention, Child Support Services, Income Support, Income Support Learners, or Advancing Futures Bursary.
- **Income Support** provides financial assistance to individuals (aged 18 and older) who are unable to meet their basic needs.
- Mental health service 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.

Definitions and notes (continued)

- The **Persons with Developmental Disability (PDD)** Program funds a range of programs and services to help adult Albertans (aged 18 and older) with developmental disabilities be part of their communities and live independently.
- **Post-secondary** students are individuals (aged 17 or older) enrolled in publicly funded universities, public colleges, technical institutes, and non-profit private university colleges in Alberta.
- **Report population:** For this report, age groups were equated across study years. This meant that individuals over the age of 25 years were excluded from analyses by year, because no study participants were older than 25 years in the first study year. "All years combined" analyses did include these oldest study participants, however.
- **Residential mobility** was defined as the number of unique postal codes within the Alberta Health Care Insurance Plan registry during the study period. Health care premiums ceased to be collected on January 1st, 2009; addresses in the registry have been updated less often since that time, reducing their accuracy. Number of moves was summed across study years for the All years measure.
- Socio-economic status (SES) captures the social and material environments in which youth live. A youth was assigned a socio-economic status via an index based on the Statistics Canada dissemination area in which he or she resided1. Six indicators were included in the index: percent without a high school diploma, the employment rate, average income, percent of single families, percent of persons living alone, and percent of persons separated, divorced, or widowed. Socio-economic status values fell into five quintiles. All years was based on the most common dissemination area across the study period.
- **Special needs** students are students (aged 2.5 to 19 years) who are eligible to receive special education programming services.
- **Study population:** The study included individuals with a date of birth between April 1, 1980 and March 31, 2011 and who received services from one of the programs in the study or were registered in the Alberta Health Care Insurance Plan 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.
- **Tables** are shown by fiscal year as of March 31st in the study year (e.g. 2005/06 is shown as 2006).

Data sources

Ministry	Database	Use in this report
Advanced education	Learner and Enrolment Reporting System	Post-secondary enrolment
Education	Corporate Data Warehouse (CDW)	Primary and secondary education achievement
Health	Inpatient – Discharge Abstract Database	Hospitalization data
Health	Ambulatory Care (ACCS)	Emergency room visit data
Health	Alberta Health Care Insurance Plan	Population registry
Health	Practitioner payments	Physician visit data
Human Services	Child Youth Information Module (CYIM)	Child Intervention data
Human Services	Family Support for Children with Disabilities Information System (FSCDIS)	Family Supports for Children with Disabilities data
Human Services	Central Client Directory (CCD)	Income support data, Assured Income for the
Human Services	Tracking of Maintenance Information System (TOMIS)	Child Support Services dependents data
Human Services	Consolidated Service System (CSS)	Persons with Developmental Disabilities data
Justice and Solicitor General	Justice Online Information Network (JOIN)	Offence data
Justice and Solicitor General	Alberta Community Offender Management System (ACOM)	Corrections data (community)
Justice and Solicitor General	Correctional Offender Management Information System (CoMIS)	Corrections data (custody)

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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.

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:

Advanced Education Community and Social Services Education Health Indigenous Relations Children's Services
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.



Addendum: A profile of young Albertans with Fetal Alcohol Spectrum Disorder Child and Youth Data Laboratory (CYDL)



January 3, 2018

This addendum clarifies limitations in this report, "A profile of young Albertans with Fetal Alcohol Spectrum Disorder", that emerged in discussion with stakeholders concerning the ability to make inferences about the prevalence of FASD in Alberta. Specifically this addendum includes two sections that have since been added to CYDL reports: an introduction and study limitations.

Introduction

Fetal Alcohol Spectrum Disorder (FASD) is a complex disorder caused by alcohol exposure during pregnancy. The neurocognitive and behavioral problems that emerge from prenatal alcohol exposure are lifelong. This report highlights the socio-demographic characteristics of, and use of provincial services by, young Albertans aged 0 to 25 years with FASD from 2005/06 to 2010/11.

Young Albertans were defined as having FASD if, at any point during the study period, they either: (a) had a diagnostic code for FASD from a health service (ambulatory care, or emergency room visit, or hospitalization), or, (b) accessed a service for FASD from Family Support for Children with Disabilities (FSCD). Because the ability to define FASD in the study population is based on the presence of diagnostic codes from services in administrative data, it's important to note that this study is not estimating the prevalence or incidence of FASD in Alberta.

Study Limitations

When interpreting results, readers should be aware of the limitations of the study:

- **Not all individuals with FASD were identified.** Individuals with FASD may have been missed if they received a diagnostic code from a health or FSCD service for FASD before or after the study period. Individuals with FASD may also have been missed if they did not receive a diagnostic code for FASD from a health or disability service for FASD, despite accessing FSCD or a health service during the study.
- Individuals with FASD who were younger at the start of the study are overrepresented. A greater number of individuals who were younger (ages 6-10 years) at the start of the study were identified as having FASD (see Table 4, p.14, for the age distribution of the study population by year). This is because in any given study year, individuals with FASD in younger age groups used services more than those in the older age groups. This meant that if an individual was young at the start of the study, they would have spent more time in a "high service" age group during the study period, and therefore had a greater opportunity to receive a diagnostic code for FASD.
- **Time trends should be interpreted with caution.** The age distribution of the study population changed over the study period as the younger Albertans with FASD in the study population aged (see Table 4). Therefore, the time trends presented in this report may have been shaped by the changing characteristics of the aging study population.
- The proportion of young Albertans who received FSCD may be overestimated. Because individuals were identified as having FASD through diagnostic codes received from FSCD, this study may overestimate the proportion of young Albertans with FASD using this disability service.
- Results cannot be generalized to youth not registered in Alberta Health Care Insurance Plan (AHCIP). Because a criterion for inclusion in the study population is enrolment in AHCIP, results cannot be generalized to youth who were not enrolled in AHICP for at least one full year during the study period.