COSTS OF FETAL ALCOHOL SPECTRUM DISORDER IN ALBERTA, CANADA

NX Thanh and E Jonsson
Institute of Health Economics, Edmonton, Alberta

ABSTRACT

Background
Although many programs targeting fetal alcohol spectrum disorder (FASD) are implemented, the province of Alberta is still lacking information on costs of FASD.

Objectives
To estimate the costs of FASD in Alberta based on available US and Canadian research on costs of FASD, and Alberta data.

Methods
Two types of costs were estimated. The annual long-term economic cost of FASD, which referred to a projected amount of money incurred by lives of the cohort of children born with FASD each year, was estimated by multiplying the lifetime cost of caring for each child born with FASD with the number of children born with FASD each year. The annual short-term economic cost of FASD, which referred to the amount of money incurred by people who are presently living with FASD, was estimated by using a FASD cost calculator online at http://www.online-clinic.com. Both were societal costs adjusted to 2008 Canadian dollars.

Results
The annual long-term economic cost from the disorders rose from $130 to $400 million each year for the Alberta economy. The annual short-term economic cost for FASD in Alberta was from $48 to $143 million, and the daily cost for FASD in Alberta was from $105 to $316 thousand.

Conclusion
These numbers suggest a need for a provincial FASD prevention strategy. The costs of FASD can be used to evaluate the benefits of prevention programs to society.

Key words: *Fetal alcohol spectrum disorder, cost, Alberta, Canada*

Fetal alcohol spectrum disorder (FASD) is a term used for the entire array of the effects of prenatal exposure to alcohol. It is the range of effects that can occur in a person whose mother drank alcohol during pregnancy, including physical, mental, behaviour and learning disabilities. Fetal alcohol syndrome (FAS) is medically the most severe condition within FASD, characterized by prenatal and/or postnatal growth retardation, face abnormalities, and central nervous system anomalies. The worldwide incidence rates of FAS and FASD have been estimated at 1.9 and 3–5 per 1000 live births respectively.[1] The corresponding rates for the US are 0.5–2 and 10[2] and for Canada are 1–3 and 3–9 per 1000 live births.[3-5]

In Alberta, there are no scientific studies published on incidence rates of FASD. However, some documents exist that report similar rates to those in Canada, such as on the website of the Alberta FASD Cross-Ministry Committee (www.fasd-cmc.alberta.ca). Addressing FASD is a priority of the province's government.[6] The government supports programs that enhance the awareness and understanding of FASD; educate women not to drink when pregnant; and support individuals and families affected by FASD.[7] By 2004, there were more than 70 programs targeting

FASD prevention or supporting individuals and families affected by FASD in Alberta.[6] However, information on the cost of FASD is still lacking in the province. Therefore, the objective of this study is to estimate the costs of FASD in Alberta based on available US and Canadian research on costs of FASD, and Alberta data. First, we present a literature review on costs of FASD in the US and Canada; followed by methods, results and discussion on costs of FASD in Alberta.

Literature Review

FASD is a complex condition resulting in lifetime physical and mental disabilities. People with FASD need medical treatment for their physical defects and mental disorders, special education for their cognitive and behavioral disorders, correctional (justice) services for their criminal behaviours, and social and family supports for their ill health in general.[8]

To estimate the costs associated with FASD, it is important to carefully determine which cost items to include in the analysis. Getting an adequate picture of FASD costs is difficult because it is related to many sectors of society and the cost data is not always available. The difficulty in estimating the cost of services for individuals with FASD is further compounded because they receive services inappropriate to their needs; cycle through service systems, thereby incurring more costs than are necessary; or do not receive the services they need, therefore, not incurring any service or treatment costs.[9]

In the USA

Despite the difficulties, a number of published studies on the costs of FAS in the US are available. They all estimated the total annual cost of FAS to the nation and the lifetime cost of caring for each child born with FAS.[9] They identified costs by categories, such as health care costs, residential and support services, and productivity losses. Estimated annual costs vary greatly from US$75 million in 1984[10] to US$3 billion in 1992.[11] The difference in results reflects different methods of assessing the incidence rates of FAS, the cost components, the fact that the knowledge base for developing estimates has rapidly increased over time, and inflation.[9]

Even when adjusted to 2008 CAD the estimated annual cost of FAS varies greatly. Based on a discount rate of 5% and an USD/CAD exchange rate of 1.03, the costs vary from $0.25[10] to 1.17 [13] to 4.72[14] to 6.27[11] and to $16.09 billion [12] (Table 1). The cost components account for different proportions depending on the study. The treatment costs for medical services account for about 23% of total costs in the Abel and Sokol[10] study and about 50% in the Harwood et al (1985) study.[12] Residential costs account for 77% in the Abel & Sokol study and 28% in Harwood et al.

TABLE 1 Annual Cost of FAS in the U.S.A.

Source	Type of Cost	Costs (in USD billions)	Year	Incidence rate per 1000 live births	2002 Adjusted Estimate (in USD billions)	2008 Adjusted Estimate (in CAD billions)*
Abel and Sokol (1991)[10]	Treatment costs for medical services	$0.02	1984	0.33	$0.06	0.08
	Residential care for mental retardation	$0.06			$0.12	0.17
	Total	$0.08			**$0.18**	**0.25**
Harwood and Napolitano	Treatment costs for medical services	$1.21	1980	1.67	$6.01	8.30

(1985)[12]	Residential care for mental retardation	$1.17			$3.25	4.49
	Lost productivity	$0.85			$2.40	3.31
	Total	$3.24			**$11.66**	**16.09**
Abel and Sokol (1987)[13]	Treatment costs for medical services	$0.14	1984	1.9	$0.45	0.62
	Residential care for mental retardation	$0.19			$0.39	0.54
	Total	$0.32			**$0.85**	**1.17**
Rice, et al (1990)[14]	Treatment costs for medical services	$0.14	1985	1.9	$0.43	0.59
	Residential care for mental retardation	$1.47			$2.99	4.13
	Total	$1.61			**$3.42**	**4.72**
Harwood, et al (1998)[11]	Treatment costs for medical services	$0.60	1992	2.0	$1.04	1.44
	Residential care for mental retardation	$1.34			$1.94	2.68
	Lost productivity	$0.99			$1.56	2.15
	Total	$2.93			**$4.53**	**6.27**

Source: Lupton et al 2004[9]

*Adjusted from the 2002 adjusted estimate in USD using a discount rate of 5% and an USD/CAD exchanged rate of 1.03

The total lifetime cost for a person with FAS in the US and a list of the cost categories used to calculate these figures are included in table 2. Harwood and Napolitano estimated the lifetime cost of FAS at US$596,000 in 1980.[12] If this estimate is adjusted to include the change in the cost of medical care services, lost productivity, and inflation, the adjusted 2002 cost becomes US$2.0 million (CA$2.8 million in 2008) for each individual with FAS. This figure is comprised of US$1.6 million (80%) for medical treatment, special education, and residential care for persons with mental retardation, and US$0.4 million (20%) for productivity losses.[9] In 1989, the Senate Advisory Council of the Alaska State Legislature estimated the 1988 lifetime cost of each baby born with FAS at US$1.4 million.[15] After adjustment, this cost became US$2.9 million in 2002 dollars (CA$4.0 million in 2008).[9]

TABLE 2 Estimates of the total U.S.A. lifetime cost of each child with FAS

Study	Date	Costs Included	Estimate in study year (USD)	2002 adjusted estimate (USD)	2008 adjusted estimate (CAD)*
Harwood and Napolitano[12]	1980	A1, B1, C, D, F	$596,000	$2,010,000	2,774,400
Alaska State Legislature[15]	1988	A2, B2, C, E, F	$1,373,836	$2,909,785	4,016,371

Service Codes:
A1: Medical treatment services to age 21 for pre- and postnatal growth retardation, heart defects requiring surgery, spina bifida, cleft palate, surgery and treatment for audiologic deficits, inguinal hernia and hypospadias
A2: Medical treatment costs for pre- and postnatal growth retardation, heart defects requiring surgery, cleft palate, and surgery and treatment for audiologic deficits
B1: Ambulatory, home and residential care for individuals with mild to moderate mental retardation
B2: Infant learning, handicapped children, youth initiative, and developmentally disabled children's services
C: Special education services
D: Lost employment and reduced productivity
E: Social service costs, such as training and supervised work services
F: Institutional care for mental retardation to age 65

Source: Lupton et al 2004[9]
*Adjusted from the 2002 adjusted estimate in USD using a discount rate of 5% and an USD/CAD exchanged rate of 1.03

These estimates focus on the cost of FAS only. The cost of prenatal alcohol related problems is much higher. Babies born with FAE make up a much larger group. It is estimated that in the US while the rate of FAS is 0.5 to 2.0 per 1,000 live births, FAS, partial fetal alcohol syndrome (pFAS), alcohol related birth defects (ARBD), and alcohol related neurodevelopmental disorder (ARND) combined (or FASD) account for as many as 10 per 1,000 live births. Costs for individuals with FAE (pFAS, ARBD and ARND) have not been included in most studies. A number of specific cost components, such as juvenile and criminal justice, special education, substance abuse, mental health, and vocational services are not included in the cost estimates either. All these result in a gross underestimation of the costs of prenatal exposure to alcohol.

Because individuals with FASD often become involved with the juvenile and criminal justice systems there are definite costs to the justice system related to FASD. About 60% of subjects with FASD have been in trouble with the authorities, charged with a crime, or convicted of a crime.[16] The costs associated with law enforcement are significant. For example, in the US, it can cost close to US$30,000 per year to house an inmate in a federal prison.[17]

Another area of cost that is underestimated is that incurred by the family. Compared to other families, families with disabled children, including those with FASD, are more likely to have reduced resources because of a limited availability of paid employment.[18] Those resources are often used to pay for specialized goods and services related to the child's disability.

In Canada

A study in Canada[3] estimated the cost of FASD rather than FAS. The Canadian study included six

cost components: medical, education, social services, direct costs to the patient/family, productivity losses, and externalizing behaviors. The results show that the economic burden of prenatal exposure to alcohol is profound. In 2006 the adjusted average annual costs per child with FASD, ages 1 to 21 years, in Canada were estimated at CA$14,342. This is consistent with results of the study in South Dakota[19] which estimated the annual cost of taking care of an individual with FAS ranging from US$10,000 to US$30,000. The Canadian study also estimated the annual cost of FASD in Canada for ages 1 to 21 years at CA$344,208,000. This estimation was based on a low rate of FASD of three in 1000 people and a population (ages 1 to 21 years) of eight million. According to Hutson[20], if extrapolated to age 65, this cost would result in an estimated 3-4 billion dollar annual cost. The largest cost components were for education (32.6 %) and for medical (30.3 %) expenses. The family costs accounted for 19% of total costs.

The magnitude of the problem is even more serious if other estimates are considered. According to Dr. Gideon Koren, founder of the Fetal Alcohol Canadian Expertise Network and the peer reviewed Journal of FAS International, in 2006 the total Canadian lifetime costs of FASD was about CA$1 million. Since about 4,000 children are born with FASD in Canada each year, the long-term economic fallout from the disorder rises to about CA$4 billion each year.[21]

METHODS

We estimated two types of costs of FASD in Alberta. One was the annual long-term economic cost of FASD which referred to a projected amount of money incurred by lives of the cohort of children born with FASD each year. This was a societal-perspective cost and equal to the lifetime cost of caring for each child born with FASD multiplied by the number of children born with FASD each year. The lifetime cost of caring for each child born with FASD was estimated by multiplying the average age of death of FASD people with the annual cost per person with FASD. Since we did not know how long a child with FASD can live and there was no evidence on differences in average age of death between people with FASD and the general population, Alberta's average age of death, which was 71.6 in 2005[22] was used as the average age of death of FASD people. The annual cost per person with FASD was obtained from the Canadian study by Stade.[3] The cost was $14,342 in 2006 or $15,812 in 2008 Canadian dollar value, including the following components: medical, education, social services, direct costs to the patient/family, productivity losses, and externalizing behaviors.

The number of children born with FASD a year was estimated by multiplying the FASD incidence rate with the number of live births in that year. The FASD incidence rate of 3-9/1000[3-5] and the number of live births of 38,313, 39,838, 40,355 and 41,355 in 2002, 2003, 2004 and 2005 respectively[23] were used for the estimations.

In summary: LC = (L*C)*(R*B) In which:

- LC – the annual long-term economic cost of FASD
- L – the average age of death of people with FASD
- C – the annual cost per person with FASD
- R – the FASD incidence rate
- B – the number of live births a year
- (L*C) = lifetime cost of caring for each child born with FASD
- (R*B) = number of children born with FASD a year

The other was the annual short-term economic cost of FASD which referred to the amount of money incurred by people who are presently living with FASD. This was also a societal-perspective cost and estimated by using a FASD cost calculator developed by the FAS Center at the University of North Dakota available at http://www.online-clinic.com. This tool was also suggested by the SAMHSA FASD Center for Excellence.[24] The costs used in the calculator were in 1996/97 USD were based on the North Dakota studies[9,25] that included the following components: special education, juvenile justice services, health care costs, adult corrections, and their service delivery systems (e.g. foster care and residential care).

A sensitivity analysis was performed for lower and upper boundaries of the incidence rates of FAS and FASD. The costs were adjusted to 2008 Canadian dollar value using a discount rate

of 5% and an USD/CAD exchange rate of 1.03 which was the average rate of the first 10 months in 2008 available at http://www.x-rates.com (accessed on Oct. 08, 2008).

RESULTS

With the annual cost per child with FASD being $15,812 and the average age of death being 71.6 years[22], the lifetime cost of caring for each child born with FASD would be equal to $15,812* 71.6 ≈ $1.1 million. This is comparable to the lifetime cost of caring for each child born with FASD of $1 million estimated by Dr. Gideon Koren.[21] With the FASD incidence rate of 3–9/1000[3-5], the number of live births was about 40,000 a year[23], the number of children born with FASD a year would be from 120 to 370. The long-term economic cost from the disorders rose from $130 to $400 million each year for the Alberta economy (Table 3).

TABLE 3 Annual long-term costs of FASD in Alberta (2008 CAD)

	Years							
	2002		**2003**		**2004**		**2005**	
Number of live births (B)	38,313		39,838		40,355		41,458	
	Lower	**Upper**	**Lower**	**Upper**	**Lower**	**Upper**	**Lower**	**Upper**
FASD incidence rate (R)	0.003	0.009	0.003	0.009	0.003	0.009	0.003	0.009
Annual cost per person with FASD (C) ($)	$15,812	$15,812	$15,812	$15,812	$15,812	$15,812	$15,812	$15,812
Average age of death of FASD people (L)	71.6	71.6	71.6	71.6	71.6	71.6	71.6	71.6
Number of FASD children (=B*R)	115	345	120	359	121	363	124	373
Lifetime cost of caring for each child born with FASD (=L*C) (in million)	$1.1	$1.1	$1.1	$1.1	$1.1	$1.1	$1.1	$1.1
Long-term cost (LC) (in million)	$126	$379	$131	$394	$133	$400	$137	$410

With 41,456 live births per year[23], a total population of 3,413,500[26] and an FASD incidence rate of 3–9/1000 (including the FAS incidence rate of 1–3/1000 and the FAE of 2–6/1000[3-5] the online calculator gave several results as presented in Table 4. The most noticeable results were total annual costs for FASD in Alberta, which were from $48 to $143 million, and daily costs for FASD in Alberta, which were from $105 to $316 thousand. Of these, annual costs for special education and juvenile justice for children with FASD aged 5-18 years accounted for 19%.

TABLE 4 Annual short-term cost of FASD in Alberta*

Number of live births per year	41,456	
Total population	3,413,500	
	Lower	**Upper**
FAS rate per 1000 live births	1	3
FAE rate per 1000 live births	2	6
FASD rate per 1000 live births	3	9
Annual Cohort		
FAS	41	124
FAE	82	248
FASD	123	372
Cases in Total Population		
FAS	3,413	10,240
FAE	6,827	20,481
FASD	10,240	30,721
Children Birth - 18 years of age		
FAS	1,024	3,072
FAE	2,048	6,144
FASD	3,072	9,216
Adults 19 and older		
FAS	2,389	7,168
FAE	4,778	14,336
FASD	7,167	21,504
Mortality in Annual Cohort		
FAS	2	6
FAE	6	18
FASD	8	24
Years Potential Life Lost	512	1,536
Maternal Mortality (in 24 months after delivery)	12	37
Mental Retardation (cases) in total population		
FAS	1,365	4,096
FAE	546	1,638
FASD	1,911	5,734
Congenital Heart Defects (cases) in total population		
FAS	1,583	4,751
FAE	3,167	9,503
FASD	4,750	14,254
Epilepsy (cases) in total population		
FAS	204	614
FAE	409	1,228
FASD	613	1,842
Attention Deficit-Hyperactivity Disorder (cases) in total population		
FAS	1,365	4,096
FAE	2,730	8,192
FASD	4,095	12,288
Speech and Language Disorder (cases) in total population		
FAS	2,833	8,499

FAE	5,666	16,999
FASD	8,499	25,498
Sensorineural Hearing Loss (cases) in total population		
FAS	955	2,867
FAE	1,911	5,734
FASD	2,866	8,601
Cerebral Palsy (cases) in total population		
FAS	51	153
FAE	102	307
FASD	153	460
Autism or other Pervasive Developmental Disorder (cases) in total population		
FAS	58	174
FAE	116	348
FASD	174	522
Service System Data and Projected Service Use		
Foster Care Placements of children: Birth - 18 years of age		
FAS	819	2,457
FAE	1,638	4,915
FASD	2,457	7,372
Years Foster Care	1,180	3,571
Mental Illness (cases) in total population		
FAS	2,389	7,168
FAE	4,778	14,336
FASD	7,167	21,504
Years Service Mental Health System (Annual Cohort)	3,690	11,160
Additional Service Data (for Annual Cohort)		
Years Special Education (FASD)	861	2,604
Disability Adjusted Life Years	3936	11,904
Years Service Developmental Disability	1,660	5,022
Years Service Juvenile Justice System	98	297
Cost Calculations for FASD (2008 CAD)		
Annual Costs for Special Education and Juvenile Justice (children ages 5-18)	9,091,803	27,275,408
Total Annual Costs	47,535,410	142,606,230
Cost per Day	105,324	315,975
Five Year Costs	192,218,033	576,654,100

* Using formula at http://www.online-clinic.com

DISCUSSION

The long-term economic cost from the disorders rises to $130 - $400 million each year for the Alberta economy. Of this, education accounts for 33%, medical 30% and family 19%. The remaining 18% is for social services, productivity losses and externalizing behaviors.[3] Though significant, the annual long-term cost is likely underestimated because costs incurred by individuals who reside in institutions, such as facilities for disabled children, who are homeless or who are in the judicial system are not included in the calculations.

In Alberta, there are 15,032 children in the care of social services[27] and about 50% of them have FASD.[20] Thus, the cost associated with FASD children in the welfare system is significant. The Early Learning and Child Care Program invested $648 million between 2005 and 2010[28] and half of this amount will be consumed by children with FASD. It is estimated that up to

50% of young offenders have FASD.[29] The cost per prisoner per year is $13,500.[30] Taylor et al[31] estimated the total economic cost of crime in Alberta at about $2 billion (in 1998 Canadian dollars), equivalent to 2% of total provincial GDP in 1999. Therefore, the cost of FASD relating to the justice system seems to be significant.

The cost of substance abuse in Alberta was estimated at $4.4 billion in 2002.[32] Although we do not know the exact amount, we do know that a large proportion of these costs can be attributed to FASD since as many as 30% of people with FASD over the age of 11 years; 53% of male adults with FASD and 70% of female adults with FASD, have alcohol and drug use problems.[33]

The annual short-term economic cost of FASD in Alberta estimated by the online calculator is from $48 to $143 million, and the daily cost is from $105 to $316 thousand. These costs are significant and can be compared to the cost of permanent disability from three chronic diseases (including diabetes, heart disease, COPD and any combination of these) in Alberta, which was $84 million in 2000[34] (or $124 million in 2008 CAD) and annual cost of FAS in the state of Minnesota, which was $45 million in 1991 USD[24] (or $106 million in 2008 CAD).

Validity of our results to some extent can be seen through how detailed the calculator is constructed and what data are used for the calculator. The costs and disorder rates used in the calculator were estimated from studies of FASD in North Dakota over an 18 year period.[9,25] From population, number of births a year and rates of FASD, the calculator firstly estimates the annual cohort of FASD people, number of FASD cases in the population, including children with FASD aged <=18 and people with FASD >=19 years. This is reasonable because services utilized by children and adults with FASD and thereby costs per case are different.

Secondly, the calculator estimates numbers of different consequences of FASD, including number of deaths from FASD, number of mental retardation cases, number of congenital heart defects cases, number of epilepsy cases, number of attention deficit-hyperactivity disorder cases, number of speech and language disorder cases, number of sensorineural hearing loss cases, number of cerebral palsy cases, number of autism or other pervasive developmental disorder cases, number of foster care placements and years in foster care for children with FASD aged <=18 years, number of mental illness cases and years of service in mental health system, number of years of special education, number of years of service for developmental disability, and number of years of service in juvenile justice system (Table 4). From these numbers and corresponding costs per case, costs of FASD are generated.

Even though many cost components are already taken into account, authors of the calculator remind us that the estimates are best considered as minimums because many other costs are not available.[25] In spite of underestimation, the costs of FASD in Alberta show a definite need for a provincial FASD prevention strategy. There are some limitations in this study. One is that Alberta incidence rates of FASD and annual cost per child with FASD are not available. We used the Canadian numbers for the estimations. We believe that the sensitivity analysis for the incidence rates of FASD capture Alberta's number. Another limitation is related to the Canadian annual cost per child with FASD estimated by Stade.[3] This is estimated among FASD people aged 1-21 years. It is possible that this cost varies by ages, but we used the same cost for all ages. However, this is only one estimate of annual cost per child with FASD available in Canada.

In conclusion, it is clear that FASD is a public health problem in Alberta. It costs the Alberta economy a significant amount of money. A multidisciplinary FASD prevention program should be a priority. The cost of FASD, especially the lifetime cost can be used to evaluate the benefits of prevention programs to society.[12] Each prevented case of FASD results in savings equivalent to the life time cost that would be incurred by that individual if they had FASD.

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Corresponding Author*: tnguyen@ihe.ca*

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