

**ENHANCING THE RIGHTS AND WELL-BEING
OF CHILDREN, YOUTH, AND FAMILIES LIVING
WITH DISABILITIES:**

A NATIONAL ACTION PLAN

Speaking Notes

By

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Introduction

Thank you very much for that kind introduction and good morning to you all. It is a pleasure to be here today.

I want to thank Mary Clare and the conference organizers for giving me the opportunity of delivering the key note address at this year's general annual meeting of the Society for Children and Youth of BC. It has been said that professors simply cannot discuss a topic, but that habit compels us to deliver a lecture. Well, I will try to resist that habit here. At the same time, it is, as Henry David Thoreau wrote long ago, "admirable to profess" - "to have subtle thoughts, to love wisdom [and] to solve some of the problems of life, not only theoretically, but practically."

I wish to exchange ideas and information with you about improving, in practical ways, the well-being of children, youth and their families in our province and our country.

I know you have conducted a public policy review on the rights of children with disabilities in BC and the United Nations Convention on the Rights of the Child, and that you have been talking about the need for some sort of "blue print" for action and reform.

As that review states: "Children with disabilities are singled out for attention because of their heightened vulnerability, particularly for those living in poverty or in state care. Children with disabilities lack visibility in communities and society, and services for children with disabilities are generally considered "charity" or "privileges" rather than entitlements."¹

¹ Society for Children and Youth of BC, *Perspectives on the Rights of Children with Disabilities in British Columbia*, Vancouver: SCYBC, 2003, pp. x-xi.

Amidst these challenges, we are meeting at a very exciting and interesting time for public policy, politics and social planning in Canada. Current and emerging issues and initiatives include: the federal government's recently announced plans for a "new deal" for Canada's cities and communities; the formation of a Health Council, a new Canada Public Health Agency and our first ever Chief Public Health Officer for Canada; the Multilateral Framework for Early Learning and Child Care; the expansion of the community pilot project, Understanding the Early Years, to over 100 communities across the country; and a renewed focus on Aboriginal issues by Ottawa.

At the same time, in BC we have witnessed constraints in health services, numerous school closures, and cuts in funding to women's centres, among other difficulties.

As well, there is Prime Minister Martin's expressed desire to work out with the provinces and territories, a 10-year plan for significantly reforming the health care system - a plan that he sees including a program on home care and community services based on a long term agreement of predictable and sustainable funding.

So a real sense of choices, changes and challenges in public services and social policy is in the air!

This morning, therefore, I want to share with you my thinking on mapping a national action plan for children and youth with disabilities, specifically, a 10-year agenda for strengthening the foundations of personal supports, employment and learning, and income security for children, youth, and families living with disabilities.

Why a National Strategy?

The answer to this can be approached at a personal level of everyday living, and at a political level of public action.

At the lived realities of the personal level, a national action plan is essential because:

- Families play a pivotal role in meeting the needs of children with disabilities and need support – they cannot do it alone;
- Access to appropriate supports and services is inadequate;
- Appropriate services (of various types) are not available in many communities, and, where services are available, they are not adequate to meet the level of need;
- Discretionary funding of services means that children's rights are essentially treated as privileges;

- Devolution of policy and services has resulted in lack of consistency and accountability;
- Community supports and governance are central to inclusive communities.²

At the level of politics and governments, a national action plan is required:

1. To avoid continued policy drift and reacting to decisions and events. As our experience with the National Children's Alliance has shown over the past several years, a strategic approach can facilitate dialogue and collaboration across local, provincial and national organizations concerned with improving the lives of children, youth and families in Canada.
2. To infuse the child and youth community and disability community with a clear and strong sense of purposeful direction. A strategy can identify common issues that span organizations and communities, building bridges across sectors, enabling a broad consensus to emerge on a range of public policy issues.
3. To re-energize the commitment to leadership on children's and disability issues made by the Premiers and Prime Minister in 1996 as part of the social policy renewal process.
4. To raise public awareness of, and support for the UN Convention on the Rights of the Child along with the vision of full citizenship for persons with disabilities; not just article 23 of the Convention, which deals specifically with children with disabilities, but the entire package of rights and protections in the Convention.

The Case of a New Deal for Communities

Here is one example of what I have in mind in thinking strategically. In the federal Throne Speech and budget earlier this year, the Paul Martin government announced what they called a "new deal" for Canada's cities and communities. Over the next 10 years, Ottawa is providing Canadian municipalities with \$7 billion of GST rebates as well as pledging new funding for immigrant language training, support to Urban Aboriginals, aid for the community-based and non-profit sector, and assistance for local infrastructure to encourage quality of life and sustainable growth.

In the words of Prime Minister Martin, "We want communities that provide affordable housing, good transit, quality health care, excellent schools, safe neighbourhoods, and abundant green spaces."

And, in the words of your Society, we want "child and youth friendly communities," that is, neighbourhoods, communities and cities that welcome and involve children and youth and promote their well-being and safety. The Prime Minister's new deal for communities

² This list of points comes from *Perspectives on the Rights of Children with Disabilities*, p. 94.

has potential to be a great opportunity then to engage children and youth in the process of making our cities and communities better places for children, youth and their families.

A key part of this new deal for Canadian communities must be a new deal for Canadian children, youth and families. We need to ensure that investments in municipal infrastructure, whether for sports, leisure, recreational, housing, service centres or other facilities, is family-friendly and inclusive for all persons.

General Features of the Disability Strategic Action Plan

- Phased in over a ten-year period, 2005-06 to 2014-15
- A simultaneous consideration of the three “building blocks” of employment and learning, supports, and income, including the sequencing of priority reforms and their interactions
- Accountability and public reporting mechanisms on desired results and outcomes
- Built-in opportunities for meaningful engagement with individuals, including youth and elders, plus families and the disability community.

The action plan, as I picture it, would be an “umbrella strategy” that establishes the broad outline and content of a reform agenda, leaving many policy details and program specifics to be determined through consultations and negotiations among governments and deliberate plan and a deliberative process.

Reflect on income security.

According to Statistics Canada research, in 2001, 12 per cent of children in BC were considered to be living in households with low after-tax incomes. Measures on the cost of living show that 20 per cent of households are struggling to make ends meet in BC, due in large part, to high costs for housing and food. Next to Newfoundland and Labrador, BC has the highest rate of relative poverty in the country. The recent annual report by the Provincial Health Officer notes that “we can do more to protect children from the long-life negative effects of growing up in relative deprivation and poverty.”³

Likewise, the latest report on child poverty in Canada by Campaign 2000, finds that one million children across the country are growing up poor. Solutions proposed by the coalition include increased child tax benefits, a national child care program, and more

³ Office of the Provincial Health Officer, *The Health and Well-Being of People in British Columbia, A Report on the Health of British Columbians, Provincial Health Officer’s Annual Report 2002*, Victoria Ministry of Health Planning, 2003, p. 40.

affordable housing. The federal Minister of Social Development agrees that more must be done to reduce and prevent poverty.⁴

Think about employment.

Young people [age 15 to 24] have the highest unemployment rate in the province. In late 2001, the BC government introduced a training wage of \$6 per hour for workers with less than 500 hours of paid work experience as compared to the \$8 hourly rate for the minimum wage. The aim was to stimulate youth employment by encouraging employers to hire less experienced help at a lower cost. We would need an independent evaluation of this initiative to assess whether or not the lower minimum wage rate is having the desired aim of helping youth to enter and remain in the labour force, and whether other measures here or in other jurisdictions are more desirable and effective.⁵

Consider child care services.

We know that the supply of child care spaces grew far more slowly in the 1990s than in the 1980s, due to government restraint, thereby aggravating an already serious shortage of quality child care spaces. Steps were taken in 2000 with the Early Childhood Development Agreement between governments, and then further with the intergovernmental agreement in March 2003 called the Early Learning and Child Care Initiative. Under this most recent initiative, the goal is to improve access to affordable, quality, provincially and territorially regulated child care and early learning programs and services for children age six and under and their parents.

While the federal government is committing additional funds to child care over the next five years, it is uncertain what the plans are of the provincial government. As in other areas, it may be that the emphasis will be on the reorganization of services rather than the allocation of new investments in this area. The Minister of Community, Aboriginal and Women's Services, Murray Coell, is quoted as saying that he thinks "there is enough money" devoted to child care in the province, adding that: "I think there is always a need to use that money in a better co-ordinated way. The federal government is also interested in bringing more money to the table nationally. So the co-ordination of that would be a positive thing."⁶

The key point I wish to make here is this: even with the infusion of additional federal funds, there will continue to be a significant shortfall of affordable and accessible quality child care to working families in British Columbia, many of whom are at or near the poverty line.⁷

⁴ See Campaign 2000, *Pathways to Progress: Structural Solutions to Address Child Poverty*, Ottawa: campaign 2000, May 2004. See also, Canadian Press, "Activists blame Liberal policies for a million children in poverty," May 5, 2004.

⁵ The Office of the Provincial Health Officer has made this point, p. 31.

⁶ Quoted in Jeff Rudd, "Government to overhaul BC child-care service," *Times Colonist*, Victoria: April 30, 2004, p. A5.

⁷ Norma Greenaway, "Minimum-wage earners stay at poverty level after welfare," *Times Colonist*, Victoria: May 4, 2004, p. C2.

A related issue is the overall stability and quality of the child care sector. Researchers Paul Kershaw and Hillel Goelman point out the problem of what they call the “hidden fragility” in the child care sector in BC. Their research confirms that there is significant turnover in the licensed-centre-based and family child care programs in the province. They found that nearly one-third of centre-based programs and about one-half of family day care programs that were in operation in 1997 were no longer functioning in 2001. This fragility is somewhat hidden to policy makers in that the overall number of spaces was relatively constant over this period, masking the upheaval of local services coming and going.⁸

⁸ Based on a paper to be presented at the Canadian Political Science Association annual meetings, Winnipeg, June 2004.

**Time Periods and Policy Building Blocks on Disability Reform:
With Selected Options, 2005-2015**

Policy Building Blocks/Time Periods	Employment and Learning	Personal Supports	Income Security
<p>Short-Term (1 – 2 years)</p> <p>2005/2006</p>	<p>New FPT Labour Market Agreement for Canadians with Disabilities with a schedule for increased federal investments over the next 5 years</p> <p>Expand the Aboriginal Human Resources Development Strategy - disability part (AHRDS-D)</p> <p>Develop action plan for federal public service to be a “model employer”</p>	<p>Commit funding for a 2006 PALS and the associated analysis</p> <p>Further analysis of existing data sets (2001 PALS and other sources) dealing with supports and services</p> <p>Intergovernmental and community dialogues on building consensus on a national vision and plan for personal supports (laying the groundwork for medium term actions)</p> <p>Consider making grants for the purchase of disability supports non-taxable or deductible</p>	<p>Review and reconcile definitions of disability among the Disability Tax Credit, the CPP-D and Canada Student Loans Program</p> <p>Extension of the DTC to individuals, otherwise qualifying, with mood disorders, learning disabilities and episodic conditions</p> <p>Better communication to raise public awareness of programs such as the GIS, the DTC and the METC</p> <p>Improved administration and appeals procedures for disability-related income and tax measures</p>

<p>Medium-Term (3 - 5 years)</p> <p>2007/2010</p>	<p>Review Employment Equity Act and program (2007)</p> <p>Enhance focus and application of Employment Benefits and Support Services with specific targets for persons with disabilities under Employment Insurance</p> <p>Improve income tax measures that recognize the cost of accommodating employees and others with disabilities</p>	<p>FPT Agreement on Personal Supports for Canadians with Disabilities (with federal contributions growing over a 5 year period): a NCB-style approach in which the federal government assumes primary responsibility for income security and the provinces/territories invest in disability supports matched by federal contributions</p> <p>Early in this stage, commit funding for a 2011 PALS and the associated analysis/research and dissemination</p>	<p>Expand Child Disability Benefit to youth with disabilities aged 18 to 25 (perhaps expanded in two steps over a few years)</p> <p>Broaden scope and value of the EI Compassionate Care</p> <p>As noted under personal supports, federal government assumes primary responsibility for income security while the provinces/territories invest in disability supports. This would involve a gradual build up of investments</p>
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<p>Longer-Term (6 – 10 years)</p> <p>2011/2015</p>	<p>A successor FPT Labour Market Agreement for Canadians with Disabilities</p> <p>Review Employment Equity Act and program (2012)</p>	<p>Evaluate, amend, and approve a second FPT Agreement on Personal Supports</p>	<p>Create a Canada Disability Benefit for all age groups that would combine the DTC and revised Child and Youth Disability Benefit</p> <p>Replace the EI Compassionate care program with a Family-Caregiver support initiative that would offer EI coverage for those caring for persons with severe disabilities or who are gravely ill and dying. (Would be for those not eligible for leave through a post-acute care home care strategy in health care)</p>
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Intended Benefits and Results: What would policy look like in 2015 for children, youth, and families living with disabilities?

1. Relief of poverty (low-incomes) through a reasonable minimum level of income support at the national level (and thus less reliance on provincial/territorial social assistance for persons with disabilities). The proposed extensions to the Child Disability Benefit and the new **Canada Disability Benefit** seek to reduce the depth of poverty, alleviate the financial barriers to access personal supports and services, and to more fully recognize the disability-related costs of living. The

Canada Disability Benefit would be income-tested (on family income) and indexed fully to inflation, focused not solely on the extremely poor but including the low to modest-income individuals and families. The value of the benefit would be enhanced over a number of years through a series of incremental investments. The definition of disability would recognize severe and prolonged mental and physical disabilities as well as episodic conditions. The Department of Social Development would administer the benefit and there would be a clear and transparent appeals system perhaps using the Office of the Commissioner for Review Tribunals.

2. Better access to a range of essential personal supports and services for everyday living (thus reducing disparities in the level of and access to such supports and services) largely through a **FPT Agreement on Personal Supports for Canadians with Disabilities**. Goals would be to increase the availability of appropriate services and supports, to foster the portability of supports across communities and life situations, and to foster independent/inclusive community living. The Agreement would respect that the primary responsibility for program and service design and delivery are the jurisdiction of the provinces and territories. A key principle would be that fiscal transfers from the federal government would result in a net increase of disability-related services and supports. This model encourages a shift from segregated institutional care to more integrated community living options (thus advancing inclusion and self-determination). The Agreement would also endorse a social model of disability with attention to environmental barriers along with a cross-disability approach. The Agreement would fund a menu of programming options in such priority areas as technical aids and devices help with activities of everyday living, home and vehicular modifications, respite care for families providing a huge portion of the caring responsibility, and individualized funding and support planning.

Perhaps by 2015 we will see services for children and families and services for those with developmental disabilities actually transferred from the provincial ministry to regional authorities! Recent delays, postponing reforms originally planned for 2003 to 2006 or 2007, offers an opportunity for advancing the rights of children. Processes should be established to ensure that the Convention is routinely used as a lens, along with a disability/inclusion lens, for assessing the reorganization and transfer of service delivery, and to monitor and evaluate the compliance of laws, policies and programs.⁹

3. Enhanced opportunities for, and accommodation of adults with disabilities to participate in employment and learning, through a **new FPT Labour Market Strategy, a “model employer” role by the federal government, and expanded Employment Benefits and Support Services for persons with disabilities**. Among other goals, these measures would ensure the availability of job accommodations in workplaces and the creation of adequately trained and

⁹ Society for Children and Youth of BC, Position Statement No. 9, “Children with Disabilities and Other Special Needs,” May 2002, p. 4.

remunerated personnel in communities to provide services and supports requested by people living with disabilities. Employment policies and rules that promoted more flexible workplaces for parents caring for children and youth with disabilities is another priority area. A long-term goal would be that people with disabilities be proportionately represented in the labour force. A related outcome would be greater ability of parents/guardians of persons with disabilities to enter, re-enter, remain and advance within the labour force (and thus enhance their earnings, benefits and pensions).

NEXT STEPS

So, those are some policy ideas for a national action plan to promote the effective implementation of the UN Convention on the Rights of the Child; a national plan that seeks to realize human rights and meet our international obligations for all children, including the most vulnerable and least visible.

Whatever all the details and specifics might eventually be, the plan must meet the test of tackling barriers, questioning discriminatory attitudes and practices, and satisfy the test of advancing equity, inclusion and the well-being of children and youth with disabilities in BC and the rest of Canada.

Thank you.