

## Canadian Coalition for Family Supportive Policy

### DECLARATION -

A public policy agenda to support families who have a family member with a disability - March 2004

June 2004



*The Marlan Family*

During 2002-03, a number of national family-based organizations and coalitions joined together to build a Canadian Coalition for Family Supportive Policy (CCFSP). This national coalition is committed to advancing the citizenship, rights and full participation of persons with disabilities in their communities. We fully recognize the gifts and contributions that persons with disabilities bring to their families, communities, schools and workplaces. The purpose of this family-based coalition is to promote a shared vision and to move forward a national agenda to support families to secure a good life for their family member with a disability. For our coalition, the rights and needs of persons with disabilities are paramount. We also know that families provide an essential bridge to the realization of citizenship in the daily lives of children, youth and often adults with disabilities.

Comprehensive supports to strengthen families are laid out within the framework of four main policy goals. These sup-

ports are understood to encompass the right to access health care supports and services and the right of an individual to choose the services and supports they deem necessary and appropriate. It is expected that this coalition will provide a leadership role in promoting the advancement of a pan-Canadian public policy agenda and ensure that efforts are made to engage persons with disabilities, families, community sectors and governments in the process.

We have come together to promote a more proactive role for the federal government and to secure investments and the development of family-friendly public policies. The family-based policy agenda complements and supports the promotion of a citizenship policy agenda for people with disabilities.

#### Definition of Family:

A family consists of two or more people, whether living together or apart, related by blood, marriage, adoption or a commitment to care for one another.

## Considering:

THAT disability is determined by social, economic, political, cultural and natural environments;

THAT there has been a privatization of responsibility on families who have a family member with a disability;

THAT family members value the rights, inclusion and citizenship of their family member with a disability, just as they do any other family member;

THAT families want to continue to provide supports to a family member with a disability, but that they want some economic contribution and support for this purpose (e.g. compensation, future economic security, workplace flexibility, information, coordination and planning, respite, etc.);

THAT 2.3 million family members provide significant levels of support and assistance to a family member, with minimal or no financial compensation. The majority of people who need disability supports -- children, youth, and adults -- are supported entirely by their family members and friends;<sup>1</sup>

THAT among parents of 34,000 children with disabilities who indicated unmet needs for help with housework and family responsibilities, 71 per cent identified costs as the reason for unmet needs.<sup>2</sup>

<sup>1</sup>The Roeher Institute, *Moving In Unison into Action: Towards a Policy Strategy for Improving Access to Disability Supports* (North York: The Roeher Institute, 2002).

<sup>2</sup>Statistics Canada, Housing, Family and Social Statistics Division. *Participation and Activity Limitation Survey, 2001 - Children with Disabilities and their families* (Ottawa: Minister of Industry, 2003).

## **GUIDING PRINCIPLES:**

- **Families are the cornerstone to inclusive community life.**
- **Families come in all shapes and sizes.**
- **Children should grow up in families and all families are entitled to the necessary supports to raise their children at home.**
- **In supporting families, it is understood that the equality rights of individuals with disabilities that ensure access to needed health care and other disability related supports must be foundational in developing and implementing family supports.**
- **It is normal for all families to need different forms of support at different times.**
- **Supporting and strengthening families contributes to community well-being.**
- **For families, inclusion is naturally rooted in their love for their sons and daughters.**
- **Policies should be designed to strengthen all families, respect and honour family choices, facilitate participation in all aspects of family and community life and recognize family contributions.**
- **Supports to families should not be provided in place of the supports which children, youth or adults with disabilities require.**

## **The Canadian Coalition for Family Supportive Policy is committed to four main policy goals to move forward an agenda which supports families to secure a good life for their family member with a disability:**

1) To ensure families have access to needed supports (i.e. respite, home adaptations, information, planning and coordination supports, family-to-family support, direct funding options). Families need to have a choice of services delivered through these programs.

2) To safeguard the economic security of families (develop a strategy to address the disability associated costs incurred by families and advance and ensure the economic security of families who have a family member with a disability -- i.e. giving recognition of family contributions through the tax system).

3) To develop communities that advance and promote citizenship for persons with disabilities and their families (increasing the inclusion and participation in all aspects of community life -- early childhood care, education, health care, transportation, employment, leisure and recreational activities, etc.).

4) To provide families with tools and mechanisms to assist them in planning for their family member with a disability after the parents die.

*In each of these domains, the individual rights and needs of a family member with a disability must be addressed. Policy objectives with articulated roles for governments, civil society and researchers along with accountability and monitoring mechanisms need to be further defined. The guiding principles provide the foundation for the policy objectives.*

*Marilyn and David Perkins*

## **RECOMMENDATIONS:**

**The following are specific policy objectives under each of the main policy goals. These recommendations call on governments, employers and civil society to ensure:**

### **1. That families have access to needed supports.**

**Family Leadership Development** - Invest in a family leadership initiative to support the ongoing capacity-building and the networking and sharing of knowledge among families who have a family member with a disability across Canada.

#### **Develop a National Respite Strategy -**

This initiative would frame respite as an outcome. Such a strategy would deliver individualized and flexible support package options, giving families a choice and the ability to tailor respite supports to meet their unique needs.

#### **Develop a Federal/Provincial/Territorial and Aboriginal Investment Strategy for Families -**

A two plank federal investment strategy calling for a federal transfer of block funding to provincial, territorial and aboriginal governments to:

- a) expand provisions for disability-related supports to children, youth and their families based on principles of choice, flexibility, portability and community inclusion.
- b) expand flexible and individualized funding opportunities, and planning and coordination supports for families.



### **2. The economic security and recognition of the contributions of families.**

**Assure the economic security of families who face present or future income losses by needing to leave the workforce to care for a family member with a disability-**

- ▶ **Canada Pension Plan** - Expand the Drop-Out provisions, and allow for contributions to CPP for those who stay out of the labour market to care for a family member with disability-related needs.
- ▶ **Canada Labour Code** - Amend the Canada Labour Code to include family leave provision for those who must leave paid jobs temporarily to care for a family member with disability-related needs.
- ▶ **Employment Insurance Paid Leave** - Provide paid leave for family members who must leave their jobs temporarily to care for a family member with disability-related needs.

**Recognize the direct economic impact on families caring for a family member with a disability. The federal government can use the tax system as a vehicle to recognize the contributions that families make -**

- ▶ **Family Tax Benefit** - Create a refundable tax benefit for family members providing significant levels of support for a family member with a disability (e.g. by combining, expanding and making refundable the current infirm dependents credit and the caregivers credit).

## **RECOMMENDATIONS**

### **(Continued):**

#### **3. The development of community citizenship.**

##### **Invest in advancing the capacity building of inclusive communities.**

**Child Care** - Ensure the advancement of inclusion within the current Multi-Lateral Framework Agreement (objectives, reporting, evaluation frameworks and investment plans that have specific inclusion indicators and monitoring mechanisms).

**Community Capacity** - An essential step in fostering inclusive communities is increasing the capacity of communities to understand disability-specific issues and to challenge negative and stereotypical attitudes and perceptions of disability. This requires investments in disability and aboriginal organizations to provide the leadership, information, knowledge and partnerships for building inclusive communities.

**Investment in Infrastructure** - Ensure that the federal government invests in structural and social infrastructure of cities and communities (including aboriginal communities on and off reserve). Provisions and conditions for full accessibility of new infrastructure need to be included in all investments. Investment in social infrastructure is also necessary for advancing community citizenship.



*The Beayni Family*

**Community Transition Fund** - A fund directed towards strategic initiatives that enable the development/enhancement of community supports and services, in accordance with the principles and objectives of the *In Unison* report. The fund would call for, among other things, renewed efforts in all provinces and territories for deinstitutionalization activity.

#### **4. Planning for the future. Develop a National Disability Investment Fund, which will --**

- a) provide a mechanism for savings and investment, including tax incentives for financial contributions made by families;
- b) recognize and encourage families' financial contributions to the current and future security and well-being of their family members with disabilities;
- c) pool family and individual investments from trusts, RRSPs, RRIFs and a newly created Disability Savings Plan to maximize the rate of return, minimize fees and finance a vehicle to assist individuals and families with low incomes overcome isolation and loneliness and secure a good life for the future.

#### **Partner Contacts:**

Canadian Association for Community Living,  
Janis Douglas -  
(416) 661-9611

Canadian Down Syndrome Society,  
Elizabeth Dolman -  
(403) 270-8500

Canadian Association of William's Syndrome,  
Diane Reid -  
(403) 257-3581

Planned Lifetime Advocacy Network,  
Jack Styan -  
(604) 439-9566

Canadian Caregiver Coalition,  
Esther Roberts -  
(613) 233-5694

First Nations Child & Family Caring Society of Canada,  
Samantha Nadjiwan -  
(613) 230-5885

*The development and investments in family supportive policy for families who have a family member with a disability are key to strengthening and enabling families across Canada. Only once we begin to address the main areas will our governments and society begin to give recognition and acknowledgment to the roles and contributions that these Canadian citizens make in building a strong and inclusive Canada.*

**For more information,  
please e-mail:  
[ccfsp@cacl.ca](mailto:ccfsp@cacl.ca).**