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Economic Impact of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorder (FASD) *a systematic literature review*

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TABLE OF CONTENTS

Acknowledgments	3
List of tables	5
List of figures	5
Executive summary	6
Introduction	7
Objective	7
Method	8
Systematic literature search	8
Data extraction	8
Results	10
Interrater reliability	10
Derivation of costs for comparison	10
Canadian studies	10
U.S. studies	20
Lifetime cost	30
Other (brief) cost estimates of FAS/FASD	30
Anecdotal estimates of FASD costs in Canada	33
Discussion and conclusion	34
References	36

LIST OF TABLES

Table 1. Keywords used in the present systematic review of the literature	9
Table 2. Annual cost and lifetime cost (in Canadian dollars) per individual associated with FASD in Canadian studies	11
Table 3. Average annual cost of FAS/FAE per case	13
Table 4. Average annual cost of FASD per case	15
Table 5. Adjusted annual costs per individual with FASD according to age	16
Table 6. Annual short-term cost of FASD in Alberta	18
Table 7. Annual cost and lifetime cost (in U.S. dollars) per individual associated with FAS in the U.S. studies	21
Table 8. Lifetime cost estimates of specific birth defects associated with FAS	23
Table 9. Expected cost of direct services in 1980 due to FAS using regimen proposed in Table 8	24
Table 10. Annual cost estimates associated with FAS-related intrauterine growth retardation	25
Table 11. Annual cost estimates for treatment of select organic and sensorineural disorders	25
Table 12. Alternate methods of estimating costs for FAS patients requiring 24-hours residence care due to mental retardation (MR)	26
Table 13. Summary of annual cost for select problems related to FAS	27
Table 14. Summary of annual cost for select problems related to FAS	27
Table 15. Estimated cost of FAS, 1985	28
Table 16. Health and other services for FAS, 1992	29
Table 17. Brief FAS/FASD cost estimates	31
Table 18. Average annual cost (% of total) of FAS/pFAS per case over 12 months (n = 44)	32

LIST OF FIGURES

Figure 1. Flow diagram describing selection of FAS/FASD cost studies for the systematic review	10
Figure 2. Estimated prevalence and medical burden of FAS and FASD in Ontario, Canada	33

EXECUTIVE SUMMARY

Objective

The objective of this study was to conduct a systematic review of the literature related to the measurement of the economic impact of fetal alcohol syndrome (FAS) and fetal alcohol spectrum disorder (FASD) in different countries and to categorize the available literature.

Method

A systematic literature search of the studies concerning the economic impact of FAS/FASD was conducted using multiple electronic bibliographic databases.

Results

The literature on the economic burden of FAS/FASD is scarce. A limited number of studies are found in Canada and the United States, and data from the rest of the world are largely absent. Existing estimates of the economic impact of FAS/FASD demonstrate significant cost implications on the individual, the family and the society. However, these estimates vary considerably due to the different methodologies used by the different studies. Strengths, limitations and gaps in the existing methodologies of calculating the economic costs of FASD and the main cost drivers are identified and discussed in this report.

Discussion

There is an urgent need to develop a sound methodology for calculating the economic impact of FASD to society, considering the systems those affected by FASD are likely to come in contact with throughout their lives, as well as the life/developmental stages of those affected, the direct and indirect cost to systems, individuals and families, including the lost productivity of the parents/caregivers, and the lost potential of the affected individuals.

Note: This is a revised report as of November 2011; the first version of this report was prepared and submitted to the Public Health Agency of Canada (PHAC) in August 2009.

INTRODUCTION

Fetal alcohol spectrum disorder (FASD) is a serious public health, social and economic issue that affects people living all over Canada, as well as throughout the world. FASD is a non-diagnostic umbrella term used to describe the range of disabilities that may affect people whose mothers consumed alcohol during pregnancy. Furthermore, the disabilities associated with FASD involve a wide continuum of challenges that range in severity. The diagnoses of FASD are:

- fetal alcohol syndrome (FAS)
- partial fetal alcohol syndrome (pFAS)
- alcohol-related neurodevelopmental disorder (ARND)
- alcohol-related birth defects (ARBD).

People affected by FASD most often experience an array of health problems such as birth defects, growth deficits, cognitive delay and speech and language difficulties. Those who are affected by FASD are also more susceptible to cardiac anomalies, urogenital defects, skeletal abnormalities and visual and hearing problems.

Because of the wide range of possible disabilities, people who are affected by FASD may have special needs that require lifelong assistance. Without the crucial support required, people affected by FASD are at a high risk of developing secondary disabilities related to mental health problems, trouble with the law, dropping out of school, becoming unemployed, becoming homeless and/or developing alcohol and other drug problems. This, in turn, produces tremendous costs to society.

An estimation of the cost of FASD, especially lifetime cost, is central to describing the extent of its impact on society and to evaluating the benefits of prevention programs. Thus, an estimation of the cost of FASD is useful from a public policy perspective (Bloss, 1994; Harwood & Napolitano, 1985).

On March 21 and 22, 2007, in Ottawa, the first National Roundtable discussion was held on the *Development of a Canadian Model for Calculating the Economic Impact of FASD* and was proposed as a baseline model that can be refined and filled in to create a comprehensive picture of the economic impact of FASD in Canada (PHAC, 2008).

Objective

The objective of this study was to conduct a systematic review of the literature related to the measurement of the economic impact and cost drivers associated with FAS/FASD in different countries and to categorize the available literature.

METHOD

Systematic literature search

A systematic literature search of studies concerning the economic impact of FAS/FASD was conducted using multiple electronic bibliographic databases, which included Ovid MEDLINE, PubMed, EMBASE, Web of Science (including Science Citation Index, Social Sciences Citation Index, Arts and Humanities Citation Index), PsycINFO, ERIC, CINAHL, and OVID (combines several databases), Social Work Abstracts, EBSCOhost, the Cochrane Database of Systematic Reviews, Canadian Centre on Substance Abuse Library Collection Database, Centre for Addiction and Mental Health Library Database, Criminal Justice Abstracts, and Google Scholar.

In addition, the following economic databases were searched: the Alcohol and Alcohol Problems Science Database ETOH (<http://etoh.niaaa.nih.gov/Archive.htm>), the NHS EED (Economic Evaluation Database; <http://www.crd.york.ac.uk/crdweb/>) and the Cost-Effectiveness Analysis Registry (Economic database; <http://www.tufts-nemc.org/cearegistry/>).

Moreover, other websites were searched for relevant literature: Alberta Alcohol and Drug Abuse Commission (AADAC); Canadian Institute of Health Research (CIHR); Canadian Paediatric Society (CPS); Canadian Public Health Association (CPHA); Centre of Excellence for Early Childhood Development (CEECD); Centres for Excellence in Women's Health (CEWH); Health Canada; *Journal of Fetal Alcohol Research*; National Center on Birth Defects and Developmental Disabilities; Public Health Agency of Canada (PHAC); SAMHSA Fetal Alcohol Spectrum Disorder (FASD) Center for Excellence; Society of Obstetricians and Gynaecologists of Canada (SOGC); Status of Women Canada (SWC); The Women's Addiction Foundation; Human Resources and

Skills Development Canada (HRSDC) Office of Disability Issues; Indian and Northern Affairs Canada (INAC); First Nations and Inuit Health Branch (FNIHB), Health Canada; Centre of Excellence for Children and Adolescents with Special Needs; and Centers for Disease Control and Prevention, USA.

In addition, we conducted manual reviews of the content pages of the major epidemiological journals and citations in any of the relevant articles. We also consulted with experts in the relevant field to obtain more comprehensive data. The search was not limited geographically or to English language publications only. The available published and unpublished literature was searched from January 1960 to November 2011 inclusive.

Multiple combinations of the keywords were used, depending on the search engine. The keywords used are presented in Table 1.

The following combinations of search categories were performed: 1 AND 3; 1 AND 2 AND 3; and 1 AND 3 AND 4.

Data extraction

Two investigators (DB and SP) independently extracted information from the identified studies. Training of raters to achieve sufficient (>0.80) interrater reliability was conducted.

Interrater reliability, also called interrater agreement or concordance, is a statistical measure of the degree of agreement among raters. It gives a score of how much homogeneity, or consensus, there is in the ratings given by different raters. To calculate interrater reliability, Fleiss' kappa statistics using attribute agreement analysis was used. All analyses related to interrater reliability were computed using Minitab statistical software (2007). A third investigator (SL) checked the table entries for accuracy, against the original article.

Using a standardized spreadsheet (Microsoft Office Excel), each study was coded for the following variables: reference, year(s) of study, country where the study was conducted, and direct, indirect and other cost drivers.

Table 1. Keywords used in the present systematic review of the literature

	Keywords
1. Disease condition	Fetal alcohol spectrum disorder (FASD), fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS), fetal alcohol effects (FAE), alcohol-related neurodevelopmental disorder (ARND), alcohol-related birth defects (ARBD) In addition: prenatal alcohol exposure, pregnancy, alcohol, use, abuse
2. Outcomes	Disability, disability adjusted life years (DALY), quality adjusted life years (QALY), morbidity, premature mortality, potential years of life lost (PYLL), productivity losses
3. Cost	Social cost, economic cost, direct and indirect costs, intangible cost
4. Systems/categories of cost	Health care (hospitalizations, hospital days, ambulatory care, emergency room visits, family physician visits, prescription drugs), mental health, addiction services, child welfare, early childcare, education (special needs, assessment, suspensions, staff time and salaries), social services (home support services, residential care, respite care), criminality, housing assistance, employment (training co-workers and managers, training FASD-affected employees, lost wages, repeated job training due to repeated job loss)

RESULTS

The contents of 233 abstracts or full-text manuscripts identified during the literature search were reviewed to determine whether they met the criteria for inclusion. Ninety-five potentially relevant studies were identified and screened. Of these 95 studies, 72 were further excluded due to the absence of data on cost drivers associated with FAS/FASD. As a result, only 13 well-documented cost studies with comprehensive methodologies were selected: 3 studies from Canada and 10 studies from the United States. Figure 1 presents a flow diagram describing the selection of FAS/FASD cost studies for the analysis. There were no comprehensive FASD cost studies found for any countries other than Canada and the United States.

Interrater reliability

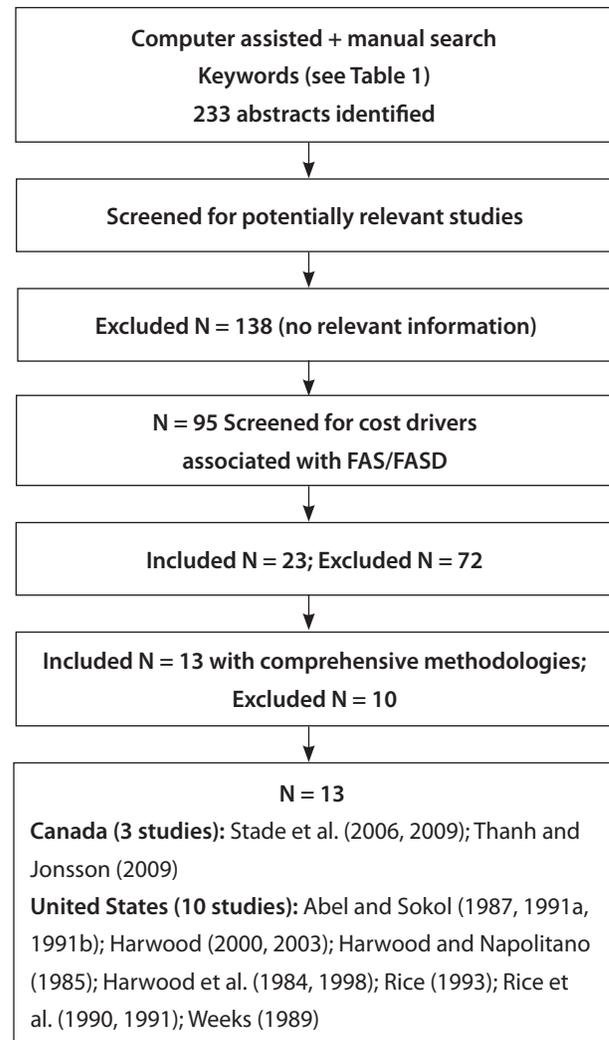
There was a very high interrater reliability (IRR; kappa = 0.81, $p < 0.0001$) among the two reviewers across all variables coded. Discrepancies were reconciled by a fourth investigator (JR), independent of the first process.

Only well-documented estimates with comprehensive methodologies were included in the analysis and are presented in Tables 2 and 7.

Derivation of costs for comparison

All studies used the local currency for estimating costs and used the same currency value as the costing year. To facilitate comparison, the estimated costs in the Canadian studies were converted to May 2010 currency values using the inflation calculator of the Bank of Canada (www.bankofcanada.ca/en/rates/inflation_calc.html). The estimated costs in U.S. studies were converted to June 2010 currency values using currency inflation

Figure 1. Flow diagram describing selection of FAS/FASD cost studies for the systematic review



rates calculated from the consumer price indexes (U.S. Department of Labor, 2009; <ftp://ftp.bls.gov/pub/special.requests/cpi/cpiiai.txt>).

Canadian studies

(all costs in Canadian dollars)

Three studies in Canada have estimated the cost associated with FASD (i.e., Stade et al., 2006, 2009; Thanh & Jonsson, 2009). Thanh and Jonsson (2009) estimated the cost for Alberta based on the methodology from Stade et al. (2006). Table 2

Table 2. Annual cost and lifetime cost (in Canadian dollars) per individual associated with FASD in Canadian studies

Reference	Year of Study; Province (if applicable)	P/I per 1,000	Age	DIRECT COST			INDIRECT COST (Productivity Losses)	OTHER COST (Out-of-Pocket)	Annual Cost for All Persons with FASD (95% CI)		Adjusted* Annual Cost for All Persons with FASD (95% CI)		
				Health Care	Education	Social Services			Total Direct Costs	Annual Cost for All Persons with FASD (95% CI)	Annual Cost per Individual (95% CI)	Adjusted* Annual Cost for All Persons with FASD (95% CI)	Adjusted* Annual Cost per Individual (95% CI)
Stade et al., 2006	2003	3 (P)	1–21	\$3,976; 30.3%	\$4,275; 32.6%	\$2,866; 21.9%	\$11,117; 84.8%	\$1,055; 8.1%	\$936; 7.1%	\$344.2 M (\$311.7 M – \$376.8 M)	\$14,342 (\$12,986 – \$15,698)	\$390.2 M (\$353.4 M – \$427.2 M)	\$16,259 (\$14,722 – \$17,796)
Stade et al., 2009	2007	3 (P)	0–53	\$6,630; 35%	\$5,260; 28%	\$4,075; 18.8%	\$15,965; 82%	\$1,431; 6.6%	\$2,814; 13%	\$5.3 B (\$4.12 B – \$6.4 B)	\$21,642 (\$19,842 – \$24,041)	\$5.5 B (\$4.3 B – \$6.7 B)	\$22,473 (\$20,604 – \$24,965)
Thanh & Jonsson, 2009 (Stade et al., 2006 cost data used)	2002–2005 (2008)	3 & 9 (I)	0–71.6	Included; 30.3%	Included; 32.6%	Included; 21.9%	84.8%	Included; 8.1%	Included; 7.1%	\$130 M – 400 M (long-term cost); \$48 M – \$143 M (short-term cost)	\$1.1 M (lifetime cost per individual)	\$148.4 M – \$428.4 M (long-term cost); \$48.5 M – \$144.5 M (short-term cost)	\$1.12 M (lifetime cost per individual)

* Adjusted for inflation (May 2010)
B: billion; CI: confidence interval; I: incidence; M: million; P: prevalence

presents the cost estimates for Canada, which are broken down into four categories: direct health care costs, other direct costs, indirect costs (productivity losses) and other costs (out-of-pocket). A condensed description of the methodologies of the above studies follows.

STADE ET AL. (2006)

This study, at the individual patient level, estimated that the total adjusted annual cost associated with FASD per child was \$14,342 (95% CI: \$12,986 – \$15,698) in 2003. At the population level, using a conservative prevalence rate of 3 per 1,000 live births (Roberts & Nanson, 2000), the cost of FASD annually within Canada of those 1 to 21 years old was \$344.2 million (95% CI: \$311,664,000 – \$376,752,000). This study estimated costs from the perspective of society, the Ministry of Health and the patient/family.

This study was conducted throughout rural and urban settings across Canada and used a prospective cross-sectional research design. Participants were elicited from FASWorld Canada, a national parent support agency representing over 11 support groups and providing service for over 700 children and their parents.

The study sample consisted of 148 parents (biological, adoptive or foster) who were living with a child between the ages of 1 and 21 who had been diagnosed with either FAS or FAE (considered as FASD) or caregivers who were responsible for the care and welfare of the child. The Health Services Utilization Inventory (HSUI) was modified to collect data and measure the quantity of different types of health services used by the parents/caregivers of children with FASD. The HSUI consisted of questions about the respondents' direct costs including costs of medical care (hospital admissions, health professional services, medication), costs of educational services (home schooling, special schooling), costs of social services (respite care, foster care) and costs to parents or caregivers (parking and transportation costs and costs of externalizing behaviours, which include acts of aggression such as damage

to people/property or stealing). The tool also included questions to assess indirect costs such as days missed from work due to caring for the child with FASD. Thus, the key cost components included direct costs (medical, education and social services), indirect costs (productivity losses) and other costs such as out-of-pocket expenses or private costs (Table 3).

Total average expenditures per child were calculated by summing the costs for each child in each cost component and dividing by the sample size. Costs were extrapolated to one year (i.e., 2003). A stepwise multiple regression analysis was used to identify important determinants of costs and to calculate the adjusted annual costs associated with FASD.

Unit costs associated with costs of treatment and care identified by the parents/caregivers in the HSUI were collected from various sources including pediatric hospitals, the Ministry of Education, the Ontario Ministry of Community and Social Services, the Ontario Schedule of Physician Benefits and the Ontario Drug Formulary.

Productivity losses were measured using the human capital approach. Indirect costs such as days of missed work due to caring for the child with FASD were estimated using information elicited from HSUI, multiplying the number of days of work missed by the parents' or caregivers' average daily wage.

Costs that are incurred because of the child's externalizing behaviours were included in the total estimate of costs. All costs incurred by parents and caregivers were assigned to the child as the unit of analysis. An incidence approach, which begins at birth, was used.

The severity of the disability and the age of the child were both significant direct predictors of cost. The study revealed that the cost for children aged 6 to 15 years was characterized by a higher degree of health care use and thus higher costs when compared to the other age groups, while the older children reflected costs of educational needs and those due to externalizing behaviours. The average

Table 3. Average annual cost of FAS/FAE per case

Component	Societal		Ministry of Health/ Social Services		Patient	
	Cost (\$)	% of total	Cost (\$)	% of total	Cost (\$)	% of total
Direct Costs: Medical	\$15,975.80 (Neonatal)		\$15,975.80 (Neonatal)			
Hospitalization	\$160.00		\$160.00		N/A	
Emergency Room/Clinic Visits	\$53.00		\$53.00		N/A	
TOTAL	\$213.00		\$213.00			
Visits to Health Professionals						
Family Doctor	\$167.72		\$167.72		N/A	
Orthopedic Surgery	\$76.80		\$76.80			
Urologist	\$55.95		\$55.95			
Allergist	\$5.71		\$5.71			
Pediatrician	\$97.93		\$97.93			
Psychiatrist	\$858.65		\$858.65			
Occupational Therapist	\$115.88		\$115.88			
Physiotherapist	\$115.80		\$115.80			
Speech Therapist	\$7.00		\$7.00			
Psychologist	\$925.00		\$925.00			
Medical Devices	\$550.00		\$470.00		\$42.50	
Medication Dispensing Fees	\$41.94		\$25.16		\$4.20	
Prescription Medications	\$449.79		\$245.80		\$166.80	
Non-Prescription Medication	\$249.60		N/A		\$249.60	
Diagnostic Tests	\$45.72		\$45.72		N/A	
TOTAL	\$3,975.88	30.3%	\$3,425.51	32.4%	\$463.10	18.9%
Direct Costs: Education						
Home Schooling	\$27.30		\$27.30		N/A	
Special Schooling	\$1,560.00		\$1,560.00		N/A	
Residential Program	\$2,688.00		\$2,688.00		N/A	
TOTAL	\$4,275.30	32.6%	\$4,275.30	40.5%		
Direct Costs: Social Services						
Respite Care	\$144.00		\$144.00		N/A	
Foster Care	\$2,122.03		\$2,122.03		N/A	
Legal Aid	\$600.00		\$600.00		N/A	
TOTAL	\$2,866.03	21.9%	\$2,866.03	27.1%		
Out-of-Pocket						
Transportation Per Visit	\$40.86		N/A		\$40.86	
Parking	\$55.25		N/A		\$55.25	
Externalizing Behaviours	\$840.00				\$840.00	
TOTAL	\$936.11	7.1%	N/A		\$936.11	38.1%
TOTAL DIRECT COSTS	\$12,053.32	91.9%				
Indirect Costs: Productivity Losses	\$1,055.25	8.1%				
TOTAL COSTS	\$13,108.57	\$10,566.84			\$2,454.46	

N/A: not applicable

Source: Stade et al. (2006)

annual costs appear to peak in early adolescence. Costs were higher in Central and Western Canada when compared to Eastern Canada.

To estimate the cost of FAS/FAE annually in Canada, a very conservative estimate of the prevalence of FAS/FAE in Canada was used (3 in 1,000 people; Roberts & Nanson, 2000). The number of people between the ages of 1 and 21 years in Canada in 2003 was approximately 8 million (Statistics Canada, 2003). Therefore, a conservative estimate of FAS/FAE in the 1- to 21-year age group in Canada in 2003 is 24,000 individuals. The adjusted annual cost of FAS/FAE in Canada for ages 1 to 21 years at the individual level is \$14,342 (95% CI: \$12,986 – \$15,698). Thus, a very conservative estimate of the cost of FAS/FAE annually to Canada is \$344,208,000 (95% CI: \$311,664,000 – \$376,752,000) or \$344.2 million (95% CI: \$311.7 million – \$376.8 million). Education accounted for 32.6% of the total costs, followed by health care at 30.3%, social services at 21.9%, productivity losses at 8.1%, and out-of-pocket expenses at 7.1%. Hutson (2006) estimated that if the annual cost of \$344.2 million was extrapolated to age 65, it would result in an estimated 3–4 billion dollar annual cost in Canada.

STADE ET AL. (2009)

This study attempted to overcome the limitations of the previous cost estimate by Stade et al. (2006) by including the costs for infants from the day of birth to 1 year of age, the costs for adults beyond the age of 21 and the costs for children residing in institutions.

This study was conducted throughout urban and rural communities in Canada, using a cross-sectional design. Participants were elicited from parent support agencies across Canada that aid over 1,000 people affected by FASD.

Children, youth and adults with FASD (diagnosed as FAS, pFAS or ARND) and their caregivers were among the 250 participants. Ten participants were adults with FASD, and 240 were parents or caregivers of a child diagnosed with FASD. All participants completed the

modified HSUI, similar to the one used in Stade et al. (2006). The modified HSUI consisted of questions about the respondents' medical care costs (hospital admissions, cost of surgeries, health professional services, medication), costs of educational services (home schooling, special schooling, infant stimulation or therapy program), costs of social services (respite care, foster care), cost of institutionalization, government pensions, adoption costs and costs to parents or caregivers (parking and transportation costs and costs of externalizing behaviours). The tool also included questions to assess indirect costs such as days missed from work due to caring for the child with FASD.

Unit prices for services and care identified by the parents/caregivers were collected separately, and the total expenditures for services used were calculated. Unit costs associated with costs of treatment and care identified by parents/caregivers in the HSUI were collected from various sources including pediatric hospitals across Canada, the Ministry of Education, Ministries of Community and Social Services, Ministries of Health and Long-Term Care, Schedules of Physician Benefits and Provincial Drug Formularies, along with others.

Productivity losses were calculated by estimating parents' or caregivers' lost wages, using the human capital approach. Indirect costs such as days of missed work due to caring for the child with FASD were estimated using information elicited from the HSUI, multiplying the number of days of work missed by the parents' or caregivers' daily wage.

Costs incurred due to externalizing behaviours (damage to people/property, stealing) were included in the total estimate of costs wherever possible. Costs were analyzed from the perspective of society, the provincial ministries of health and the patient. An incidence approach beginning from birth was used.

Key cost components included direct costs (medical, education and social services), indirect costs (productivity losses) and other costs (out-of-pocket, which included transportation, parking

Table 4. Average annual cost of FASD per case

Component	Societal Cost (\$)	Ministry of Health/ Social Services Cost (\$)	Patient Cost (\$)
Direct Costs: Medical			
Hospitalization	\$1,445.45	\$1,445.45	N/A
Emergency Room/Clinic Visits	\$660.82	\$660.82	N/A
	\$2,106.27	\$2,106.27	
Visits to Health Professionals			
Family Doctor	\$301.15	\$301.15	N/A
Orthopedic Surgery	\$67.68	\$67.68	N/A
Urologist	\$46.10	\$46.10	N/A
Allergist	\$6.08	\$6.08	N/A
Pediatrician	\$241.65	\$241.65	N/A
Psychiatrist	\$892.00	\$892.02	N/A
Occupational Therapist	\$444.12	\$352.00	\$92.12
Physiotherapist	\$91.00	\$91.00	\$00.00
Speech Therapist	\$58.54	\$28.31	\$30.23
Psychologist	\$737.39	\$122.00	\$615.39
	\$2,885.73	\$2,147.99	\$737.74
Medical Devices	\$416.02	\$282.00	\$134.02
Medication Dispensing Fees	\$56.00	\$47.50	\$8.50
Prescription Medications	\$800.00	\$592.00	\$208.00
Non-Prescription Medication	\$218.08	N/A	\$218.08
Diagnostic Tests	\$148.00	\$148.00	N/A
	\$1,638.10	\$1,069.50	\$568.60
Total	\$6,630.10	\$5,323.76	\$1,306.34
Direct Costs: Education			
Home Schooling	\$198.50	\$198.50	N/A
Special Schooling	\$3,237.60	\$3,237.60	N/A
Residential Program	\$1,600.00	\$1,000.00	\$600.00
Post-Secondary Education – Tutor	\$64.00	N/A	\$64.00
Job Education	\$160.00	\$160.00	N/A
Total	\$5,260.10	\$4,596.10	\$664.00
Direct Costs: Social Services			
Respite Care	\$151.84	\$151.84	N/A
Foster Care	\$2,000.40	\$2,000.40	N/A
Institutionalization	\$1,654.95	\$1,654.95	N/A
ODSP	\$143.34	\$143.34	N/A
Legal Aid	\$125.00	\$125.00	N/A
Total	\$4,075.53	\$4,075.53	
Out-of-Pocket			
Transportation Per Visit	\$152.16	N/A	\$152.16
Parking	\$162.00	N/A	\$162.00
Externalizing Behaviours	\$2,500.12	N/A	\$2,500.12
Total	\$2,814.28	N/A	\$2,814.28
TOTAL DIRECT COSTS	\$18,780.01	\$13,995.39	\$4,784.62
Indirect Costs: Productivity Losses	\$1,430.65		
TOTAL COSTS	\$20,210.66		

N/A: not applicable

Source: Stadel et al. (2009)

and externalizing behaviours). The average annual costs, broken down by cost components, of FASD per case reported by Stade et al. (2009) are presented in Table 4 on page 15.

The total average cost per individual with FASD was calculated by summing the costs for each participant in each cost component and dividing by the sample size. Costs were extrapolated to one year (i.e., 2007). A stepwise multiple regression analysis was used to identify the significant determinants of costs and to calculate the adjusted annual costs associated with FASD. The total unadjusted costs were calculated at the individual level by summing the costs for each child in each cost component.

Stade et al. (2009) also revealed that the costs for children 0 to 3 years of age were higher than for all other age groups. The adjusted annual costs per individual, broken down into age groups, are presented in Table 5.

As evident in Table 5, costs begin to plateau between the ages of 18 and 25 years, and costs for the 36- to 45-year and 46- to 53-year age group were the lowest. Clinical data suggest that there is not only a lack of services for the older age groups, but also an inability for young adults and adults with FASD to access services due to their cognitive and executive functioning difficulties, as well as their unwillingness to accept services.

Stade and colleagues (2009) also calculated

the annual cost of FASD in Canada of those 0 to 53 years of age with FASD using the prevalence of FASD of 10 per 1,000 live births. The number of people from day of birth to 53 years in Canada in 2007 was approximately 24.29 million (Statistics Canada, 2008). Therefore, FASD in this age cohort in Canada in 2007 is estimated to be 242,906 individuals. The adjusted annual cost of FASD in Canada for ages 0 to 21 years at the individual level is \$21,642 (95% CI: \$19,842 – \$24,041). The annual cost to Canada of those 0 to 53 years of age with FASD is \$5.3 billion (95% CI: \$4.12 billion – \$6.4 billion).

This study was limited to individuals affected by FASD from the day of birth to 53 years of age. It also did not estimate associated law enforcement costs and did not include individuals who were incarcerated at the time of data collection; thus, these oversights may have lead to an underestimation of the total cost.

THANH AND JONSSON (2009)

This study estimated two categories of costs associated with FASD in Alberta: the annual long-term costs and the annual short-term costs. The annual long-term economic cost of FASD is referred to as the projected amount of money incurred by the cohort of children born with FASD each year. This is a societal-perspective cost, equal

Table 5. Adjusted annual costs per individual with FASD according to age

Age Range (Years)	N	Mean	95% CI
0 to 2	20	\$30,222	\$26,302 – \$38,222
3 to 6	36	\$26,544	\$23,666 – \$30,328
7 to 12	60	\$28,666	\$25,446 – \$32,832
13 to 17	48	\$20,201	\$16,997 – \$24,885
18 to 21	36	\$16,544	\$14,888 – \$18,234
22 to 25	18	\$16,232	\$14,666 – \$18,002
26 to 35	12	\$15,998	\$14,021 – \$18,112
36 to 45	10	\$14,689	\$12,888 – \$16,681
46 to 53	10	\$14,810	\$12,664 – \$16,988

Source: Stade et al. (2009)

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 (71.6 years of age in 2005; CBC, 2008) of people affected by FASD with the annual cost per person with FASD (\$14,342 in 2006 or \$15,812 in 2008, obtained from Stade et al., 2006).

The number of children born with FASD per year was estimated by multiplying the FASD incidence rates of 3 and 9 per 1,000 live births (Alberta Alcohol and Drug Abuse Commission, 2004; Health Canada, 2007; Stade et al., 2006) with the number of live births for 2002 to 2005 (38,313 for 2002; 39,838 for 2003; 40,355 for 2004; and 41,355 for 2005; Reproductive Health Working Group, 2006).

The annual long-term economic cost of FASD was calculated using the following equation:

$$LC = (L \times C)(R \times B)$$

Where,

LC is the annual long-term economic cost of FASD

L is the average age of death of people with FASD

C is the annual cost per person with FASD

R is the FASD incidence rate

B is the number of live births per year

$(L \times C)$ = lifetime cost of caring for each child born with FASD

$(R \times B)$ = number of children born with FASD per year

The second cost category was based on the short-term economic cost of FASD, which refers to the amount of money incurred by people who are presently living with FASD. This was also a societal-perspective cost estimated by an FASD cost calculator developed by the FAS Center at the University of North Dakota.

The costs and disorder rates used in the calculator were in 1996–1997 U.S. dollars (USD),

based on North Dakota studies over an 18-year period (Burd & Wentz, 1997; Lupton et al., 2004) and included the following cost components: special education, juvenile justice services, health care costs, adult corrections and service delivery systems (foster care and residential treatment).

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 dollars (CND) using a discount rate of 5% and a USD/CND exchange rate of 1.03, which was the average rate of the first 10 months in 2008 (currency calculator available at www.x-rates.com).

From the total population, the number of births per year and the prevalence rates of FASD, the calculator first estimated the annual cohort of people with FASD and the number of FASD cases in the population, including those 18 years of age and under and those over the age of 19 (as services used by children and adults may differ and produce different costs).

Secondly, the calculator estimated a number of different consequences of FASD, including the number of deaths from FASD and cases of mental retardation, congenital heart defect, epilepsy, attention-deficit/hyperactivity disorder (ADHD), speech and language disorder, sensorineural hearing loss, cerebral palsy, autism or other pervasive developmental disorders. The calculator also computed the number of foster care placements and years spent in foster care, the number of years spent in special education and time spent in the juvenile justice system.

The study estimated that the lifetime cost of caring for each child born with FASD would equal $\$15,812 \times 71.6 \approx \1.1 million, assuming that the annual cost per child with FASD is \$15,812 and the average age of death is 71.6 years.

The total annual cost for FASD was estimated based on online calculations and using the following data: 41,456 live births per year (Reproductive Health Working Group, 2006), a total population of 3,413,500 in Alberta, and FASD incidence rates of 3 and 9 per 1,000 live births including FAS incidence rates of 1 and 3 per 1,000

live births and FAE incidence rates of 2 and 6 per 1,000 live births (Alberta Alcohol and Drug Abuse Commission, 2004; Stade et al., 2006). As such, the estimated total annual cost for FASD in Alberta was \$48 million to \$143 million, and estimated daily costs were \$105,000 to \$316,000 (Table 6). Of these, annual costs for special education and

juvenile justice for children with FASD aged 5 to 18 years accounted for 19%.

The study also estimated that the long-term economic cost of the disorders associated with FASD rose from \$130 to \$400 million from 2002 to 2005 in Alberta. The distribution of the costs was identical to those in the study by Stade et al. (2006).

Table 6. 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 1,000 live births	1	3
FAE rate per 1,000 live births	2	6
FASD rate per 1,000 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 to 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

	Lower	Upper
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	819	2,457
FAS	1,638	4,915
FAE	2,457	7,372
FASD	1,180	3,571
Years Foster Care		
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	3,936	11,904
Years Service Developmental Disability	1,660	5,022
Years Service Juvenile Justice System	98	297
Cost Calculations for FASD (2008 CND)		
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 www.online-clinic.com
Source: Thanh and Jonsson (2009)

It is likely that this study has under-represented the costs associated with FASD, as individuals residing in institutions, such as facilities for disabled children, those in the judicial system, and individuals who are homeless were not included in the calculations. Also, this study used national incidence rate estimates of FASD and annual cost per child with FASD. The national estimate of annual cost per child with FASD (Stade et al., 2006) is relevant for people aged 1 to 21 years and it is possible, and quite likely, that this cost varies by age group.

U.S. studies

(all costs in U.S. dollars)

The U.S. studies fall into two categories: those that estimate the total annual cost of FAS to the country and those that estimate the lifetime cost for each individual with FAS. The annual cost and lifetime cost for an individual with FAS in the United States and a list of the cost drivers included in the calculations are presented in Table 7. Brief descriptions of the methodologies of the studies follow.

Table 7. Annual cost and lifetime cost (in U.S. dollars) per individual associated with FAS in the U.S. studies

Reference	Year of Study	P/I per 1,000	Age	DIRECT COST				INDIRECT COST	OTHER DIRECT COST	Annual Cost for All Persons with FAS	Lifetime Cost per Individual with FAS	Adjusted* Annual Cost for All Persons with FAS
				Health Care	Home Care	Special Education	Total Direct Costs					
Harwood et al., 1980	1.0; 5.0; 1.67 (presented estimates are based on 1.67)	1.67	0-65	\$699 M (children \$125 M; adults \$574 M); 22%	HC & RC with day services: \$694 M; 22%	\$990 M; 31%	\$2.4 B; 75%	\$853.3 M; 25%	Not included	\$3.2 B	\$596,000	\$8.5 B
Harwood & Napolitano, 1985												\$1.6 M
Abel & Sokol, 1984	1.9	1.9	0-21	Growth retardation: \$118 M; cleft palate, Tetralogy of Fallot & sensorineural anomalies: \$18M; 42%	24-hr RC due to MR: 109 M; semi-independent supervised support: \$75.8 M; 58%	Not included	\$321 M	Not included	Not Included	\$321 M	N/A	\$674.1 M
Abel & Sokol, 1987												N/A
Weeks, 1989	1.67	1.67	0-65	Included	Included	Included	N/A	Included	Not included	N/A	\$1.4 M	N/A
Abel & Sokol, 1984	0.33	0.33	0-21	Treatment cost: \$16.9 M; 22.7%	24-hr RC due to MR: \$57.7 M; 77.3%	Not included	\$74.6 M	Not included	Not included	\$74.6 M	N/A	\$156.7 M
Abel & Sokol, 1987	1.9	1.9	0-21	Treatment cost: \$104.5 M; 42%	24-hr RC due to MR: \$145.2 M; 58%	Not included	\$249.7M	Not included	Not included	\$249.7M	N/A	\$479.4 M

Reference	Year of Study	P/I per 1,000	Age	DIRECT COST				INDIRECT COST (Productivity Losses)	OTHER DIRECT COST	Annual Cost for All Persons with FAS		Adjusted* Annual Cost for All Persons with FAS	
				Health Care	Home Care	Special Education	Total Direct Costs			Cost; percentage of total cost	Lifetime Cost per Individual	Annual Cost	Adjusted* Lifetime Cost per Individual
Rice et al., 1990, 1991	1985	1.9	0-65	Treatment: RC for 21+ yrs \$135 M; 8.4% included	Not included	Not included	Research \$3 M; 0.2%		\$1.6 B	N/A	\$3.25 B	N/A	
				79.9%; full-time RC <21 yrs \$110 M, 6.8%; semi-independent supervised care \$76 M, 4.7%	Not included	Not included							
Rice, 1993 (update of Rice et al., 1990; 1991)	1990	1.9	0-65	Included	Included	Not included	Included		\$2.1 B	N/A	\$3.6 B	N/A	
Harwood et al., 1998 (update of Harwood et al., 1984 and Harwood & Napolitano, 1985)	1992	2	0-65	Included	Included	N/A	Included	Not included	\$1.9 B	N/A	\$3.04 B	N/A	
Harwood 2000 (update of Harwood et al., 1998)	1998	2	0-65	Included	Included	\$2.9 B	\$1.25 B	Not included	\$4.2 B	N/A	\$5.5 B	N/A	
Harwood 2003 (update of Harwood, 2000)	2003	2	0-65	Included	Included	\$3.9 B	\$1.5 B	Not included	\$5.4 B	N/A	\$6.5 B	N/A	

* Adjusted for inflation (June 2010)

B: billion; HC: home care; I: incidence; M: million; MR: mental retardation; N/A: not available; P: prevalence; RC: residential care

HARWOOD ET AL. (1984); HARWOOD AND NAPOLITANO (1985)

Using a societal perspective and data from Russell (1980), Harwood and colleagues (1984, 1985) generated cost estimates for the year 1980 of between \$1.937 and \$9.687 billion with a median estimate of \$3.236 billion, using alternative FAS

incidence rates (based on a review of prospective studies) of 1, 5, and 1.67 per 1,000 live births, respectively. Total lifetime cost was estimated at \$596,000 per FAS birth.

Costs included estimates of medical treatment, home and residential care, special educational services and productivity losses for individuals

Table 8. Lifetime cost estimates of specific birth defects associated with FAS

(A) Specific Birth Defect	(B) Annual Cost of Treatment	(C) Length of Treatment Period	(D) Lifetime Cost	Estimation of Prevalence in FAS (percentage)
Prenatal growth retardation	Neonatal intensive care: 7 days at \$500 per day	Once	\$3,500	80
Postnatal growth retardation	Hospital evaluation \$750	Once	750	80
Audiological deficits	A. Neonatal intensive care: auditory screening at \$105/procedure	Once	105	100
Serous otitis media	B. Series of audiological evaluations: 1st evaluation at \$45/visit, subsequent evaluations at \$25/visit	Every 3 months for 1st year of life	120	56
Mild sensorineural hearing loss		Semi-annually through adolescence	600	56
	C. Surgery (myringotomies) at \$400 physician's fee	Once	400	56
	D. Hearing aids at \$500/aid including office visits	Through ages 10–12	500	33
Minimal brain dysfunction	Special education "Resource room" at \$7,400/year	Ages 5–18	103,600	52.5
Mild–moderate mental retardation	A. Ambulatory care with special education at \$15,000/year	Ages 3–21	270,000	45
	B. Home care with day services at \$6,200/year	Ages 22–65	272,800	36
	C. Residential care with day services at \$18,500/year	Ages 22–65	814,000	9
Severe mental retardation	Institutionalization at \$25,000/year	Ages 5–65	1,500,000	2.5
Heart defects requiring surgery	\$17,500 + \$750 annual checkup	5 years	21,250	5
Cleft palate	Series of operations plus speech therapy	10–15 years	45,000	12.5
Kidney defects	Treatment required not yet known		N/A	N/A
Neurotube	\$35,000 per year	5–10 years	262,500	0.5

N/A: not applicable

Source: Harwood and Napolitano (1985)

with FAS of all ages (0–65). The values and the estimated costs of particular treatments are presented in Table 8 on page 23.

The incidence rate of 1.67 implies that there were 380,000 individuals with FAS in 1980 with direct service costs of \$2.4 billion: 114,000 children with FAS, with health treatment costs of \$125 million and educational service costs of \$990 million; and 267,000 adults with FAS, with health treatment costs of \$574 million and other services costs of \$694 million (Table 9).

Productivity losses due to mental retardation amounted to \$853.3 million for a mid-range incidence rate of FAS (1.67 cases per 1,000) in 1980.

ABEL AND SOKOL (1987)

This study estimated costs from the perspective of the health care system from birth to 21 years of age. The study used an FAS incidence of 1.9 per 1,000 live births, which was drawn, on average, from several prospective and retrospective studies.

This study estimated the economic cost of FAS to the health care system to be \$321 million in 1984.

The study estimated the costs of providing special services for pre- and postnatal growth retardation requiring neonatal intensive care, surgical repair of FAS-related birth defects and subsequent treatment (Tables 10 and 11), care for patients with FAS who have moderate or severe cognitive disabilities, and the cost of semi-independent supervised support for patients with FAS who have mild cognitive disabilities.

Pre- and postnatal growth retardation

The estimation of the cost of treatment for infants with FAS was adapted from the analysis of cost estimates used by the Institute of Medicine (1985) and consisted of several components: initial hospitalization in intensive care; costs of repeat hospitalization during the following year for surviving children; and non-institutional, non-hospital morbidity costs for children surviving the first year of life.

Table 9. Expected cost of direct services in 1980 due to FAS using regimen proposed in Table 8

Ages	Total Population in Age Cohorts (thousands)	Annual Expected Cost of Treatment (\$)	Total Cost at Prevalence Rate					
			Conservative 1/1,000		Mid-range 1/600		High 1/200	
			Cost		Cost		Cost	
			Persons	(\$ millions)	Persons	(\$ millions)	Persons	(\$ millions)
0	3,598	4,122	3,598	14.8	6,900	24.8	17,990	74.2
1	3,212	578	3,212	1.9	5,364	3.1	16,060	9.3
2	3,212	967	3,212	3.2	5,364	5.2	16,060	15.5
3–4	6,425	7,328	6,425	47.1	10,730	78.6	32,125	235.4
5	3,453	12,713	3,453	43.9	5,767	73.3	17,265	219.5
6–7	6,906	11,876	6,906	82.0	11,533	137.0	34,530	410.1
8–9	6,906	11,701	6,906	80.8	11,533	135.0	34,530	404.0
10–14	17,846	11,663	17,846	208.1	29,803	347.6	89,230	1,040.7
15–18	16,483	11,260	16,483	185.6	27,527	310.0	82,415	928.0
19–21	13,143	7,375	13,143	96.9	21,949	161.9	65,715	484.7
22–64	120,765	4,522	120,765	546.1	201,678	912.0	603,825	2,730.5
65+	25,708	4,522	25,708	116.3	42,932	194.1	128,540	581.3
Total	227,657	404,638	227,657	1,426.6	380,187	2,382.4	1,138,285	7,133.1

Source: Harwood and Napolitano (1985)

Table 10. Annual cost estimates associated with FAS-related intrauterine growth retardation

	Total Cases	Cost for Intensive Care (\$)	Total Cost (\$)
Growth retardation at birth	5,608 ^a		
1500–2500 g	4,167 ^b	\$20,000	\$44,446,000
<1500 g	1,441 ^c	\$40,000	\$57,640,000
Rehospitalization of low birthweight infants	5,159 ^d		
1500–2500 g	3,833 ^e	12.5 days @ \$372/day ^f	\$17,818,800
<1500 g	1,326	16.2 days @ \$372/day ^f	\$7,991,006
Single-year morbidity	955 ^g	\$1,405	\$1,341,775
Total annual cost			\$118,127,581

a Total no. of FAS, patients weighing <2500 (7,028 x 79.8%).

b 74.3% of total; of these, 40% require intensive care.

c 25.7% of total. All require intensive care.

d Based on 8% mortality rate.

e 74.3% of total.

f Length of stay and cost per day based on Institute of Medicine (1985) estimates.

g Based on 2% mortality and 18.9% morbidity rate for rehospitalized infants.

Source: Abel and Sokol (1987)

Table 11. Annual cost estimates for treatment of select organic and sensorineural disorders

Disorder	Number of Cases	Cost per Patient	Total Annual Cost
Cleft Palate (11.5%)^a	808 ^a	18,830	15,214,640
Surgical consultation (\$700) and repair (\$1,100–\$1,500) ^b		\$2,000	
Hospital recovery (21 days @ \$650/day) ^b		13,650	
Speech evaluation (\$60) and therapy (\$30/session, twice weekly) ^b		3,180	
Heart defects			
Tetralogy of Fallot (3.2%) ^c	225 ^c	9,000	2,025,000
Surgical repair		4,000	
Hospital recovery (3 days intensive care @ \$1,100/day and 6 days regular care @ \$650/day) ^d		5,000	
Auditory defects (4.8%)^e	337 ^e	630	212,310
Serous otitis media (myringotomy)		\$150	
Initial Auditory Screen (\$75), 4 follow-up/yr (\$25), hearing aid evaluation and skeleton (\$50), hearing aid orientation (\$30), hearing aid (\$300)		480	
Ophthalmological defects			
Strabismus, retinal tortuosity, myopia, astigmatism		Unknown	
Dental defects		Unknown	

a Based on incidence in case literature and extrapolated to annual FAS population, 11.5% (7,024).

b D. Wageman, Children's Hospital, Wayne State University, personal communication.

c Based on incidence in case literature and extrapolated to annual FAS population, 3.2% (7,024).

d Children's Hospital, Wayne State University, personal communication.

e D. Wageman, personal communication.

Source: Abel and Sokol (1987)

Organic and sensorineural anomalies

Reports of disorders typically requiring surgical correction were used in the study. Incidence and costs associated with cleft palate, Tetralogy of Fallot, sensorineural handicap (e.g., hearing loss, hearing aids) and ophthalmological and dental defects were estimated.

Mental retardation

Two methods were used to estimate costs for FAS patients requiring 24-hours residence care due to mental retardation: (1) retrospective—determining the proportion of people with mental retardation already in special facilities for whom FAS has been diagnosed and extrapolating to the total population of people with mental retardation; and (2) prospective—determining the incidence of mental retardation among those with FAS for a cohort up to age 21 (Table 12).

Table 12. Alternate methods of estimating costs for FAS patients requiring 24-hours residence care due to mental retardation (MR)

Retrospective Projection <i>Based on incidence of FAS among mentally retarded</i>	Prospective Projection <i>Based on MR among FAS patients</i>
Total no. 24-h MR residents = 205,336	No. FAS cases/year = 7,024
No. FAS residents = 4969 ^a	Rate of MR = 15.3%
Median annual cost/24-h resident = \$22,885	Total FAS cases with MR/year = 1,075
	Less 18% mortality rate = 881
	Total no. over 21 year period = 18,506
Total annual cost for all FAS residents = \$113,720,000	Less 25% ascertainment rate = 4,626
	Total annual cost = \$105,866,010 ^b
Average no. of residents = 4,777	
Average total cost = \$109,800,789	

a Based on total of 205,336 and rate of 24.2 per 1,000 live births.

b Does not include additional \$75 870 816 for semi-independent supervised support.

Source: Abel and Sokol (1987)

Steps in estimating the costs for treating FAS patients

First, the authors determined the number and percentage of FAS patients with low birth weight by cataloguing all FAS case histories in the literature with respect to birth weight. Second, they calculated rehospitalization costs during the first year, using the Institute of Medicine (1985) estimates of neonatal mortality rate (8/100). These costs were estimated by considering children with moderate and very low birth weight separately (due to differences in length of stay). The third component of the Institute of Medicine's (1985) estimate involved long-term single-year morbidity costs. The Institute estimated an additional 2% mortality and that 18.9% of infants with low birth weight who survive their first year would have long-term morbidity.

ABEL AND SOKOL (1991a)

This study is a revised estimate of Abel and Sokol (1987) and, likewise, was based on a health care perspective; however, it used a much lower incidence rate of 0.33 per 1,000 live births (compared to 1.9 per 1,000 live births; Abel & Sokol, 1987). This conservative estimate was derived from prospective studies, which did not include estimates for Native Americans and other racial or ethnic groups that might face a higher risk of being diagnosed with FAS. In addition, the cost of semi-independent supervised support for patients with mild cognitive disabilities was excluded from this study since this support is usually required after the age 21. This study also did not include costs incurred by people with FAS beyond age 21. This estimate included medical treatment costs for children with FAS and residential care costs due to mental retardation (Table 13).

Table 13. Summary of annual cost for select problems related to FAS

Condition	Cost	Percentage of Total
Low birth weight	\$12,390,940	16.62
Heart defects	\$1,904,736	2.55
Spina bifida	\$216,489	0.29
Cleft palate	\$565,552	0.76
Serous otitis media	\$1,252,242	1.68
Sensorineural auditory defects	\$104,640	0.14
Inguinal hernia	\$172,774	0.23
Hypospadias	\$296,480	0.40
Mental retardation (full-time residential care)	\$57,657,248	77.3
Total	\$74,561,101	

Source: Abel and Sokol (1991a)

Based on these considerations, the estimated annual cost of treating FAS was much lower—\$74.6 million in 1984, as compared to \$321 million in Abel and Sokol (1987). More than 77% of the costs were associated with residential care due to mental retardation. This estimate was strictly limited to FAS and did not include ARBD, the prevalence of which is probably much higher.

Costs were estimated in two ways. First, by determining the proportion of people with mental retardation already in special facilities for whom FAS has been diagnosed, and extrapolating to the total population of people with mental retardation. This estimate was then “corrected” for personal item costs that would be incurred whether or not the individual suffered from mental retardation (e.g., food, clothing). Second, a prospective approach was adopted to determine the prevalence of mental retardation among those with FAS for a cohort up to age 21. Estimates for decreased productivity or related economic impact were not included.

Based on these considerations, and correcting for a background prevalence of 2.3% and personal consumption costs that would have been incurred in any case, the prospective approach estimated that annual total cost for full-time residential

patients was approximately \$33.8 million. Averaging of the retrospective and prospective estimates yielded an annual average cost of about \$57.7 million due to FAS.

As in the previous study, pain and suffering and other aspects contributing to quality of life were not taken into account. Although attempts have been made to place a dollar value on these aspects, they are at best problematic. Also, estimates for anesthesia associated with surgical procedures were not included since these are often billed on an hourly basis and vary considerably depending on the procedure.

ABEL AND SOKOL (1991b)

In this study, the total annual cost for 1987 was estimated at \$250 million (Table 14).

Table 14. Summary of annual cost for select problems related to FAS

Condition	Cost	Percentage of Total
Low birth weight	\$76,579,143	30.66
Heart defects	\$12,001,725	4.81
Spina bifida	\$1,319,552	0.53
Cleft palate	\$3,496,634	1.40
Serous otitis media	\$7,266,420	2.91
Sensorineural auditory defects	\$939,840	0.38
Inguinal hernia	\$1,070,356	0.43
Hypospadias	\$1,831,200	0.73
Mental retardation (full-time residential care)	\$145,246,608	58.36
Total	\$249,751,478	

Source: Abel and Sokol (1991b)

The authors included corrections for background rates of low birth weight and costs normally incurred for housing and food, regardless of whether an individual required institutionalization. The study included additional anomalies along with hospital costs noted in diagnosis-related groups, but did not include lost productivity costs, semi-independent support

services (e.g., persons living in community settings with ambulatory care and special education services) or residential services due to mental retardation after age 21.

The updated estimate of \$250 million is about \$70 million less than previous estimates due to a lower number of cases with low birth weight, a correction for costs that would otherwise have occurred, and exclusion of approximately \$75 million for annual semi-independent support for individuals with IQs in the range of 70–85. Of the \$250 million, 58% is accounted for residential care due to mental retardation.

RICE ET AL. (1990, 1991)

From the perspective of the health care system, Rice et al. (1990, 1991) estimated the annual cost of treating birth defects associated with FAS at \$1.6 billion, based on an incidence rate of 1.9 per 1,000 live births. The researchers used the same methodology as Abel and Sokol (1987) for their \$321 million estimate.

Cost drivers included the cost of care for FAS-related birth defects and cognitive disability, and residential care for patients with mental retardation who were over 21 years of age. Residential care and

support services for people with mental retardation over the age of 21 accounted for \$1.3 billion (79.9%), neonatal intensive care for treating growth retardation accounted for \$118 million (7.3%) and full-time residential care for persons under the age of 21 with severe mental retardation accounted for \$110 million (6.8%; Table 15).

RICE (1993)

Based on increasing population rates and health care costs between 1985 and 1990, Rice (1993) projected a \$2.1 billion total cost in the year 1990.

HARWOOD ET AL. (1998)

This study estimated annual costs to be \$1.944 billion in 1992, based on a prevalence rate of 2 per 1,000 live births (Table 16). This study re-estimated (1) the nature and cost of specific types of treatment, (2) the proportion of FAS cases requiring services and (3) the duration of services. This estimate included the following cost drivers: treatment and care services up to the age of 21, home and residential care up to the age of 65 for people with moderate to severe mental retardation, special education services and productivity losses.

Table 15. Estimated cost of FAS, 1985

Condition	Cost (million USD)	Percent of Distribution
Growth retardation (intensive care costs)	118	7.3
Growth retardation at birth	91	5.6
Rehospitalization of low birthweight infants	26	1.6
Single year morbidity	1	0.06
Abnormalities requiring surgical correction	17	1.1
Cleft palate	15	0.9
Heart defects	2	0.1
Auditory defects	0.2	0.01
Full-time residential care (for severely retarded) <i>under age 21</i>	110	6.8
Semi-independent supervised care (for moderately retarded)	76	4.7
Residential care for adults <i>over age 21</i>	1,287	79.9
Research	3	0.2
Total	1,611	100

Source: Rice et al. (1990)

Table 16. Health and other services for FAS, 1992

Specific Birth Defect	Annual Cost of Treatment	Length of Treatment Period	Percent in FAS	Population Served	Total Cost (millions)
Prenatal growth retardation	Neonatal intensive care: 7 days at \$2,000/day	Once, first year	80.0%	6,365	\$89.1
Postnatal growth retardation	Hospital evaluation \$2,357	Once, first year	80.0%	6,365	\$15.0
Audiological deficits	Neonatal screening \$97	Once, first year	100.0%	7,956	\$0.8
	AVR test, \$263	Once, first year	56.0%	4,455	\$1.2
	Acoustic impedance test \$51	Once, first year	56.0%	4,455	\$0.2
Serous otitis media	Surgery \$1,315 incl. recovery	Once, first year	81.0%	6,444	\$8.5
Midsensorineural hearing loss	Hearing aid evaluation \$124	Once by 12 yrs.	27.0%	2,205	\$0.3
	Hearing aids \$750	Once by 12 yrs.	27.0%	2,205	\$1.7
	Hearing aid check \$230	Once by 12 yrs.	27.0%	2,205	\$0.5
	Hearing aid check orientation \$81	Once by 12 yrs.	27.0%	2,205	\$0.2
Minimal brain dysfunction	Special education: one teacher plus one 7-hour educational assistance per 10 students at \$5,650/year	Ages 5–18	53.0%	52,955	\$299.2
Mild–moderate mental retardation	Special education: one teacher plus one 7-hour and one 4-hour educational assistance per 7.5 students at \$7,790/year	Ages 5–21	18.0%	20,661	\$161.0
	Home care \$32,850/year	Ages 22–65	14.4%	20,751	\$681.7
	Residential care \$36,500	Ages 22–65	3.6%	5,188	\$189.4
Severe mental retardation	Residential care \$36,500	Ages 5–65	5.0%	12,945	\$472.5
Cleft palate	Series of operations plus follow-up for hearing and speech, \$20,000	Once by 15 yrs.	12.5%	990	\$19.8
	Speech therapy at \$35/session weekly	One year, between ages 5 and 15	12.5%	997	\$1.8
Neurotube	Surgery at \$10,312	Once by 10 yrs.	1.8%	150	\$1.5
TOTAL					\$1,944.2

Source: Harwood et al. (1998)

HARWOOD (2000, 2003)

Harwood (2000) further updated his 1998 study by adjusting for the change in national health care expenditures, the consumer price index for medical services, changes in the U.S. adult population and the hourly compensation index for

productivity losses. Based on these adjustments, estimated costs rose to \$4.15 billion by 1998 (direct costs \$2.9 billion; indirect costs \$1.25 billion), and to \$5.4 billion by 2003 (direct costs \$3.9 billion, a 6.1% annual increase; indirect costs \$1.50 billion, a 4% annual increase).

Lifetime cost

Only two U.S. studies estimated the total lifetime cost for a person with FAS (Harwood & Napolitano, 1985; Weeks, 1989). These studies were presented in Table 7.

Harwood and Napolitano (1985) reported a lifetime cost of \$596,000 in 1980. Based on this lifetime estimate, Lupton and colleagues (2004) demonstrated how these costs for one case of FAS are spread out over the person's lifetime. After adjustment for inflation, the \$596,000 in 1980 became \$2 million in 2002. This estimate comprises \$1.6 million (80%) for health care, special education and residential care for individuals with mental retardation, and \$0.4 million (20%) for productivity losses (Lupton et al., 2004).

Furthermore, the cumulative cost of one case of FAS up to the age of 65 would have the following breakdown: \$130,000 in the first five years, \$360,000 in 10 years, \$587,000 in 15 years, and more than \$1 million in 30 years (Lupton et al., 2004).

Another study by Weeks (1989) reported a lifetime cost for each child born with FAS of \$1.374 million in Alaska in 1988. This study adapted the methodology used by Harwood and Napolitano (1985) and included the following costs: developmental disability services, special education, social service costs, adult vocational services and institutional care for mental retardation up to the age of 65.

This estimate is much higher than the estimate made by Harwood and Napolitano (1985), since costs in Alaska are generally higher than national costs. Therefore, this estimate is not used as a reliable estimate for the United States (Lupton et al., 2004).

Other (brief) cost estimates of FAS/FASD

Table 17 presents studies that briefly calculated the costs attributable to FAS/FASD either alone or as a facet of the total alcohol-attributable costs in Canada, the United States and Sweden. For the majority of the U.S. studies, the FAS cost estimates have been reported for certain U.S. states only (as indicated in the table). All of the cost estimates included in this table were not regarded as comprehensive by the investigators of this report, and thus were not included in the primary literature review (i.e., not included in Table 2 or Table 7).

The Fuchs et al. (2008) study deserves special attention since it is a first study to estimate the cost of children with FASD in foster care in Canada (no such estimates exist in any other countries). The authors examined the financial cost of child welfare care for children with FASD identified in the Child and Family Service Information System (CFSIS) in Manitoba in 2006. Three categories of costs were examined: basic maintenance, special rate/special needs and exceptional circumstances. The cost for the 400 children in a random sample was \$3,124,600 for basic maintenance, \$6,074,974 for special rate/special needs and \$230,752 for exceptional circumstances. This totalled \$9,504,094, with an average of \$23,760 for the year or \$65 per day, per child in 2006.

It was estimated that children aged 11 to 15 years had the highest average cost per child at \$26,021 or \$71 per day, per child. They also had the highest total cost of \$4,865,910. Children 16 and older had the next highest average at \$24,742 or \$68 per day, per child with a total cost of \$1,781,404. The 6 to 10-year-old age group had a yearly average of \$20,633 and a daily average of \$57 per child with a total of \$2,496,616. The youngest children had the lowest total cost at \$360,165 and the lowest averages with \$18,008 or \$49 per day, per child.

Table 17. Brief FAS/FASD cost estimates

Reference	Country, State/ Province (if applicable)	FAS/FASD, Prevalence	Cost Components	Total Annual Cost, Currency, Base Year
Fuchs et al., 2008	Canada, Manitoba	FASD	Child care (welfare) services (n = 400 children)	\$9.5 M, CND, 2006
Heien & Pittman, 1989	USA, Nationwide	FAS, 1 per 600	Special education, training and rehabilitation	\$3.7 B, USD, 1983
Johansson et al., 2006	Sweden	FAS, N/R	Health care: inpatient and outpatient	\$186,000, SEK, 2002
Kloehn et al., 1997	USA, Minnesota	FAS, 1.9 per 1,000	Treatment and care: neonatal intensive care, surgical correction for physical birth defects and residential and semi- independent care	\$44.8 M, USD, 1991
Klug & Burd, 2003 ^a	USA, North Dakota	FAS, N/R	Health care system	Cost savings: \$128,810 in 10 years; \$491,820 in 20 years, USD, 1996–1997
McDowell Group, 2005	USA, Alaska	FAS, 1.5 per 1,000	Medical care and residential services	\$47 M, USD, 2003
Miller et al., 2006 ^b	USA, Nationwide	FAS, 2 per 1,000	Medical care, lost work and quality of life	\$926 M, USD, 2001
PHAC, 2003	Canada, Atlantic provinces	FAS, 1 per 1,000 and 3 per 1,000	Medical care, educational and social services	\$57 M and \$171 M, respectively, CND, 2001
Popovici et al., 2009 ^b	USA, Florida	FAS, 2 per 1,000	Medical care, special education, resi- dential care and support services	\$75 M, USD, 2007
Rosen et al., 2008	USA, California	FAS, 2 per 1,000	Medical care, work loss and quality of life	\$1.9 B, USD, 2005
Russell, 1980	USA, New York	FAS & FASD, N/R	Medical care, remedial education and custodial care (n = 386 children with FAS; n = 1,563 with ARBD)	\$66 M, USD, 1978
Stanage et al., 1983	USA, South Dakota	FAS, 1 per 1,000 and 2 per 1,000	N/R	\$7.2 to \$14.4 M and \$21.6 to \$43.2 M, respectively, USD, 1982

^a Cost savings study (prevention of one case per year)

^b Alcohol-related harm attributable to underage drinking (<21 years of age) investigated (only FAS-affected children born to mothers under age 21)

ARBD: alcohol-related birth defects; B: billion; CND: Canadian dollars; M: million; N/R: not reported; SEK: Swedish currency; USD: U.S. dollars

A recent study was conducted in the Western Cape of South Africa, which used an interviewer-administered questionnaire among caregivers of children (0–12 years) with FAS/pFAS to estimate the use of health care services, the annual direct and indirect health care costs per child, as well as the total cost to society for providing health care services to children with FAS/pFAS (Credé et al., 2011). This study estimated that the total average annual cost per child was \$1,039.38 USD (95% CI: \$808.68 – \$1,270.07) and the total annual

societal cost was \$70,960,053.68 USD (95% CI: \$5,528,895.48 – \$86,709,971.13). Table 18 presents the breakdown of the average annual cost per child with FAS/pFAS incurred by the Department of Health, by caregivers and by Social Services in the Western Cape of South Africa. This study was not regarded as comprehensive by the investigators of this report since the cost estimate was specific to health care, and thus was not included in the primary literature review.

Table 18. Average annual cost (% of total) of FAS/pFAS per case over 12 months (n = 44)

Average Provider Costs (Department of Health)		
Hospitalization		
Government hospital		\$227.43 (21.88%)
Private hospital		N/A
Outpatient department visits		\$429.28 (41.30%)
Primary level clinic visits		\$184.54 (17.75%)
Private doctor visits		N/A
Traditional healer visits		N/A
Total cost to provider per patient		\$841.25 (59.52%)
Average patient costs		
	Direct cost	Indirect cost
Hospitalization		
Government hospital	\$6.74 (0.65%)	\$2.03 (0.19%)
Private hospital	\$3.07 (0.30%)	\$0.43 (0.04%)
Outpatient department visits	\$23.59 (2.27%)	\$21.55 (2.07%)
Primary level clinic visits	\$9.95 (0.96%)	\$27.24 (2.62%)
Private doctor visits	\$26.70 (2.57%)	\$13.63 (1.31%)
Traditional healer visits	\$2.70 (0.26%)	\$0.03 (<0.01%)
Days off caring for ill child	N/A	\$60.47 (5.82%)
Total cost to patient	\$198.13 (14.02%)	
Total societal costs for health care service use	\$1,039.38	
Average cost to social services		
Child support grant	\$186.84	
Foster care grant	\$154.41	
Care-dependency grant	\$32.76	
Total cost to social services	\$374.01 (26.46%)	
TOTAL SOCIETAL COST INCLUDING COST TO SOCIAL SERVICES	\$1,413.39	

N/A: not available

Source: Credé et al. (2011)

Anecdotal estimates of FASD costs in Canada

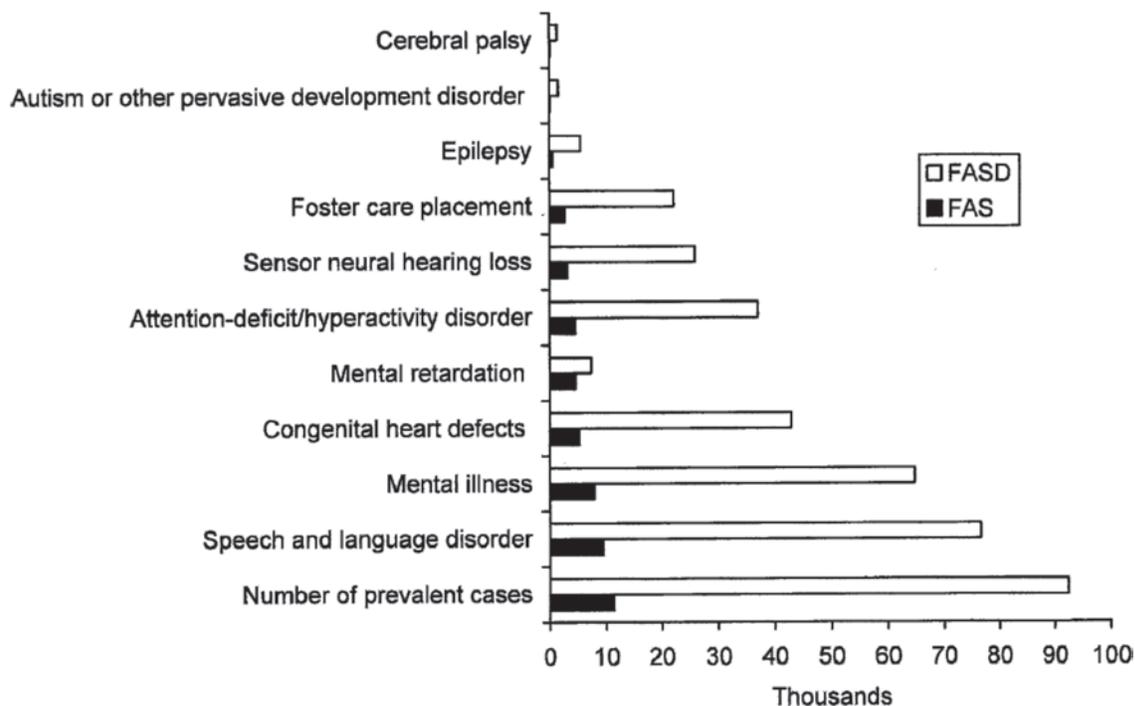
There are several anecdotal reports on estimates of costs associated with FAS/FASD in Canada. It is reported that 3,000 babies are born with FASD per year in Canada (Healthy Canada, n.d.). According to Bonnie Buxton, co-founder of International FAS Awareness Day, children presently living in Canada with FASD will cost at least \$600 billion, a size similar to the entire national debt (McLean, 2000).

Dr. Gideon Koren, founder of the Fetal Alcohol Canadian Expertise Network and the peer-reviewed *Journal of FAS International*, reported that the total Canadian lifetime costs of FASD

per individual was about \$1 million in 2006. The long-term economic fallout swells to a staggering \$4 billion, considering that 4,000 children are born with FASD in Canada each year (Koren, 2006).

Hopkins et al. (2008) reported that the estimated prevalence of FASD in Ontario, with a population of 12.8 million (Statistics Canada, 2007), is 116,480 cases, of which 11% are severe cases (ARND and ARBD) and 89% are mild cases of FAS. The authors used the incidence rate of FASD in Canada at 9.1 per 1,000 live births and estimated 43 new severe cases and 349 mild cases in 2007. Figure 2, adapted from Hopkins et al. (2008), presents the predicted rates of comorbidities for prevalent cases in Ontario.

Figure 2. Estimated prevalence and medical burden of FAS and FASD in Ontario, Canada



Source: Burd (2008); adapted from Hopkins et al. (2008)

DISCUSSION AND CONCLUSION

Based on the few existing studies in Canada, it is clear that FASD is a public health problem and costs a tremendous amount of money to society. Even though many cost components are already taken into account in the Canadian studies, the total cost associated with FASD is still underestimated because several cost components have not been included, primarily due to the unavailability of data. Among those costs are costs of law enforcement, welfare, research and prevention, and intangible costs.

The U.S. studies fall into two categories of estimation: the total annual cost of FAS to the country, and the lifetime cost for each individual with FAS. Our literature review revealed several cost drivers for individuals with FAS included in the U.S. studies (direct costs, including health care costs and residential and support services; and indirect costs, including productivity losses). The lowest annual cost estimate was reported by Abel and Sokol (1987) with \$75 million for 1984 (\$134 million adjusted for 2009). The highest range of cost estimates came from the study by Harwood (2003) with \$5.4 billion for 2003 (\$6.2 billion adjusted for 2009).

These wide ranges in the estimated costs of well-documented, rigorous studies reflect the fact that these studies used different methodologies and assumptions, including different prevalence rates of FAS and different cost components.

Lupton et al. (2004) identified several reasons for the variations noted in the cost estimates:

1. Different FAS prevalence rates (the higher the prevalence, the higher the cost)
2. Different age ranges included (the higher the range, the higher the cost)
3. Different cost drivers included
4. Co-morbidities included differently in different studies
5. Different assumptions in rates of service utilization
6. Use of different costs of services
7. Knowledge base for developing estimates rapidly increasing over time
8. Inflation

The cost drivers also accounted for different proportions in the reviewed studies. Thus, in Abel and Sokol (1991a) the costs for health care accounted for 23% and costs for residential care due to mental retardation accounted for 77% of total costs. Similarly, in Rice et al. (1990, 1991) residential care for people with mental retardation accounted for about 80% of total costs. In the Harwood and Napolitano (1985) study, health care and residential costs accounted for about 44% of the total costs and special education accounted for 31%. Studies by Abel and Sokol (1987, 1991a, 1991b) did not include costs of lost productivity or costs of treatment and residential services due to mental retardation after the age of 21.

It is difficult to estimate the cost of FASD, since the total cost is derived from many sectors of society. However, it is important to include all components of the total cost in order to get a true estimate, or at least an estimate that reflects reality as closely as possible. Additionally, data are not readily available. People with FASD usually do not receive adequate services; at times they often encounter unnecessary costs due to cycling through service systems, or they do not receive adequate care or treatment and thus incur less costs (Lupton et al., 2004).

Many researchers agree that the expenses associated with FASD, such as medical and educational costs, are not difficult to estimate (Hutson, 2006; Lupton et al., 2004). At the same time, certain cost drivers, such as those associated with the child welfare system and the criminal justice system, are challenging because of the lack of data (Hutson, 2006; Lupton et al., 2004). Regardless, it is crucial to include these costs in estimates.

Thus, the current literature search revealed

that FAS studies in the United States leave out many possible cost drivers in their estimations, including medical services for physical anomalies, special education, welfare payments to family, substance abuse treatment/services, mental health and vocational services, criminal justice system costs, services for mild physical problems and learning disabilities, and lost productivity of caregivers and affected persons. Several reviews have also come to this conclusion (see Hutson, 2006; Lupton, 2003; Lupton et al., 2004). The Canadian studies (e.g., Stade et al., 2006, 2009) did not include children in the care of social services, although there is reason to believe that children with FASD are overrepresented in the child welfare system, and thus the total cost associated with FASD might be underestimated (Hutson, 2006; Farris-Manning & Zandstra, 2003). Fuchs and colleagues (2005) reported that in Manitoba one-third of children in care fall within a broad definition of disability and 17% of children in care are affected by diagnosed or suspected FASD.

A large portion of cost associated with law enforcement is not accounted for in the existing Canadian and U.S. estimates. A recent literature review (Popova et al., 2011) revealed that the rate of incarceration among young offenders with FASD in Canadian studies ranges from 10.9% (Rojas & Gretton, 2007) to 22.3% (Fast et al., 1999). Furthermore, based on the available Canadian data, this study estimates that youths with FASD are 19 times more likely to be incarcerated than youths without FASD in a given year.

In one American study, among a sample of 253 individuals affected by FASD, 60% reported having been charged, convicted or in trouble with the authorities for criminal behaviours, and 42% of adults had been incarcerated for a crime (Streissguth et al., 1996). The cost per

person in prison per year is \$13,500 (Kellerman & Kellerman, 2000). Based on this, Taylor and Anielski (2001) estimated the total economic cost of crime in Alberta at about \$2 billion in 1998, which is equivalent to 2% of total provincial gross domestic product (GDP) in 1999.

Moreover, existing studies in the United States included the cost of FAS only. Therefore, the costs associated with pFAS, ARBD and ARND are not accounted for in these studies, and thus costs are likely to be at least 10 times higher than the existing FAS cost estimates (Astley, 2002; May & Gossage, 2001; Sampson et al., 1997).

Based on the observed literature, there are currently no comprehensive assessments of the economic impact of FASD in Canada or in any other countries. The majority of the studies that do exist limit their range to a number of different cost components or, furthermore, certain populations. There is an urgent need to provide accurate cost estimates of FASD that encompass all aspects and various sectors of this disability.

Based on observed methodologies of existing studies estimating cost associated with FAS/FASD, the next stage of this project is to develop a comprehensive economic impact model for FASD in Canada. This model will be built based on guidelines developed from the first National Roundtable on the *Development of Canadian Model for Calculating the Economic Impact of FASD*, which took place on March 21 and 22, 2007, in Ottawa (PHAC, 2008). As mentioned above, it is crucial to include justice system costs in the model. The main components of costs in the justice system to be included, as part of the overall model, will be adopted from the document developed from a second National Roundtable in February 2008 (PHAC, www.phac-aspc.gc.ca/fasd-etcaf/pubs/ei-me08-eng.php).

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