



INFORMATION BRIEF #2

Preschoolers with Autism: Comparing Service Use and Costs in Nova Scotia and New Brunswick

Autism spectrum disorder (ASD) diagnoses have increased dramatically to 1.5% of Canadian children¹. Providing services for these families is a major challenge for public health, education and social services. Many provincial governments invest considerable resources in specialized early intensive behavioural intervention (EIBI) programs for children with ASD. Yet what is offered does not meet all needs. In particular, long wait lists mean that families often supplement government programs with complementary services and products. Not only are these paid for out-of-pocket by families, but their quality and benefits are uncertain. Governments should seek to understand how service use and costs, including lost workforce productivity, are influenced by diagnostic assessment practices and service delivery models chosen by each province and territory. Policy changes associated with such understanding have the potential to improve children's outcomes² and alleviate burdens to families.



The Preschool Autism Treatment Impact (PATI) study found that:

- Prolonged waits for government-funded EIBI in Nova Scotia meant that most parents sought and used other services in the meantime.
- Even when relatively resource-heavy public treatment programs were offered, parents incurred significant costs related to other behavioural, educational, and social services.
- Families in New Brunswick incurred greater out-of-pocket costs and productivity losses during EIBI than families in Nova Scotia.

Key Questions

- Which health, education and community services were used by families?
- What public, family and societal costs were associated with interventions?
- What can we learn from differences in provincial service delivery models?

The PATI study is the first large-scale comparative study of ASD services within Canada, and the first to involve government representatives directly as formal research partners.

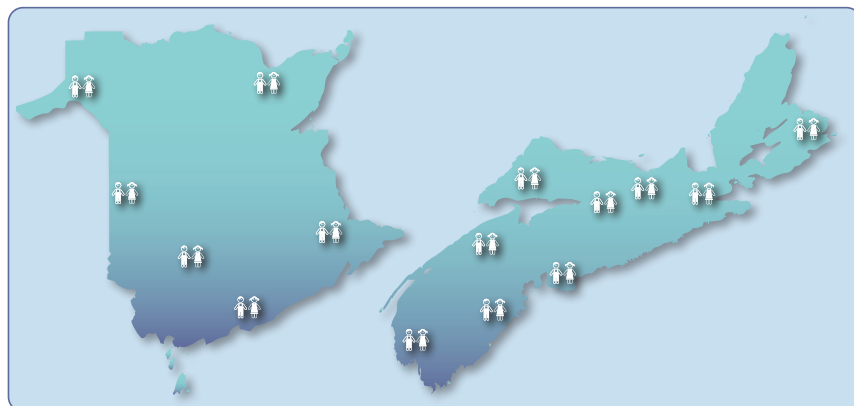


¹ Public Health Agency of Canada (2018)

² The PATI study also measured child outcomes for both provinces





Data for the PATI study were collected between 2013 and 2017 from 6 agencies in New Brunswick and 9 regional teams in Nova Scotia



Similar Provinces, Different Costs

In addition to child outcomes, the PATI study researchers measured parent-reported service use and costs for over 600 preschool children with ASD. Data were gathered for the 12 months prior to and during the first year of EIBI. The two provinces, although adjacent and demographically similar, differ in many ways: ASD diagnostic approaches, treatment methods and duration, service delivery and funding models. These differences can help to explain provincial variations in child outcomes³, service use and costs to governments, families and society.

	New Brunswick 	Nova Scotia 
EIBI delivery	Regional delivery through Department of Education contracts with six independent private agencies	Administered within public healthcare system by specialist teams in district health authorities
Average time from diagnosis to start of treatment	4 months	13.5 months
Child characteristics at start of treatment	Compared to NS: <ul style="list-style-type: none"> • More children per capita enrolled • Younger: average age: 3.5 years • Higher adaptive skills • Less severe ASD symptoms 	Compared to NB: <ul style="list-style-type: none"> • Fewer children per capita enrolled • Older: average age: 4.5 years • Lower adaptive skills • More severe ASD symptoms
Treatment Duration	Approximately 1000 hours per year; From diagnosis until school entry	Approximately 550 hours total; Only offered for one year

Average Costs to Governments

During 1 st year of EIBI, per child	\$29,015	\$90,200
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Average Costs to Families

Year prior to EIBI, per child	\$3,046	\$2,560
During 1 st year of EIBI, per child	\$3,713	\$1,130






Costs to Society ⁴



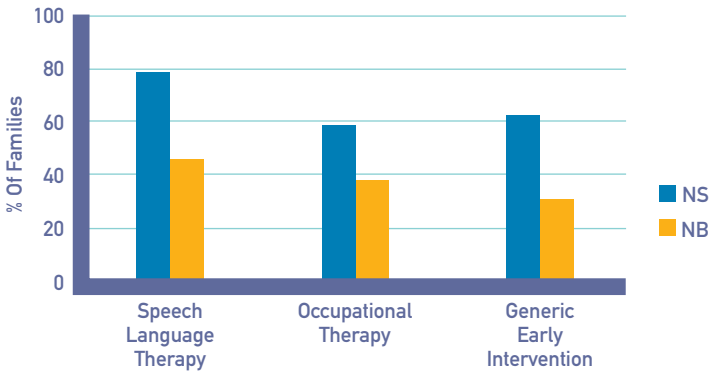
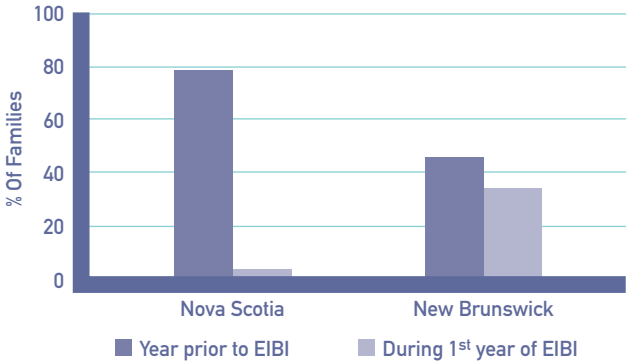
Year prior to EIBI, per child	\$14,516	\$8,278
During 1 st year of EIBI, per child	\$41,318	\$94,611

³ The PATI study also measured child outcomes for both provinces

⁴ Societal costs = Sum of public payer and family costs + indirect costs (parent/caregiver productivity losses, and private provider expenditures not directly paid by families, such as services reimbursed by insurance).



Wait Times for EIBI	Consequences of Long Wait Times for EIBI
 13.5 Months	 <ul style="list-style-type: none"> Increased: • Out-of-pocket expenses for families that accessed other services while waiting • Burden on the public sector to provide services for children/families who were waiting for EIBI • Private provider expenditures such as services reimbursed by health insurance companies
 4 Months	 <ul style="list-style-type: none"> Decreased: • Potential benefit of EIBI
	 <ul style="list-style-type: none"> Unequal: • Access to private services due to economic burden on families • Outcomes for children

Nova Scotia 	PATI Study Results	New Brunswick 												
<p>On average, families waited more than a year from diagnosis to enrollment in EIBI. More parents in Nova Scotia sought and used other public and private resources while waiting.</p>	<p>Services used in the year prior to EIBI start</p>  <table border="1"> <caption>Services used in the year prior to EIBI start</caption> <thead> <tr> <th>Service</th> <th>NS (%)</th> <th>NB (%)</th> </tr> </thead> <tbody> <tr> <td>Speech Language Therapy</td> <td>~78</td> <td>~46</td> </tr> <tr> <td>Occupational Therapy</td> <td>~58</td> <td>~38</td> </tr> <tr> <td>Generic Early Intervention</td> <td>~62</td> <td>~31</td> </tr> </tbody> </table>	Service	NS (%)	NB (%)	Speech Language Therapy	~78	~46	Occupational Therapy	~58	~38	Generic Early Intervention	~62	~31	<p>The time from diagnosis to enrollment in EIBI was brief; Fewer families than in Nova Scotia accessed services while waiting.</p>
Service	NS (%)	NB (%)												
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Occupational Therapy	~58	~38												
Generic Early Intervention	~62	~31												
<p>In Nova Scotia, use of speech-language therapy declined to 3% during EIBI because this was integrated into the government program.</p>	<p>Speech-Language Therapy Use</p>  <table border="1"> <caption>Speech-Language Therapy Use</caption> <thead> <tr> <th>Province</th> <th>Year prior to EIBI (%)</th> <th>During 1st year of EIBI (%)</th> </tr> </thead> <tbody> <tr> <td>Nova Scotia</td> <td>~78</td> <td>~3</td> </tr> <tr> <td>New Brunswick</td> <td>~46</td> <td>~33</td> </tr> </tbody> </table>	Province	Year prior to EIBI (%)	During 1st year of EIBI (%)	Nova Scotia	~78	~3	New Brunswick	~46	~33	<p>In New Brunswick, speech-language therapy was not part of government EIBI; 33% of families continued to use these services during their 1st year of EIBI.</p>			
Province	Year prior to EIBI (%)	During 1st year of EIBI (%)												
Nova Scotia	~78	~3												
New Brunswick	~46	~33												
67%	Families who purchased special products and materials ⁵ for their children with ASD prior to EIBI	46%												
42%	Families who paid out-of-pocket for complementary services prior to EIBI ⁶	18%												
36%	Families who used additional healthcare services ⁷ prior to EIBI	46%												

⁵ e.g., educational materials, learning aids, communication aids, devices, exercise equipment, adaptations to the home

⁶ e.g., special diets; music therapy; various playgroups; equine therapy; naturopathic services

⁷ May include psychologist, behaviour therapist, social worker, nutritionist, physiotherapist, and physicians (pediatricians, neurologist, gastroenterologist, ophthalmologist)



Cost to Government



\$29,015

Annual cost estimate of EIBI program per child
(less than 1/3 that of Nova Scotia)

- Cost estimate was based on a set fee-for-service paid by government to private agencies, and a fund transfer for community-based activities to support parents.
- Cost-estimate was annual, but on average younger children remained in the New Brunswick program for more than one year, significantly increasing the total cost per child.
- No provincial coordination of services.
- Salary rates were lower in New Brunswick because of non-unionized staff.
- Operating and overhead costs were not available from private agencies, therefore the cost is under-estimated.

Costs to Families⁸



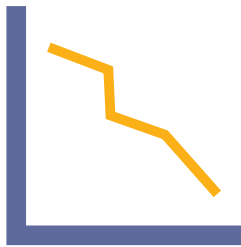
\$3,046 Year Prior to EIBI

\$3,713 During 1st Year of EIBI

Out-of-pocket costs during EIBI
(3X that of Nova Scotia families)

- Speech-language therapy was not integrated into government EIBI, driving parents to seek this therapy both before and during EIBI, through public or private providers.
- Many families incurred costs for travel to EIBI treatment centres.

Productivity Loss⁹



\$9,062 Prior to Start of EIBI

\$7,558 During 1st Year of EIBI

Overall productivity losses for
New Brunswick families during EIBI
(almost 3X that of Nova Scotia families)

- EIBI in New Brunswick was delivered outside the home; This can be convenient for working parents, but those who experience substantial and frequent travel incurred significant time losses and productivity costs.

Notes

- All costs in 2017 CAD
- Personnel training costs and government administrative costs were not included
- Information on data collection and methodology: www.bit.ly/PATICosts
- New Brunswick made major changes to service delivery in 2017, including salary increases for providers and a shift to a single contracted agency to increase consistency and oversight.

⁸ Average annual family out-of-pocket costs per child

⁹ Calculated by multiplying the parent-reported hours missed from paid employment or usual daytime activities by the 2014 average Canadian hourly rate for employees (Statistics Canada)



Cost to Government



- Estimates were based on detailed costs from each district health authority (including labour costs, operating expenses, and staff travel)
- Salary rates were higher in Nova Scotia because of unionized healthcare staff
- Provincial coordination included all operating costs

\$90,200

Annual cost estimate of government EIBI program per child (more than 3X that of New Brunswick)

Costs to Families¹⁰



- On average, families waited more than one year for EIBI after receiving their child's diagnosis of ASD. This delay led to higher costs to families who accessed private services while waiting
- During EIBI, providers travelled to meet children in homes/daycares, eliminating travel costs for families

\$2,560 Year prior to EIBI

\$1,130 During 1st year of EIBI

Families in Nova Scotia had higher service use in the period prior to EIBI than families in New Brunswick

Productivity Loss¹¹



- EIBI in Nova Scotia was delivered in family homes and daycares, therefore these parents did not incur time losses for travel that were as great as for families in New Brunswick

\$3,777 Prior to EIBI

\$2,719 During 1st year of EIBI

Overall productivity losses for Nova Scotia families both before and during EIBI were close to 1/3 those of families in New Brunswick

Notes

- All costs in 2017 CAD
- Information on data collection and methodology: www.bit.ly/PATICosts

¹⁰ Average annual family out-of-pocket costs per child

¹¹ Calculated by multiplying the parent-reported hours missed from paid employment or usual daytime activities by the 2014 average Canadian hourly rate for employees (Statistics Canada)



Lessons Learned from the PATI Study



PATI study results indicate significant differences between New Brunswick and Nova Scotia in use and costs of services for preschoolers with ASD. These differences reflect, in part, provincial variations in characteristics of children accessing EIBI, wait times for services (including diagnosis), and provincial service delivery models. The PATI study suggests areas for improvement.

Evidence From PATI Study	Next Steps
A range of services is offered and funded by distinct sectors: health, education, and community services.	Inter-departmental mechanisms should be created to coordinate and strengthen oversight of current programs.
Even when time between diagnosis and starting EIBI is short, many parents perceive a need for speech-language and occupational therapy.	Publicly funded ASD intervention programs should be based on integrated service delivery models.
Average wait from diagnosis to start of EIBI differed significantly (4 months in NB and 13 months in NS).	Shortening wait times for diagnostic assessments and treatment should be priorities.
When EIBI is delivered outside the home in a location that requires frequent and substantial travel, parents incur significant time losses and productivity costs.	Publicly funded ASD intervention programs should be delivered in readily accessible locations for families, ideally in children's 'natural environments'.
The public cost of intervention was higher in NS in part because of higher salary rates for unionized, more highly qualified healthcare staff. On average, NS workers remained in the program longer.	Higher salaries may lead to better retention, which in turn may lead to more experienced interventionists and possibly to higher quality treatment.
Parents incur significant out-of-pocket costs for services, materials and products that may be of questionable therapeutic benefit.	Given the many products and services claiming to be of benefit, access to high-quality information and decision tools would help guide parents in their choices.

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Research Support
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