

Executive Summary of Putting a Canadian Face on Learning Disabilities Study (PACFOLD)

Background

Putting a Canadian Face on Learning Disabilities (PACFOLD) is a groundbreaking applied research study initiated in 2004 by the Learning Disabilities Association of Canada (LDAC), with a \$302,000 contribution from the Social Development Partnership Program - Disability Component. The opinions and interpretations in this study are those of its authors, and do not necessarily reflect those of the Government of Canada.

The study was completed by a team of top Canadian researchers, headed by coprincipal investigators, Dr. Alexander M. Wilson, Director of the Meighen Centre at Mount Allison University in New Brunswick, and Adele Furrie, an Ottawa-based expert in disability statistics. They were joined by researchers, Dr. Elizabeth Walcot-Gayda, Postdoctoral Fellow at the University of Sherbrooke in Quebec, Dr. Catherine Deri Armstrong, Department of Economics of the University of Ottawa, and Andrew Archer, an information data retrieval expert. The goal of the research study was to find out what it means to be a child, youth or adult with learning disabilities in Canada.

This three-phase study with its focus on knowledge—obtaining, quantifying and disseminating—provides a better understanding of the impact of learning disabilities on the lives of Canadian children, youth and adults.

The PACFOLD study is unique, because it represents the first time any disability organization in Canada has requested access to Statistics Canada data surveys. Ten different data sets were examined, making it the most comprehensive look ever at the impact of living with a learning disability (LD) in Canada.

Methodology - Phase 1 - Obtaining the Knowledge

Members of the research team determined that the parameters of the literature framework (an initial examination of existing literature in the field of LD conducted by the research team) would focus on persons aged 5 to 44 years. The current practice of identifying those at risk for learning disabilities usually starts when a child enters the school system, generally around the age of 5. Therefore, research on the impact of learning disabilities at an early age focuses on the age of 5 as a starting point. The age of 44 was identified as the upper end of the research for two reasons. The term "learning disability" was first applied in the early 1960's, and those identified by diagnosticians in the late 1960's and early 1970's are now in this age bracket. The early educational focus of identification has led to sparse documentation for older Canadians who had already left the school system by that time, and many today still do not have a diagnosis of LD.

Six key areas were identified as significantly impacting upon persons with learning disabilities and their families. Key areas include: education, personal and social development, employment, parent and family, health, and finance. Studies were reviewed in 4 age groupings that were consistent with age groupings found in relevant Canadian surveys.

The literature framework concentrated on Canadian research whenever possible. The criteria for selection of studies was determined to be articles published between 1990 and the present, and which focused on original research, including quantitative and qualitative studies that met current standards for such studies.

Each section of the framework concluded with a listing of potential indicators by age group that would give direction to an intensive examination of relevant Canadian statistical databases. Once the indicators were identified and documented, the statistical surveys were examined to determine if there were specific questions that would elicit the information necessary to outline the impact of learning disabilities on Canadians in their daily lives. Ten surveys were identified that included questions to identify the population with learning disabilities, and to provide data to generate many of the indicators identified in the literature framework.

Availability of Indicators of Selected Statistic Canada Surveys

Key areas/	HAL	HALS	PALS	PALS	IAL	LSUDA	YITS/	APS	NLSC	CCHS
Data Surveys	S	Adults	0-14	Adults	S		PISA	5-14	Y	
	0-14									
1. Education	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2. Employment	_	Yes		Yes	Yes	Yes				Yes
3. Personal/	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
social										
relationships										
4. Family	Yes	Yes	Yes	Yes	Yes	Yes	n/a	Yes	Yes	Yes
5. Health	Yes	Yes	Yes	Yes	Yes	n/a	n/a	Yes	Yes	Yes
6. Finance	Yes	Yes	Yes	Yes	n/a	n/a	n/a	n/a	n/a	Yes

—: not applicable n/a: Not available – area not covered on the survey

HALS: Health and Activity Limitation Survey (1991) 0-14 and adults	NLSCY: National Longitudinal Survey of Children and Youth (4 cycles - 1994-2001)				
PALS: Participation and Activity	APS: Aboriginal Peoples Survey				
Limitation Survey (2001) 0-14 and	(1991)				
adults					
LSUDA: Literacy Skills Used in Daily	IALS: International Adult Literacy				
Living (1989)	Survey (1994)				
PISA: Program of International	YITS: Youth in Transition Survey				
Student Assessment (2000)	(2000)				
CCHS: Canadian Community Health					
Survey Cycle 1.2 (2002)					

Phase II - Quantifying the Knowledge

Data was extracted using framework indicators from the statistical surveys that were identified as having specific questions that would elicit the information necessary to outline the impact of learning disabilities on Canadians in their daily lives.

Also, as part of Phase II, 12 focus groups were conducted consisting of adults with LD, parents of children with LD, and children with LD between the ages of 10 to 14. These were held in Halifax, Saskatoon, Ottawa, Toronto, and Winnipeg between March and November 2005, and helped to fill in some of the blanks left by the data. Each focus group session lasted 1.5 hours, and was tape-recorded. Participants were asked to sign a release granting permission to be quoted anonymously, to provide a personal voice to the statistics. The Saskatoon adult group consisted mainly of Aboriginal people. The Ottawa adult group consisted of LD individuals employed in professional occupations. Rich anecdotal information was provided in the areas of diagnosis, experiences in school, impact on the family, financial implications, and experiences at work.

Phase III – Dissemination of the Knowledge – Key Findings

Putting a Canadian Face on Learning Disabilities shows that all Canadians with learning disabilities are at a disadvantage, and highlights the impact of living with learning disabilities.

As a child (as reported by parents/guardians)

- More prone to ear infections and allergies.
- Poorer overall health status.
- Less likely to do well in school.
- Less likely to do well in math and/or reading.
- More likely to miss school.
- One-third requires aids, but lack access to them.
- Two-thirds report child's extracurricular activities were reduced because of LD.

Impact on the Family

- More likely to be caring for the LD child as a single parent.
- More likely that parent has depressive symptoms.
- More likely to be part of a low-income family.

As a young adult aged 15 to 21 years living with LD (compared to nondisabled peers)

- More likely to not have a secondary school diploma or certificate.
- Less likely to be working (even part-time) or looking for work.
- More likely to be part of a low-income family.
- More likely to report their mental health status as fair to poor.
- Less likely to handle unexpected problems appropriately.
- More likely to report suicidal thoughts, depression and distress

As a young adult aged 22 to 29 years living with LD (compared to nondisabled peers)

- Less likely to have a secondary school diploma or certificate.
- Less likely to be working.
- Those who are working, earn less.
- More likely to report their mental health status as fair to poor.
- Less likely to handle unexpected problems appropriately.
- More likely to report suicidal thoughts, depression and distress

As an adult aged 30 to 44 years living with LD (compared to non-disabled peers)

- More likely to still be living with a parent.
- More likely to be unemployed or just not seeking employment.
- Those who are employed earn less.
- More likely to score lower on literacy tests.
- Few rated their reading and writing skills as excellent or good.
- More likely to report their mental health status as fair or poor.
- Less likely to handle unexpected problems appropriately.
- More likely to report suicidal thoughts, depression and distress

Simply put, Canadian governments can do more to enable people with learning disabilities. People with LD are often prevented from realizing success at school, at work, and in everyday activities. Further, Canadians with LD want to succeed, as recorded in the rich anecdotal information provided by the focus groups.

At School

A significant number of youth and adults with LD have dropped out of the education system altogether, with over one-quarter of Canadians aged 22 to 29 with LD reporting less than a high school certificate as their highest academic achievement.

I quit school in grade 7. I went back, but it was hard. I quit again in grade 10. I returned to school through the Bridges to Success Program at the Learning Disabilities Association of Saskatchewan. I just recently got my GED (General Education Development, a grade 12 equivalency). I'm 24 years old.

— Saskatoon focus group participant

At Work

Lower academic standings are one of the causes leading to higher unemployment, and lower income levels among Canadians with LD. 61.3% of this same study group reported being employed the week before the 2001 census, compared to 75.7% of the total population. People with LD were far more likely to report earning negative or no earnings at 39.1% compared to 14.1% of the total population.

I quit school and worked as a waitress, but the cook couldn't read my orders, so they let me go. I had to find a job that didn't require reading. I worked as a banquet server. I tried to take a course to become a bricklayer, but there was too much math involved. Through the Bridges to Success Program at the Learning Disabilities Association of Saskatchewan, I took basic upgrading and improved my literacy skills. Now, I'm working as a cook at a very nice bistro.

— Saskatoon focus group participant

In Life

Higher unemployment and lower incomes may be the root cause of the health problems Canadians with learning disabilities face. Putting a Canadian Face on Learning Disabilities found that people with LD are 2 to 3 times more likely to report fair to poor physical, general, and mental health, and 2 to 3 times less likely to report very good to excellent physical, general and mental health than the general population.

My learning disability was devastating to every intimate relationship I had, because I didn't know about it. I became the black sheep of the family. I got involved with alcohol and drugs, and hit rock bottom. It was only when I was finally diagnosed at the age of 39, and began to understand my strengths, learned strategies and coping skills, that my life turned around. Toronto focus group participant

Persons with Learning Disabilities were more than twice as likely to report high levels of distress, depression, anxiety disorders, suicidal thoughts, visits to a mental health professional and poorer overall mental health compared to persons without disabilities.

Differences found in the adolescent group (ages 15 – 21) were even larger than in the older adults (ages 30-44) for suicidal thoughts, depression and distress.

Males with LD were more likely to report depressive episodes, anxiety disorders, consultations with a health professional and poor general mental health.

Females with LD were more likely to report high distress and suicidal thoughts relative to person without disabilities.

On balance, LD was not found to be more detrimental to mental health for one sex or the other.

However, left undiagnosed and untreated, the Canadian economic costs are high.¹

- The Canadian Mental Health Association (CMHA) reports mental illness costs Canadian business \$33 billion per year in lost productivity. Related health care costs add another \$10 to \$20 billion to that total.²
- Mental health problems account for 30 to 40 per cent of disability claims reported by Canada's major insurers and employers.

Putting a Canadian Face on Learning Disabilities uncovered compelling evidence of what our national network has witnessed anecdotally for decades—left undiagnosed, untreated and/or not accommodated, Canadians with LD are unable to reach their potential, resulting in high costs to the Canadian economy.

¹ Learning Disabilities in Canada: Economic Costs to Individuals, Families and Society, Learning Disabilities Association of Canada, January 2001

² CMHA, "Enhancing Productivity in Canada: Benefiting from the Contributions of All Canadians": A Submission to the House of Commons Standing Committee on Finance, September 2005.

Putting a Canadian Face on Learning Disabilities demonstrates how the issues Canadians with LD face are both linear and cyclical. They are linear, in that there is a direct correlation between the problems not identified in school, and/or not accommodated in school, with the end result of low literacy levels. This, in turn, impacts the employment opportunities and the financial situations of people with learning disabilities. The issues are cyclical, because these challenges feed into one another. Low literacy levels, higher rates of unemployment, lack of independence, and lower incomes contribute to higher rates of mental and physical health, and impact the relationships of people with LD.

The solution does not rest solely with the education system. While recognizing that educational institutions have been the place where many Canadians with LD discover their disability and hope to find appropriate interventions and accommodations, it is necessary to look at other public policy areas for remedies to the lifelong challenges people with learning disabilities face. The solutions should be systemic, and involve publicly funded programs, such as social services, health, employment, literacy programs, federal income tax programs, and other areas.

Canadian governments, education and labour sectors can do more to enable people with learning disabilities to realize success at school, at work and in everyday activities. Affordable and available solutions can be put in place immediately to help break the cycle of failure, and provide opportunities for success.

The Learning Disabilities Association of Canada recommends that Canadian governments at all levels:

- Invest in a universal research-based, mandated early screening and intervention model for children 4 to 8 years of age that is designed to identify and assist children at risk for school failure. This would increase Canadian literacy rates, reduce health care costs, increase employment and income potential, and improve family life among Canadians with learning disabilities.
- Negotiate with the federal Council of Ministers of Health on the costs of the primary diagnosis of learning disabilities for Canadians with LD of all ages (children, youth, and adults), and to have support for people with LD publicly funded through provincial and territorial health insurance plans or some other public funding mechanism, as is the case for other disabilities.
- Implement national incentives for people with learning disabilities to access affordable assistive technology and increase the list of adaptive technology eligible under the Medical Expense Tax Credit of the Income Tax Act to include: computers, voice activated software, scanners and readers.
- Build awareness and training among medical, mental health and educational
 professionals of the coexistence of mental health disorders and learning
 disabilities in both children and adults. This would facilitate quicker
 identification and diagnosis of LD, and provide families with early support,
 understanding and resources to reduce the likelihood of developing more
 serious mental health disorders.

- Increase funding for programs that support improving literacy skills, and enhancing paid on-the-job learning opportunities.
- Endorse a consistent definition and a comprehensive diagnostic assessment protocol for learning disabilities to be used in all publicly funded programs such as education, social service, health and other service areas.
- Build awareness and provide training among health practitioners of the
 coexistence of conditions with learning disabilities like low-birth weights, ear
 infections, allergies, asthma, depression, etc. This would facilitate quicker
 identification and diagnosis of LD, and provide families with early support,
 understanding and resources.
- Advocate for further statistical data research with a consistent definition of "disability," and specifically, "learning disability," coordinated across all future Statistics Canada surveys, with the most appropriate ways of wording screening questions to ensure that respondents with LD are neither screened out, nor so ill-defined that clear data cannot be garnered.
- Increase the sample size on future Statistics Canada surveys, in order to further understand the barriers and impact that living with learning disabilities has on various aspects of an individual's life.

For Educational Institutions:

- Include **compulsory** courses in teacher training programs on students with special needs at both the elementary and secondary school levels.
 - A portion of the compulsory course content on students with special needs should be devoted to the education of students with learning disabilities at the elementary and secondary levels in the areas of: characteristics, diagnosis, impact, and implementation of appropriate research-based reading programs, strategies, interventions and accommodations.
- Enhance professional development for teachers on learning disabilities in all provincial and territorial school districts/boards to ensure fewer students fall through the cracks in Canadian classrooms. All teachers must know:
 - What the 'signs' are of a student at risk
 - The needs and entitlements of students with learning disabilities.
 - How students with LD learn.
 - How to adapt and differentiate their teaching methods.
 - How to utilize the principles of Universal Instructional Design.
 - How to implement appropriate accommodations to meet the needs of students with learning disabilities.

For Labour:

 Increase staff and human resource personnel's knowledge of learning disabilities, and implementing appropriate accommodations for individuals with LD. Overall, these recommendations will provide equitable access for all Canadians to affordable, appropriate services early enough to make a difference in their lifelong outcomes, and will reduce the short- and long-term economic costs of failure (special education, unemployment, health, welfare, and corrections).

The Learning Disabilities Association of Canada

Since 1963, the Learning Disabilities Association of Canada (LDAC) has provided support to people with learning disabilities, their families, teachers and other professionals who help them. LDAC is a volunteer-led association representing a network of 10 provincial and two territorial Learning Disabilities Associations. From these extends a network of chapters in some 55 communities across the country with more than 7,000 members across Canada. Our role is to help provide a level playing field of opportunities and services for children, youth and adults with LD. At the national, provincial/territorial and local levels, Learning Disabilities Associations provide cutting-edge information on LD, practical solutions, and a comprehensive network of programs and resources. These services make LDAC the Canadian leader in the area of learning disabilities.

For further information, please visit www.pacfold.ca