A NATIONAL STRATEGY
FOR DISABILITY SUPPORTS:
WHERE IS THE GOVERNMENT OF CANADA
IN THIS SOCIAL PROJECT?

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“What kind of Canada do we want? ... A Canada where people with disabilities and their families ... have the support they need.”

“Ministers also reaffirmed their commitment to working in partnership for the full inclusion of Canadians with disabilities. While recognizing that people with disabilities can benefit from advancements in the broader social agenda, Ministers also agreed to jointly develop a strategy for investments in disability programs, with both short and long-term options. Ministers committed to advancing issues that are important to Canadians with disabilities, including the three building blocks of In Unison – disability supports, income, and employment.”

“Perhaps the most important action that the government can take to assist persons with disabilities is to invest in the supply of disability supports.”

Introduction
I am pleased to be part of the seminar series of the School of Rehabilitation Therapy. It is also nice to back at Queen’s, where I came as a graduate student 30 years ago, to study public administration and public policy. It is a research journey I continue to travel today.

The title of my talk is: “A National Strategy of Disability Supports: Where is the Government of Canada in this Social Project?”

Canadians with disabilities face many barriers in everyday life. In 1996, first ministers identified disability issues as a national priority for renewing social policy. The Government of Canada is on record as being committed to helping people with disabilities participate as full as possible in Canadian society as well as in helping Canadian families meet the challenges of caring for infirm family members. As yet, however, we do not have a national strategy on disability supports, raising the questions: where is the federal government on this issue? And what might it do in the near term to put in a place a national agenda and framework for action?

In this presentation, I want to make a case for why it is time for a national strategy of disability supports, describe the existing intergovernmental transfers in Canada for disability supports, and then outline a revised transfer and federal investment plan, as next steps to realize a vision of full inclusion for Canadians with disabilities.
One of my propositions is that the 2005 federal budget, delivered just a few weeks ago, is a worrisome development for Canadians with disabilities, despite the tax reforms announced. My critique is that the budget demonstrates a declining commitment by the Martin Liberals to be steadfast advocates of inclusion and to undertake transformative change in social policy for people with disabilities.

Another proposition is that we can move forward with a national strategy for investments in disability supports by building on the Multilateral Framework for Labour Market Agreements for Persons with Disabilities.

It is Time for a National Strategy on Disability Supports
Canadians with disabilities have long been disadvantaged, marginalized and stigmatized. While some important advances have occurred over the last 20 years – including some program reforms recently introduced at both the federal and provincial/territorial levels - there also have been many setbacks and erosions in supports, as well as continued challenges in everyday living and barriers to participation in schools, work, community activities, public services and facilities. Research and experience show that both generic and disability specific community services are inadequate in meeting existing needs.

Large numbers of Canadians with disabilities are not receiving the essential supports and services they require; whether the need is for aids and devices, support with daily activities, specialized housing features or work-related supports. In 2001, the most recent year surveyed, of the adults with disabilities who have some requirement for aids and devices, most have those needs met; that’s the good policy news – but 497,000 people living with disabilities in Canada had a level of unmet need, and a further 160,000 adults with disabilities had none of the aids and devices they require. Similar patterns of service gaps and unmet needs exist for support with daily activities and specialized housing features. And, the survey suggests that children with disabilities in Canada may be worse off than their adult counterparts in having their needs for aids and devices met. Those Canadians with disabilities most likely to experience unmet needs for supports and service are the most vulnerable among us, people with severe and very severe disabilities and low incomes. Consequently, people with disabilities and their families experience undue hardship and are restricted from full and active participation in economic, educational and social life. Studies show that individuals and their families in Canada bear a disproportionate share of the costs, work and responsibilities associated with addressing the everyday needs of living with disabilities.

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Research by Statistics Canada and other agencies such as the Roeher Institute, identifies persons with disabilities as one of the groups at risk of persistent poverty, a situation that refers to the existence of multiple barriers to participation and where income assistance is absolutely essential yet, by itself, is insufficient to effectively combat poverty.³

No doubt then, a critical need exists for improved and enhanced supports and services. Today, services and supports are fragmented, often unavailable or unaffordable, not portable across life transitions or place, and all too often disempowering or stigmatizing to those seeking a modicum of assistance to live in dignity and to be active citizens.

We know that the needs of Canadians for disability supports and for more inclusive general services will grow and change due to:

- Our aging population,
- Pressures on smaller sized families available to provide informal care,
- Public expectations of more flexible service provision and stronger accountability,
- Further deinstitutionalization of persons with disabilities from facilities into communities, and
- Labour market needs for well-educated and skilled people.

Disability supports is an issue of employment – indeed, that has been the prime focus of much programming of late. Disability supports is also an issue of mobility and human rights; of independent living, learning and community participation; of personal and social development; of supporting families and caregivers; and, in a definitive way, an issue of inclusion, citizenship and dignity.

A Clear Sign that Existing Arrangements Are Not Working Now

A recent special report by The Globe and Mail demonstrates, powerfully and disturbingly, that current arrangements are not desirable, effective or likely sustainable. In a set of articles, The Globe and Mail documented the plight of more than 8,500 young and middle-aged people with disabilities across the country, that are “stagnating” in nursing homes for the elderly. As the reporter expressed it: “For Canada’s physically and developmentally disabled, who have fought for the past two decades against institutionalization, it must seem as if they are stuck in neutral. With too few community supports, scant affordable housing or aged parents who can no longer care for them, they may find they have no option but a nursing home.”⁴ According to the national director of programs and services for Muscular Dystrophy, “There’s a lack of accessible disability

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supports. There’s not enough of them, and when there are government-provided programs, they are very hard to access.”

The federal Conservative Party’s health critic, Steven Fletcher, paralyzed from the neck down as the result of a car accident when he was 23 years old, recounts that at the time, “I was faced with a nursing home, which is basically a ghetto for people with severe disabilities. I had to fight like crazy to stay out of the institution.” Mr. Fletcher, elected as a Member of Parliament in the June 2004 federal election lives in his own home and has health care aides 24 hours a day, paid in part by automobile insurance. Upon his arrival in Ottawa as an MP, accommodations have been undertaken, quite properly, to accommodate Mr. Fletcher, his wheelchair and attendant. For many other Canadians with disabilities, such financing and support systems are unavailable. Because they cannot afford and access attendant care or other home supports, many persons with disabilities are unable to live independently, who might otherwise, and often are maneuvered or compelled into institutions. While for some, the experience in an institution may be positive, for far too many young people with a disability, life in a nursing home can be degrading and depressing.

What observations can we draw from this set of recent articles? As a social issue, with a complex mix of factors, this situation seems to be relatively low on the political and public radar of awareness. As well, there has been a loss of progress and even some slippage in the de-institutionalization of persons with disabilities in Canada, with the adverse result that the expedient of nursing home placements diminishes the human and social development of people, due to segregation, isolation and increased vulnerability.

It is little wonder that investing in a national strategy on disability-related supports is the top priority of the disability community, a goal expressed in various consensus statements and consultation meetings over the last decade, the most recent of which was in January 2005. As well, federal, provincial and territorial governments have expressed commitment to this shared goal since 1998, and newly reaffirmed in the November 2004 communiqué of social service ministers.

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5 Teren Clarke, quoted in Priest, “Nursing homes.”
6 Quoted in Priest, “Nursing homes.”
8 This point was emphasized in a recent press release by the Council, of Canadians with Disabilities and the Canadian Association for Community Living. See note 9.
On its own, the federal government of Paul Martin also declared in the Speech from the Throne of last October that Ottawa will “be a steadfast advocate of inclusion.” And in December 2004, the Standing Committee on Finance, in their annual pre-budget consultation report, recommended that “the federal government meet with provincial/territorial governments and groups representing the disabled [sic] with a view to concluding a federal/provincial/territorial national disability strategy.”

“To leave a lasting a distinctive mark on social policy,” Jim Rice and I have recently noted that, “Martin must identify a key policy area and focus on transformational reform.” We suggested that a Canadian disability strategy could well serve as a new national social project, as one of the few bold new initiatives that the Martin Liberals might and could undertake during his tenure as Prime Minister, thus making a historic contribution and leaving an important policy legacy.

The recent federal budget makes one pause, however, and wonder where the federal government is really at on this issue.

**The 2005 Federal Budget and Liberal Commitments to Canadians with Disabilities: Delivering, Dithering or Declining?**

Immediate media reaction to the 2005 federal budget tagged it as a “something for everyone” budget, a political spin most likely welcomed by the Martin Liberals. This characterization, while predictable, given the government’s minority status in Parliament, is, I argue, dangerously misleading for what the budget means (and does not mean) for disadvantaged and marginalized groups in Canadian society such as persons with physical and mental disabilities.

It has been said that with this budget Prime Minister Martin opened the floodgates of spending, showering billions around the country. If this is true, then what Canadians with disabilities receive from this budget in new spending can only be described as a mere trickle. Of the $6.3 billion in new social spending planned over the next five years announced in this budget, $300 million, or just over four per cent, is specifically earmarked for Canadians with disabilities and family caregivers.

The 2005 budget surprisingly fails to deliver on Liberal commitments to Canadians with disabilities made over recent months and years. The actions that are undertaken reflect only partially Canadian values and Liberal pledges on removing barriers, advancing

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12 See the lead editorial, “The Prime Minister opens the floodgates,” in *The Globe and Mail*, February 24, 2005, p. A18. The editorial states “Mr. Martin put aside his tightwad days and spread money around the country like a broken garden hose.”

13 See *The Budget Plan*, chapter 3. If we include new investments for First Nation special education, the total is $420 million in disability-related initiatives over the next five fiscal years.
inclusion, fostering security and widening opportunity. While the government’s agenda for Canada’s future is described as “ambitious,” this claim rings hollow with respect to disability issues, an area in which there is a total absence in this budget of a long-term plan and vision as well as the lack of significant investments across a range of programs, services and transfers.¹⁴

What we are seeing here is an apparent decline in commitment by this latest budget, a postponement of attention to this group of Canadians and, perhaps of greater concern, a waning of sustained interest in matters of priority concern to Canadians living with disabilities. This is more worrisome and serious than rhetorical charges of dithering, which at least imply that a government knows the issues and options on the agenda that are before it, but hesitates and wavers prior to acting.

In the 2005 federal budget, new disability measures are a series of modest changes to tax measures that will make an important difference to only a relatively small proportion of persons living with disabilities. The main initiatives are:

- Extending eligibility for the disability tax credit (DTC) to individuals who face multiple restrictions that together have a substantial impact on their everyday lives.
- Extending the DTC to more individuals requiring extensive life-sustaining therapy on an ongoing basis.
- Increasing the maximum annual Child Disability Benefit to $2,000 per child.
- Expanding the list of expenses eligible for the disability supports deduction and the medical expense tax credit.

As well, this budget doubles, to $10,000, the maximum amount of medical and disability-related expenses that caregivers can claim on behalf of their dependants.

From the perspective of the overall fiscal plan, obvious social needs, and expressed intergovernmental priorities, the measures for Canadians with disabilities are really minor steps in delivering on commitments to Canadians with disabilities and their families.

National disability organizations have responded to the latest federal budget with what may be called polite yet profound disappointment. The Council of Canadians with Disabilities has stated that, “The improved tax measures are a positive step in the right direction in addressing the need for investments in supports. But, they are of no benefit to the vast majority of Canadians with disabilities who live in poverty and have no taxable income.” Marie White, the chairperson of the CCD, asks, “What will it take to get governments to address the real need? What will it take to get governments to address our

¹⁴ For example, The Budget Plan refers to the upcoming triennial review of the Canada Pension Plan by the federal and provincial governments. While mention is made about financial sustainability and diverse transitions to retirement, there is absolutely no mention of the Disability program component of CPP that is, after all, the largest public disability insurance plan in the country.
priority – the investment in disability related services and supports?” 15 The Canadian Association for Community Living (CACL), while welcoming the implementation of the tax reforms, expresses frustration and regret that the Martin government has not move ahead on other commitments to Canadians with disabilities.

Disappointment by the disability community over the latest federal budget is conditioned by a number of factors: first, that “the tax system is limited in its ability to address the systemic issues of poverty, unemployment and exclusion effectively;” 16 second, that the research evidence clearly documents significant gaps in needed services and supports by children and adults with disabilities in Canada; third, that House of Commons committees, public attitudes, and federal/provincial/territorial Ministers of Social Services have all recognized the importance of new investments in disability supports to advance the full participation of persons with disabilities; and, fourth, that the 2004 federal budget, which was relatively more fiscally cautious, included investments in employment, disability supports and income, and thus had been interpreted by many disability activists as laying the platform for a national disability strategy. 17

In addition, what text there is in the budget speech on issues of disability, and there is not very much, is problematic in what it says and in what is not said. 18 Implicit in the language used and in the issues highlighted in the budget speech is the old view of disability as a personal tragedy and bio-medical phenomenon, resulting in a situation that intrinsically is burdensome for family caregivers. Absent is any reference to the more contemporary social model of disability that addresses attitudinal, institutional and environmental factors; absent too, is any reference to equality rights and full citizenship, a terminology and philosophy apparent in previous budget speeches.

So, what to do? In his budget speech, Finance Minister Ralph Goodale declares, “this government will deliver!” For “[t]he disabled and their caregivers,” among others, “This government will deliver.” 19 The immediate and obvious question for Canadians with disabilities is: when will the government deliver, on what exactly, and through which policy instruments?

The budget does contain a favourable fiscal context and some design elements for a possible strategic approach to disability supports. Budget surpluses are projected in each of the next five years, along with steady economic growth, low and stable inflation and a declining national debt. A number of other policy areas in the budget are guided by

17 For example, see the response to the 2004 federal budget by the CACL, Budget 2004 – A National Disability Agenda to Take Shape.” Available at http://www.cacl.ca.
18 See the Budget Speech, February 23, 2005, p. 7.
19 The Budget Speech, February 23, 2005, pp. 4 and 5.
general goals, and the pacing of implementation over several years, using a five year fiscal framework to provide reliable and long-term funding. As an approach to innovating social policy, these are aspects of “directed incrementalism” – the setting of bold goals and working toward them step-by-step over the medium to long term.\textsuperscript{20}

I want to turn to sketching the outlines of an approach to formulating a national strategy on disability supports using the federal spending power of direct expenditures, more specifically intergovernmental transfer payments.

**Why a Federal Transfer?**

Federal grants in aid of particular expenditures in disability services have a fairly long and evolving history. The transfer of funds from the federal government to the provinces has been an important aspect of disability supports and intergovernmental relations in Canada for about 50 years.

Arrangements in the 1950s were formalized with legislation in 1961 on the Vocational Rehabilitation of Disabled Persons (VRDP), a program which ran from the early 1960s to the late 1990s when it was replaced with the Employability Assistance for Persons with Disabilities (EAPD), a multilateral agreement in effect from 1998 to 2003, when it, in turn, was succeeded by the Multilateral Framework on Labour Market Agreements for Persons with Disabilities, with bilateral agreements in effect from 2004 to 2006.

There has been, then, a solid history of governments working in partnership, based on the use of the federal spending power and a shared commitment to improve opportunities for Canadians with disabilities, specifically working age adults and increasingly on employment-related activities.

It is more than mere historical interest, that while other shared cost transfer arrangements in social policy disappeared or declined in the 1990s, this mechanism was preserved and subsequently revised with successive arrangements. This policy choice is politically significant, telling us something of the values that Canadians hold and the belief in a continued role by the federal government in the field of disability services and supports.

The rationale for a continued federal role in this field through intergovernmental transfers includes the following ideas:

- ✓ To address the core mandate and underlying mission of the Department of Social Development Canada;

- ✓ To support the portability of services and the mobility rights of Canadians with disabilities within and across jurisdictions and life situations;

✔ To encourage the further development and enhancement of the current patchwork of disability-related supports across the country;

✔ To assist provinces and territories, with their varying degrees of fiscal capacity, to undertake the provision of a range of accessible and responsive supports; and,

✔ To advance equality rights under the Canadian Charter by sponsoring programs and activities that aim to ameliorate conditions of disadvantaged individuals because of mental or physical disability.

By increasing the size and nature of transfers to the provinces for disability supports, the federal government can directly contribute to closing the gaps between needs and services and thus truly advance the economic inclusion and social citizenship of Canadians with disabilities.²¹

Options for a Federal Transfer on Disability Supports

In transferring funds to the provinces and territories for disability supports, three basic options seem available in theory.

One option is to create an entirely new federal transfer arrangement for this initiative. There seems little appetite or support for this approach by some federal officials and by some provinces and territories. It would also likely add to the complexity of an already multifaceted system of fiscal federalism.

A second option is to add a fund within either the Canada Social Transfer or the Canada Health Transfer, in effect an earmarked supplement for financing disability supports. A concern with using either of these transfers is that given their large expenditures for other policy matters, disability issues could easily be dwarfed within them in terms of public support, political attention, and future investments. Another concern, with respect to the CST is that few accountability mechanisms are associated with this transfer arrangement. And, with respect to the CHT, a concern is that it would reinforce a medical model of disability rather than the social model preferred by most in the disability community.

[Rather than using either the CST or CHT for disability-specific supports, another approach would be to ensure that these transfer arrangements reflect in their goals, values and administrative principles that vision of inclusion and empowerment expressed by In Unison and other policy statements.]

A third option is to adapt and build on the federal transfer that already exists for disability supports. This approach involves engaging the disability community and other

²¹ For a compelling argument by a leading Canadian economist on the need for federal transfers as a means of accomplishing national equity and efficiency objectives, see Robin Boadway, Should the Canadian Federation be Rebalanced? Working Paper 2004 (1), Kingston: Institute for Intergovernmental Relations, Queen’s University.
governments in a process of planning for a successor agreement to the Multilateral Framework for Labour Agreements for Persons with Disabilities.

While this option raises issues of its own, such as the fact that Quebec and the territories are not signatories to the Multilateral Framework\(^{22}\), it has a number of advantages: there is here a record of intergovernmental collaboration; it is a transfer familiar to groups in the disability community; it recognizes that provinces have primary responsibility in this area; administrative and accountability systems are in place; and, the arrangement is up for review in any case for 2006.

**What is the Multilateral Framework?**

With some input from the disability community as well as other stakeholders (business, labour, Aboriginal organizations), Ministers responsible for Social Services endorsed the Multilateral Framework for Labour Market Agreements for Persons with Disabilities in 2002.\(^ {23}\)

The goal of the Multilateral Framework is to improve the employment status of Canadians with disabilities. Behind this goal are the three objectives of enhancing the employability of persons with disabilities, increasing employment opportunities, and building on the existing knowledge base of people and employers. Thus, the focus is on working age adults with disabilities.

Several principles, agreed to by governments, underlie this initiative. The first, and perhaps overarching one states in part: “Persons with disabilities should be fully included in Canada’s social and economic mainstream, a key element of which is successful participation in the labour market.” Other principles speak to the need for a diverse set of approaches; access to mainstream and targeted programming; and the importance of supports and services that are “individualized, holistic, linked to other needed support systems” as well as “easy to access, portable across life situations, timely and inclusive.”

The Multilateral Framework has a cost-shared funding model. The federal government funds 50 per cent of costs incurred by provinces for programs identified as priority areas under the Framework, up to an amount allocated in bilateral agreements negotiated with each province (except Quebec).

We can further describe the Multilateral Framework as a semi-conditional and closed-ended grant. That is, there are some general parameters regarding the areas and ways in which the funds can be spent, though leaving considerable discretion to the recipient government to decide. And, as a closed-ended transfer, there is an upper limit specified beyond which the federal government does not transfer further funds for costs incurred.

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\(^{22}\) Even these are not insurmountable problems. Quebec has participated in past intergovernmental agreements for persons with disabilities under bilateral arrangements with Ottawa; and the issue of participation by the territories is linked with resolving the relation between territorial financing and territorial own-source revenues, a matter, quite frankly, for political leaders to resolve.

\(^{23}\) The following discussion draws on material at the website [http://socialunion.gc.ca](http://socialunion.gc.ca).
by provinces in providing eligible services or supports.\textsuperscript{24} In practice, in recent years this has meant that the federal share of contributions on employment-related disability supports has actually declined from about 50 per cent to 39.6 per cent in 2002-03.\textsuperscript{25}

The priority areas identified as eligible for funding by the federal government are education and training; employment participation; employment opportunities; connecting employers and persons with disabilities; and, building the knowledge base.

In terms of accountability requirements, provinces are to report on objectives, descriptions, target populations, and planned expenditures for programs and services. Baseline reports with this information were released by each jurisdiction on December 3, 2004. Reporting is also to include program indicators that specify the number of participants in programs and services; the number of participants completing a program or service where there is a specific start and end point to the intervention; and, the number of participants obtaining or maintaining employment, where the program or service supports this activity. Beginning in 2005 and annually thereafter, governments have agreed also to report on a set of “societal indicators” that include the employment rate of working age persons with disabilities; employment income; and education attainment.

**The Multilateral Framework as a Platform for Reform**

The Multilateral Framework can readily serve as the platform for a new national strategy on disability supports. A new National Strategy can build on the goals, objectives and principles, and the accountability and reporting features of the existing transfer program.

*This is a key message: it is not a huge leap from the existing framework and transfer arrangement to a more comprehensive and substantial federal investment in supports and service for Canadians with disabilities.*

A revised multilateral framework builds on the idea that employment-related supports are central to the success of persons with disabilities in the economic mainstream by adding other equally critical areas that require further public investments. The concept of supports would therefore be broadened to include an intervention, service, benefit or assistance provided to a person with a disability to assist the person and or their family in activities of everyday living and caregiving, in learning and education, and in preparing for, or attaining or maintaining employment.

Expressed in relation to the strategic outcomes of Social Development, our proposal is to build on the goal of enhancing the economic participation of adult Canadians with

\textsuperscript{24} So, under the previous agreement, the EAPD, in 2002-03, governments contributed $477 million to labour market programs for persons with disabilities, of which $288 million was provincial funding and the other $189 million was federal funding. The 2003 federal budget renewed the Government of Canada’s funding commitment under EAPD and its successor at $193 per year.

\textsuperscript{25} The 2004 federal budget announced a $30 million increase to the Multilateral Framework, raising the annual federal contribution to $222 million in the 2004-05 fiscal year.
disabilities, extending it to include promoting economic and social inclusion, participation, and well being within inclusive communities for Canadians with disabilities of all ages.

Desired outcomes from such a collaborative intergovernmental initiative, that would form the basis for the accountability and reporting system, could include:

- Expanded quantity of existing supports to alleviate major gaps in coverage;
- Improved quality of supports;
- Reduced costs to individuals and families; and
- Enhanced portability of supports.

The actual number, nature and measures for desired outcomes would be, as expected, the subject of negotiations and consultations both within and across governments and the disability community. A parallel process would take place with national Aboriginal organizations and community organizations.

Funded priority areas would span the life course and various life transitions, such as educational supports for children and youth; information and respite services for parents and other informal caregivers; and - for persons with disabilities of all groups - personal care, home supports, home modifications, local transportation arrangements, and service planning and service brokerage/coordination. These are the areas research consistently points to as essential for addressing gaps in unmet needs for supports; overcoming barriers, and enabling inclusion and independent living; and supporting consumer control and improving the quality of life for Canadians with disabilities.

Federal funding under a new policy framework would be available to provinces and territories for this kind of array of personal supports for Canadians with disabilities and their families. Since the intent is to increase the supply and quality of much needed disability supports, there would need to be agreement of no “clawback” of new federal investments in disability supports by recipient governments.

Recognizing and respecting that disability supports and services is an area of primarily provincial jurisdiction under the constitution, the actual mix of areas funded in a given jurisdiction would be determined by that provincial or territorial government, in the context of shared goals and principles, and in consultation with representatives of the disability community in the jurisdiction. The approach I propose is not a national system with a standardized design with commands and controls by Ottawa; rather, I envisage a national strategy with shared policy objectives and desired outcomes informed by guiding principles and jurisdictionally-based accountabilities.

The federal government would also offer adequate funding to enable national and provincial/territorial disability organizations to have the capacity to engage effectively in such consultations. A related question for the community and government to ponder is the necessity and potential effectiveness of a national council on disability, like the ones.
in health or learning that would act as a mechanism both to do public reporting and give some profile to the federal role.

Over time, this initiative, with new, predictable and stable federal investments, will build a more secure base for the full age range and life situations of Canadians with disabilities, creating the foundation for their fuller participation in, and contribution to all facets of Canadian society.

Thank you.