

Every Canadian Counts Coalition



*A Canadian coalition
advocating for a national disability program to support
the more than 1.9 million Canadians
living with long-term, chronic disabilities*

Presentation to OASIS Board, July 2019

Topics

1. The Problem and the Proposed Solution
2. Since 2014/Where are we?
3. Looking ahead

Problems

- Long waiting lists for often inadequate and inequitable supports and services (inconsistent application)
- “Falling off the cliff” during life transitions
- Inability to relocate and take supports with you
- Limited provincial funding and resources
- Onerous bureaucracy
- Poor data and information
- Fragmentation within sector



The Support System: Fragmented Competitiveness

(Much Effort, Shifting Focus, Decreasing Marginal Returns)

	M	BLIND	DEAF	MD	BI	DD	Autism	Down	CP	SC
Income	x	x	x	x	x	x	x	x	x	x
Employ	x	x	x	x	x	x	x	x	x	x
Access	x	x	x	x	x	x	x	x	x	x
House	x	x	x	x	x	x	x	x	x	x
Integrate	x	x	x	x	x	x	x	x	x	x
Educate	x	x	x	x	x	x	x	x	x	x
Transition	x	x	x	x	x	70's	Now	1960's	x	1980's

Disability Insurance

Furthermore...

- Canada's system is increasingly under strain and increasingly failing:
 - Aging population generates fear and anxiety in the care giving community
 - Capacity of families to cope is decreasing while costs to governments and society are increasing
 - Demand is growing – in part because of new possibilities
 - The system is unsustainable in its current operational and financing environment and not meeting need

A new advocacy needed

- From:
 - ideological and moral posturing in an effort to obtain what we can and gain favour
- To:
 - A call for funded investment instrument that is person centred to meet need, offer choice, and build opportunity while strengthening the economy

An insurance approach provides that instrument

What is Every Canadian Counts?

The ECC Coalition is a national not-for-profit organization. We are a group of Canadians advocating for creation of a national cross-disability support program for those with long-term, chronic disabilities.

This coalition includes:

- individuals living with disabilities and their families
- organizations, agencies and groups that support or advocate for people with disabilities
- concerned citizens



3. ECCC's Proposal

A national publicly-funded disability program that will...

- Cover all Canadians living with long-term disabilities throughout their lives
- Provide essential supports and services
- Ensure portability & minimum standards across Canada
- Improve data collection and sharing of best practices in the disability sector
- Introduce new federal funding to the disability sector

2014

- Early days (year 1)
 - The arrival of ECCC met with mixed reaction in the DD community
 - Important formative support from some
 - OASIS
 - OCAPDD
 - Significant and almost debilitating resistance from others
 - DD sector not fruitful ground at first
 - Political terrain federally not conducive (but neither was it in Australia)

2015-16

- Broadened our advocacy to beyond DD
 - Initially CNIB, March of Dimes, Neil Squires, DAWN, Rick Hansen initially
 - Lesson: great interest and a more advanced culture of collaboration among many and this is what generated energy and momentum to continue
 - Also helped by a change in government which saw the creation of a Minister Responsible for Persons with Disabilities

2017-19

Expanded Network of Engagement

- Target groups:
 - Advocacy/support institutions
 - Family Groups and Unions
 - Students and Researchers
 - Governments



Advocacy Groups (1)

Accessibility Centre (Ottawa)

Advocating Parents of Nova Scotia

Autism Speaks Canada

Assembly of First Nations

Barrier Free Canada

Brain Injury Canada

CACL

Cdn Association of the Deaf

Canadian Association of Health Sciences

CCRW (Cdn Council of Rehabilitation and Work)

Cdn Cooperative Association

CASDA

Cdn Centre on Disability Studies

Cdn Economics Association

Cdn Hard of Hearing Association

Cdn Hearing Society

Cdn Home Care Association

Cdn Human Rights Commission

Citizen Advocacy

CNIB

Coalition of Persons with Disabilities (Nfld & Lbdr)

Communication Disabilities Access Canada

Council of Canadians with Disabilities

DAWN Canada

Advocacy Groups (2)

Deaf-Blind (Ontario)

DEEN Support Services

Dignity 2016

Disability Alliance BC

Disability Justice Network of Ontario (DJNO)

Disabled Persons International

Disabled Women's Network of Canada

Independent Living Canada

Kinaxis

Kinova

Kiwanis

l'Arche

Lifetime Networks Ottawa (PLAN affiliate)

March of Dimes

Medicare for Autism Now

Mental Health Commission of Canada

MitoCanada

MS Society of Canada

Muscle Canada (Muscular Dystrophy)

Neil Squires

Ontario Association on Developmental Disabilities (OADD)

OASIS

Ont Fed Cerebral Palsy

People First Canada

People First Nova Scotia

Planned Lifetime Networks

Rick Hanson Foundation

Roll a Mile

SALAS

Sam Sullivan Foundation

Shriner's

SSAH & Passport Coalition

SBHAC (Spina Bifida & Hydrocephalus Association of Canada)

Spinal Cord Injury Canada

TAMIR

TCE

Unions

- BTAC - Building Trades Association of Canada
- CLC
- CUPW
- PSAC
- NUPGE
- CNA (Cdn Nurses Association)

Student Associations/Family Groups

	STUDENT GROUPS
	Ontario Undergraduate Student Alliance
FAMILY GROUPS	Canadian Alliance of Student Associations
Families for a Secure Future	NEADS (National Educational Association of Disabled Students)
Family Alliance Ontario	
Family Net (BC)	RESEARCH
Hamilton Family Network	CCDS - Queen's University
The Real People Campaign	Canadian Neurological Sciences Federation
Toronto Family Network	Neurological Health Charities Canada
Windsor-Essex Family Network	Ontario Neurological Foundation
	PONDA
	Ryerson University
	Tamarack Institute
	Tetra Society



Advocacy with Government

- Approached all parties
 - Minister Qualtrough
 - Arranged a meeting with NDIS Chair in Sydney, Australia
 - Stephan Lauzon (Chair, Social Affairs Committee)
 - Jim Munson Senate
 - Anita Van den Beld (Champion)
 - Sen. Enverga, MP Mike Lake (Conservatives)
 - Alex Cullen/ Cheryl Hardcastle NDP
 - Blue Sky Strategy Group

Policy Process

- Actively engaged in the funding criteria review process undertaken by the Ministry 2015-16
- Latched on the policy cycle for the Liberals, just missed the NDP one by days and lost lead for the Conservatives
- Resolution before the Liberal Election Platform Committee to undertake research into the feasibility viability and desirability of a national insurance program.

A National Disability Insurance Program

WHEREAS people with chronic disabilities need essential supports if they are to become fully engaged citizens;

WHEREAS the current disability support systems Canada is universally characterized by fragmentation, inconsistent and unfair and inadequate resource provision where thousands are left without supports;

WHEREAS the Provinces have indicated that they are incapable of meeting the need on their own without federal help (Ontario's Drummond Report - Article 8.6);

WHEREAS Australia has addressed effectively these problems¹ through the launch of its National Disability Insurance Scheme in 2013 with 93% of those effected rating the new program as 'very good';

WHEREAS a review by the Ministry of Finance Australia confirmed that the predicted benefits to the Australian economy have been realized and cost were in line with predictions²;

WHEREAS the problems and challenges that Canadians face are similar to the experience of the Australians; ³

BE IT RESOLVED that the Government of Canada commence negotiations with the other Political Parties, Provinces and Territories to undertake research to assess the viability, feasibility and essential design features of a national disability insurance program for Canada as per the Australian example;

¹ A New Disability Policy Framework for Australia - THE WAY FORWARD - Report of the Disability Investment Group, 2008

² National Disability Insurance Scheme (NDIS) Costs, Commissioned study, Productivity Commission Position Paper June 14, 2017

³ Disability Care and Support - Productivity Commission - Inquiry Report - Commonwealth of Australia 2011

The time is right...

- Canadian politicians support a national approach but emphasize that **unity is required for change to happen**
- Stakeholders eager for change
- Canadian public receptive
- Government is listening and active

Organizational Development

- Regional Rep Development
 - Alison O'Neil in BC*; Brenda Hardiman in Nova Scotia;* Jen Coughlin PEI; Jonathan Marchand Quebec
- Policy Paper
 - *"MOVING FORWARD: Building the Framework for an Inclusive Future for People with Disabilities and their Families in Canada"*
- Invited to join CCRW Round Table
- Advisory Committee
 - Bruce Bonyhady (founder of NDIS Australia)
 - Michael Kendrick (International Consultant)
 - John Cooper (former Deputy Auditor General of Canada)

So where are we?

- Accessibility legislation has passed –
 - From accessibility to **Inclusion**
- Funding streams force co-operation (CCRW)
- Government has been ‘banging heads’
- FALA Group - over 50 development services agencies and organizations was key to mobilizing to get the Accessibility legislation passed

FALA GROUP

(Federal Accessibility Legislation Alliance, 'My Canada Includes Me')

- Looking ahead 'My Canada Includes Me' will:
 - Support, present, and amplify a unified voice
 - Reduce duplication; better communication with government
 - Inform/influence policy
 - Support & be a watchdog for The Accessible Canada Act
 - Provide a platform for collaboration, sharing of best-practices, developing & implementing nation-wide strategies for inclusion
 - A place to go to connect with others for change
 - Looking to support ECC any way it can

Looking ahead for ECCC

- The Need
 - A Champion
- The role:
 - A) if it makes the election platform, job done?
 - The route of Pharmacare – Special Advisor
 - B) Quality oversight (monitoring and evaluation) like EAC – there have been implementation issues in Australia

Australia

- Implementation Issues
 - Too market oriented (funding model)
 - Medicalized despite wish not to be so
 - Tier 2 disabilities lost out
 - Too fast in roll out resulting in re-assessments
 - BUT
 - Public fully on board
 - Much innovation and creativity
 - A lot of people's lives are better

The Road to Success

- big social and economic reforms are always very challenging for everyone involved and so resilience, a clear focus on the ultimate goals and a deep commitment to overcome the consequences of major disruptive forces are essential for success.

Against this background, I think there are three key lessons::

- First, sector unity is essential. As you know, it was the unity of the disability sector which led to the NDIS itself. Now, sector unity is underpinning the rollout of the NDIS and efforts to ensure that its Vision is fully realised.
- Second, bipartisanship and the support of the Commonwealth and State and territory governments was essential for the NDIS to be established. Now, the continuing commitment of all governments is leading to strong actions to ensure that its implementation goes well.
- Third, with any major reform there will be elements which do not go according to plan. There must therefore be an unshakeable commitment to listen, learn, build and deliver based on the emerging evidence and feedback from people with disability, their families and carers.
- All of these factors are operating in Australia today and so, notwithstanding many teething issues, I remain convinced that the NDIS will become the benchmark for disability policy globally.

The Public Insurance Model

- A lifetime approach to care and support (replace specialist disability services)
- In the tradition of Medicare – universal health care
 - assess risk of disability on the general population;
 - calculate costs of meeting essential lifetime needs
 - estimate premium

The Public Insurance Model

- Instead of capped programs and services which people need to find and access
- Fund on the basis of needs to drives nature of care and support
- Funded from general tax revenue
- Implemented over 7- 10 years

Who would be eligible?

- People with a severe or profound disability
- Those who always or sometimes need help with a core activity or task, would be eligible for life
- Carers would also be recognized and supported in their roles. Opportunities to combine caring and work would be encouraged
- People covered by province/territory-based accident compensation schemes would continue to be covered under them

What Services would be covered?

- Coordinated services based on need including respite, aids, equipment, transport, home modifications and community and day programs
- Other support funded outside the scheme such as income support, housing and employment services would be integrated in a holistic approach
- Emphasis on early intervention and access to education and training to maximise long-term independence and potential

Principles

- Participants have a plan and goals that focus on maximising independence and social and economic participation
- Works alongside disability support pensions and other measures such as health, education and other public services, which have universal service obligations, including those with disability
- Not means tested
- Not charity - an equitable insurance model
- Early intervention and sustained supports
- Individualized funding
- Choice over how funding is managed
- Modes of support are many (no one template of support delivery)

4. The Insurance Model

- Why an insurance approach?
 - Expenditure is factored out over the life of an individual
 - Total future costs of all insured
 - Incentive to make strategic investments that maximize lifetime opportunities and reduce long term costs (cost reduced by enabling independence)
 - Continuous comparison between experience and forecasts
 - Early intervention on autism was one result
 - Outcomes performance and risk management integral

What are the benefits?

- **People with disability and their families have certainty and clarity about their options from the point of determination of a disability.**
- **Eligible people entitled to services determined on an individualized plan and needs basis, giving them access to an appropriate whole-of-life suite of services and support.**
- **Families have more choices about the combination of work and informal care for family members at various life stages, as in other families.**
- **Addresses the current unmet and under-met need for care and support and the unsustainable reliance on carers.**

What are the benefits?

- Clear incentives in the service system to invest in timely interventions that promote independence and produce long-term benefits.
- A sound platform of lifetime support to enable a range of innovative private contributions from individuals and families.

Questions, Comments, Thoughts?





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