



CPRN Discussion Paper

Enabling Citizenship: Full Inclusion of Children with Disabilities and their Parents

By Fraser Valentine

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Foreword

When the Family Network of CPRN was working on *What is the Best Policy Mix for Canada's Young Children?*, it became clear that families with children with disabilities faced a tougher set of challenges than most. They struggle, against the odds, to give all their children the best possible care and nurture. We therefore resolved to undertake a study that paid particular attention to the way in which society supports these families. Our goal was to ask: What would it take to ensure that “all children” truly meant *all* children.

Children with disabilities are over-represented in families with low income for two reasons: first, because the extra time required for care leaves less time for the parents to do paid work, and second, because these families face higher out-of-pocket expenses in order to look after children with disabilities. These families also present particular challenges for health and social service agencies. The numbers may be small in any given community, but the needs are great. The needs are also highly diverse, so that there is no general prescription for the service package they require. While governments have been working hard to define an overall policy strategy with respect to policies for adults with disabilities, children are not part of that strategy, nor are they a focus of the discussion on the National Children's Agenda.

We therefore commissioned two papers. The first one inventories, and then analyses, the policies and programs in place in all 10 provinces and the federal government. The second examines the governance challenges that remain as provinces attempt to create an integrated approach to serving the needs of these families and their children. Each paper was then reviewed with experts and stakeholders at a two-day Roundtable hosted by CPRN.

This first paper, on the policies and programs across jurisdictions, was written by Fraser Valentine of the University of Toronto. The paper includes a comprehensive set of 12 tables and four boxes, which detail current interventions. Building on this detail, he then uses the enabling conditions for healthy child development identified in CPRN's earlier work as the organizing framework to analyze the needs of these families and the existing policies. The enabling conditions are adequate income, effective parenting, and supportive community environments. He describes the unique financial and parenting challenges that families that have children with disabilities face, and the wide variation in the policies and investment choices undertaken by employers, governments and communities. He demonstrates that these parents and their children do not benefit from full access to work, education, and individual and community supports and services. They are not, therefore, living as full citizens.

I wish to thank Fraser Valentine for his relentless pursuit of the details and his careful analysis of the current state of policy in this complex area. I also wish to thank the experts and stakeholders who provided advice throughout the project, as members of the virtual Advisory Committee, and the even larger group who participated in the Roundtable. Last but not least, I would like to thank the funders of this project. All of these people have helped CPRN to document the barriers that remain for children with disabilities and their families.

Judith Maxwell
June 2001

Preface

At certain moments in time, discrete pieces of a puzzle are set into place to reveal a bigger picture, one that is more than the sum of its parts. So, too, is it for ideas. Discrete concepts have emerged from research into and analysis of the “best policy mix” for Canada’s children, and of the components and dimensions of citizenship. Here, we weave together several key findings that have materialized from these two research enterprises, and begin to explore how they fit together to help us think in concrete terms about how to make Canada a more just, prosperous and caring society.

Before the whole can be understood as connected, the puzzle pieces need to be elaborated. Four key concepts will be discussed:

1. The requirements needed for individuals to become *full and active citizens*
2. The foundations of a *best policy mix* for children
3. The *nested environments* in which children live and grow, and of which society is made, and
4. The *three enabling conditions* that, together, produce positive outcomes for all children, including those with disabilities.

Once these elements are described, an argument will be made for how they can inform – and indeed are an essential part of – the way in which we think about Canadian children with disabilities and their families.

The Importance of Citizenship and Its Link to Policy

Citizenship is a complex theoretical concept and set of practices that order the dynamic relationships between individuals and the state, and among individuals. It has three dimensions:

- *Rights and responsibilities* – which go hand in hand
- *Access* – to resources, as well as to opportunities to participate in society, and
- *Feelings of belonging* – in the broad sense of national identity, and in the everyday sense of identifying with the local neighbourhood and the community as a whole.

“Full citizenship” is a condition of *active engagement* in order to claim rights, exercise responsibilities, participate in political and community life, and identify with and feel connected to the community. Full citizenship has been identified for centuries as one of the underpinnings of both liberal democratic and capitalist societies, and is therefore key to their robust economic and social development. Successful engagement in the community and meaningful contributions to it require *equality* among citizens – equality of opportunity, of rights, and before the law. People also need to have a sense of *attachment* to their community in order to engage. Another requirement of engagement is *equity* in treatment and the *recognition of difference*.

The *United Nations Convention on the Rights of the Child* recognizes that all children are citizens-in-becoming and, therefore, have fundamental rights that must be available to them (that is, provision, protection, and participation rights). Full implementation of this *Convention* and others like it, however, requires more than formal equality of treatment. It may necessitate *differential* treatment in order to allow children with disabilities to achieve their full potential. Moreover, the citizenship status of the parents of children with disabilities may also be at stake. Policies in the public, private and voluntary sector can help or hinder the capacity of parents to engage in the community and exercise full citizenship. *All parents require certain basic supports*. For parents of children with disabilities, the needs and challenges are the same as those of any parent, although actual program delivery may need to be adapted to their particular circumstances.

For instance, access to family leave is needed by *all* parents to enable them to be absent from work in order to deal with family issues – doctor’s appointments, school visits, the illness of a family member, and so on. Enjoying access to such a leave is one of the rights of citizenship in many places, and is an example of equitable treatment of those who must balance work and family life. However, parents of children with disabilities may have additional demands stemming from their child’s disability. Parents in this situation would benefit from added *flexibility* in taking family leave. This is where the recognition of difference comes into play.

As this example shows, the ability of parents to engage in society and achieve full citizenship is affected by policy – in this instance, employment policy, which can be promoted through various public policy instruments. In theory, adults in our society are able to achieve full citizenship at all times. But public policy may limit their ability to fully engage in the community, thereby changing their relationship to the state and to each other. Relationships among individuals and their friends, neighbours, employers, and public institutions can change, depending on the nature of the policies in place in schools, workplaces, voluntary organizations, and so on.

When policies in the public, private and voluntary sectors do not *help* parents balance their work and family lives, increased “time and resource pressure” in the family can lead to a decrease in involvement in – and attachment to – the community. This can result in decreased engagement in community life, and the exclusion of parents and their children. Full citizenship may therefore be compromised. In turn, this can affect the overall quality of community life – in the here and now, and in the future. In short, as a result of child and family policies, society as a whole can flourish or flounder.

The Foundations of a “Best Policy Mix” for Children

A *best policy mix* for children is one that provides a variety of options that enable parents to exercise choice – in how to best raise their children, and in how to contribute to their community. A mix of complementary policies in the public, private and voluntary sector creates the environment needed to foster positive outcomes for children. But a best policy mix also contributes to the capacity of parents to exercise full citizenship now, and provides a solid foundation for the future citizenship of all of Canada’s children.

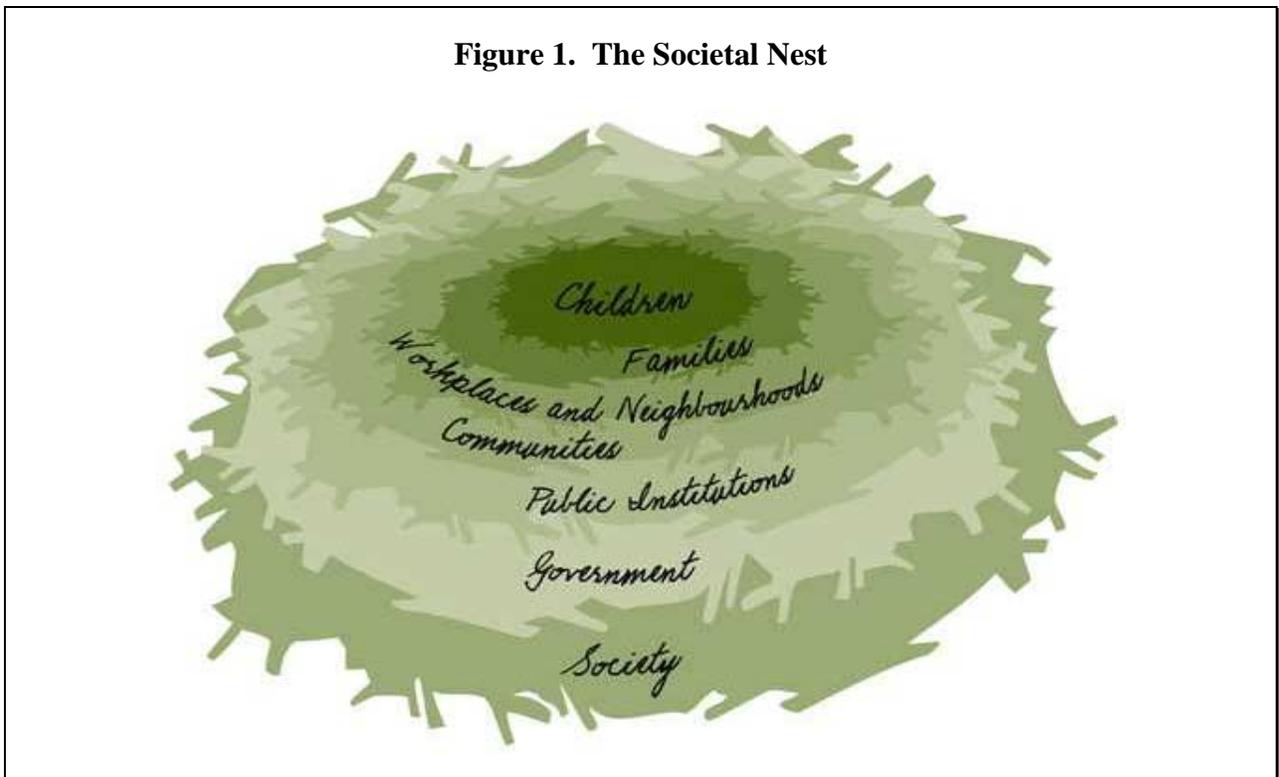
In order to have a best policy mix for children, we need:

- A strong societal nest
- Three enabling conditions, and
- Access, equity and belonging for the entire family.

These foundations, which are necessary to achieve a best policy mix for all of Canada’s children, are briefly discussed below.

The Societal Nest

Earlier work by the Family Network of CPRN focused on policies for preschool and school-aged children. A “nest” metaphor was developed to illustrate the interconnected nature of policy actors and how they support families with children (although it applies equally well to individuals and families without children). We maintain that children are “nested” in multiple environments – the child within the family, the family within the larger community of neighbourhoods and workplaces, the community as defined by different geographic and political boundaries, the public institutions (such as schools) that provide community infrastructure, and the governments that provide the resources and policies that allow each of these nests to function well. Each of these distinct spatial and political environments are also social nests in which children and, in turn, families are nurtured (see Figure 1).



We are all supported by the outer layers of the nest. As well, we all play different roles within these layers – as parents, through our work responsibilities, and through the voluntary activities we undertake within our own communities. Therefore, we can ask:

What are the stressors, and where are the intersection points in the societal nest?

Many factors have affected the capacity of parents to meet their children’s needs:

- *New patterns of employment* related, for example, to labour market restructuring; increased female labour force participation, part-time work, and self-employment; as well as new skill requirements for the knowledge-based economy
- *Restructured families* such as more lone-parent and blended families, changes to practices with respect to the extended family, as well as increased geographic mobility, and
- *Changing approaches to public policy* including the dominance of policy goals intended to reduce debts and deficits, and to create an environment more focused on efficiency and outcome achievement.

Within the societal nest, it is clear that parents need the *support* of employers and communities, as well as the *support and investment* of governments – all of which can be realized through policy. The results of such support and investment combine to produce the “three enabling conditions” that lead to positive child outcomes.

Three Enabling Conditions

Research evidence on child outcomes demonstrates clear consequences for children following from the ability of parents to provide for their families, financially and through sound parenting practices. In general terms, child outcomes refer to measures of physical, emotional and behavioural achievements or failures, relative to an age-specific peer group and taking into account the abilities of the child.

Research by CPRN and others provides a new language for discussing the needs of all children so they develop their assets and reach their potential. It emphasizes the positive, instead of focussing only on deficits or failures. It points to how developmental achievements in early childhood are foundations that are built upon throughout childhood and adolescence, which lead to success in adult life in the home and the workplace, and which serve as a foundation for enhancing civic life in Canadian communities – now and into the future. It also shows that that *all* children and *all* families need access to and can benefit from public resources and programs at different times in their lives.

Numerous factors have a strong statistical association with specific child outcomes. These include family income, family composition, parenting practices, neighbourhood composition, and so on. These “inputs” combine to create the *three enabling conditions* that can lead to improved child outcomes: adequate income, effective parenting, and supportive community environments. A number of actions can be taken to foster these conditions.

Adequate income, especially earned income, can be assured by recognizing the cost of raising children, significantly reducing the cost of child care for employed parents, and providing additional income support to families with low earned incomes, social assistance payments, or maintenance payments. For parents of children with special needs, access to adequate income is often a significant challenge.

Effective parenting can be supported through improved paid and unpaid parental leaves, flexible employment hours and schedules, improved access to health and developmental programs as well as community resource centres, and enhanced availability of developmental child care and preschool for both employed and stay-at-home parents. All parents, including those of children who have disabilities, need such supports.

Supportive community environments can be provided for children through access to reliable education, health, social, and recreational services, by providing integrated delivery for all of these services, by creating “child friendly” spaces and systems, and by collaborating across sectors to promote better outcomes for all children. Integration of children with disabilities and their parents into community life with the support of their communities is, as we have noted, a major challenge.

Linking the Enabling Conditions to Citizenship

We can see that the three enabling conditions provide important opportunities and resources for children – health care, developmental child care, a good education, relevant and responsive social services, and recreation and leisure programs that are accessible to all children. For the most part, however, efforts to create these three conditions are directed to parents. A basket of complementary policies in the public, private and voluntary sectors can empower parents to do the best they can to support their children’s development in the here and now, and to set a pattern of successful participation in society, now and in the future. Table 1 maps the links between citizenship and the three enabling conditions that contribute to positive child outcomes.

Table 1. Mapping the Links

Dimensions of Citizenship	Enabling Conditions
Rights and responsibilities	Adequate income Effective parenting Supportive communities
Access	Adequate income Effective parenting Supportive communities
Belonging	Supportive communities

From this, we can begin to imagine how a lack of appropriate support from some or all of the policy actors in the societal nest can reduce parents' chances of assuming their responsibility for fostering the enabling conditions that will maximize their children's life chances. If the enabling conditions are compromised, children's rights may be compromised in the here and now, as may be the rights of their parents to acquire full citizenship, thus affecting their ability to contribute to the communities we share. Clearly, what is "best" for children is good for *all* of us.

There are two main reasons that we should be concerned about the well-being of all of Canada's children, including those with disabilities. First, we should be concerned if we value children in their own right and care about the kind of life they experience, no matter their individual characteristics and abilities. Second, we should be concerned if we value what children will become as parents, workers, friends, and participants in their own communities. These two reasons for concern are interconnected. If children do not achieve their potential in childhood, and enjoy their childhood for what it is, there is far less chance that they will achieve and demonstrate their capabilities in adulthood. Therefore, they will neither fully experience the joys of childhood nor enjoy a high quality of life as adults in their homes, families, communities or workplaces. Their capacity to achieve full citizenship may not be realized, which will affect the quality of life experienced by them, their families, and society as a whole.

The challenges of creating a high quality life for Canadian citizens and of adequately organizing intergenerational equity will only be met if Canada has made sound investments in the foundations of both its economic and social development. Although a healthy economy is essential for achieving these tasks, so too is a healthy social environment. *Vibrant social development requires the healthy development of all children.* Through social development, children not only enjoy their lives but begin to experience their rights and responsibilities as citizens. Canada's well-being as a country, as measured by the most reliable international standards, depends upon its capacity and its willingness to provide healthy social and natural environments, as well as adequate health care, education, income and other resources to all of its citizens, including its most vulnerable and its youngest.

What is "Best" for Children is Good for All of Us

This raises the much debated issue of who is responsible for children. It is clear from research on public values and current public policy that Canadians believe parents are primarily responsible for their children. Yet, Canadians also maintain that parents require the support of governments, employers, public institutions, and fellow citizens to enable them to assume that responsibility and thereby act in the best interests of their children. Clearly, Canada has an obligation to children in the here and now, through the provision of the specific types of rights articulated in the *United Nations Convention on the Rights of the Child* – provision, protection, and participation rights. These rights relate to the creation of a foundation for citizenship, as follows.

As “rights,” they are part of the *rights and responsibilities* dimension of citizenship. Provision rights are directly related to another dimension of citizenship – *access*, especially to resources, which, as we have seen, must be directed to children and to their parents. Protection rights are related to both *equality* and *equity*, which are requirements for engagement in society, as are participation rights, which contribute to practical citizenship training as well. Finally, as members of the societal nest, we are *all* responsible for children and, because of the *Convention*, we are obligated to consider the “best interests of the child.”

Knowing that we are obliged to consider the “best interests of the child,” we can examine how and where in the societal nest that patterns of healthy child development can be fostered for all children, including those with disabilities:

- In *families* – where the initial development of each child’s unique talents and possibilities is supported and nurtured by parents
- In *non-parental care settings* – where toddlers and preschoolers learn to play and share with others, and begin to acquire skills that set the tone for learning in school and throughout life
- In *schools* – where children build on their early strengths, expand their capabilities, learn independently and in groups, and enjoy informal and structured play
- Through *organized recreation* – where children can improve their physical and psychosocial health, and develop the skills of cooperation, team work, and leadership, and
- Through *voluntarism* – where, as young people’s identities develop, they begin to contribute to their communities.

Parents, politicians, and community and business leaders all need a deeper understanding of changing social circumstances, the pressures these place on all families, the needs these pressures create, and the effects these factors have on children. Given our multiple roles in the societal nest, we can see the importance of the various roles we play, and the relevance of the policy environments that surround all of us – and have a significant impact on children and their families. Decisions made by all these actors in the societal nest contribute to the “policy mix” available to support children and their families.

The distribution of resources is clearly relevant to the best mix of policies needed to foster positive outcomes for all children. It is also relevant to citizenship, since theorists agree that there is no real citizenship without the notion of equality among citizens. If rights, responsibilities and access are unequally distributed, then the citizenship status of some is limited. Acting in the “best interests of *all* children” raises issues, then, of *access* to resources; as well as to opportunities for children and parents to fully engage in society; *equity* in treatment and the recognition of difference; and *belonging* to national and local communities.

Research evidence about the three enabling conditions demonstrates that *all* children and *all* parents require a basic level of support from the policy actors that form the societal nest. What is clear, however, is that the playing field is not level. Some parents face additional challenges – lone parents, the working poor, Aboriginal peoples, new Canadians, parents of children with special needs, and so on.

These families may require supplemental support, ranging from incremental to significant assistance at various times in the family life cycle, to enable them to provide for their children and effectively parent them. This means that various policy actors in the societal nest need to anticipate and respond to such needs in order to level the playing field. This will ensure that *all* parents have an equal opportunity to create the enabling conditions that will lead to positive child outcomes for *all* of Canada's children.

The Current Research

This two-volume research report on policies for children with disabilities blends the underlying concepts set forth in the Family Network's earlier and ongoing research on citizenship and on the best policy mix for Canadians. One area of family policy in which citizenship seemed to be compromised was in the lived experience of families who have a child with disabilities. The needs of these families and children appeared to have fallen through the cracks of the children's agenda and the disability agenda, both of which have been so important to the *Social Union Framework Agreement* and related discussions of recent years.

Therefore, in the summer of 2000, CPRN sought to answer the following questions: Why is there a lack of integration of children with disabilities in the broader *disability* agenda? Why does the broader *children's* agenda so often lose sight of the needs of children with disabilities and their families?

The research project *If "All Children" Truly Meant All Children: Children with Disabilities in Policy and Policy Processes* is the result of this exploration. The project had two main objectives, which are addressed in separate discussion papers: (1) to map the current policy environment affecting children with disabilities and their families; and (2) to identify the governance and accountability structures that will allow this agenda to move forward.

In *Enabling Citizenship: Full Inclusion of Children with Disabilities and their Parents*, University of Toronto Ph.D. candidate Fraser Valentine used CPRN's unique methodology to identify, cluster and analyze policies for children with disabilities. One intent was to determine the kinds of policies in Canada that are used to support the achievement of the three enabling conditions that are essential for good child outcomes – adequate income, effective parenting, and supportive community environments. Meeting these three conditions would help to ensure that children with disabilities (from birth to age 18) and their parents are included in Canadian society as full citizens. The resulting report consists of an analytic essay and a program and policy scan that provides an overview of the current state of policies for children with disabilities in Canada. The research uncovers a continuing lack of coherence in approaches and vision, both within provinces and by the federal government.

In *Governing in an Integrated Fashion: Lessons from the Disability Domain*, the governance regime of disability policy, especially that affecting children with disabilities, is described and analyzed by Michael J. Prince, Lansdowne Professor of Social Policy, and Associate Dean, Faculty of Human and Social Development at the University of Victoria. His report includes an examination of the respective roles of policy-makers in the public, private and voluntary sectors, as well as in the Aboriginal sector and in the informal support networks used by and within families. This report finds some of the reasons for the inadequacies of policies for children with disabilities in the governance and accountability of this policy sphere. It calls for better integration between decision-making and service delivery, and greater clarity regarding the roles of policymakers in the public, private, voluntary, Aboriginal, and informal support sectors.

The challenge now is to identify the best policy mix for *all* children. We have learned from previous work that this usually involves using a variety or “mix” of policy instruments. It involves policy actors at all levels of the societal nest and requires coordination among them. It focuses on creating positive outcomes for children and, therefore, fosters the three enabling conditions that lead to positive child outcomes. Finally, it recognizes that “full citizenship for parents” is an essential outcome of the best policy mix for children, which creates a virtuous circle of social development.

Knowing that we all play many roles in the societal nest, we offer this set of questions, which may help us consider our own opportunities to support children and families, and thereby contribute to the creation and maintenance of strong communities.

- In what ways are we fostering the three enabling conditions that lead to improved outcomes for children with disabilities and their families – adequate income, effective parenting, and supportive community environments?
- Is there a “best mix of policies” in our community that empowers parents to do the best they can for their children and to help them enable their children to realize their potential to the fullest?
- Are we supporting integrated service delivery that makes it possible for children and parents to access the resources they need at different times in the life cycle and at transition points?
- Do our communities promote equity for *all* children and *all* parents? Do our actions create a sense of belonging for all?

We hope that you will find these two companion reports on policies for children with disabilities stimulating and thought provoking, and that they will lead you to examine how you can support a best policy mix for all children in your own family, work and community lives.

Sharon M. Stroick, Ph.D., MCIP
Manager, Family Network
June 2001

Executive Summary

This discussion paper is the first of a two-phase research project, both of which are extensions of the analysis carried out in the *Best Policy Mix for Canada's Children* research program. This study extends the *Best Mix* approach to an examination of federal and provincial government policies and investments as they affect preschool and school-aged children with various disabilities, their parents, guardians and siblings. To this end, the paper consists of an analysis, accompanied by an Appendix that provide detailed inventories of current policies and programs directed towards children with disabilities and their families in Canada.

For most of the 20th century, numerous children with disabilities – especially those with developmental disabilities – were hidden from view, often removed from their families and communities, and housed in large institutions. As we move forward into the 21st century, however, children with disabilities are, for the most part, living at home with their parents or guardians and their families in communities across the country.

This shift does not mean, however, that children with disabilities are full and active members of our communities. Their particular needs have sometimes been forgotten as movement has been made in addressing the needs of adults with disabilities. Moreover, despite all the policy attention going to children in recent years, children with disabilities have sometimes been excluded. The particular needs of parents caring for children with disabilities have also been overlooked. For First Nations children with disabilities and their parents, the situation is even more pronounced. Therefore, despite the advances, many children with disabilities and their parents do not yet enjoy full citizenship rights, especially full civil and social rights.

This report uses the notion of full citizenship to assess the actual patterns of inclusion and exclusion experienced by children with disabilities and their parents and siblings when they seek the access, as well as the supports and services, that their formal rights of citizenship promise them. Citizenship is composed of three analytical dimensions: (1) rights and responsibilities, (2) access, and (3) a feeling of belonging. All three dimensions must be present in order for someone to be a full citizen, although not everyone has the same rights, responsibilities, access or feelings of belonging. The report makes visible the limited nature of citizenship for children with disabilities and their parents.

Drawing on a series of broad policy scans reflected in the inventory tables and boxes provided in Appendix A, this report demonstrates that governments have yet to provide a pan-Canadian vision for all children with disabilities and their families. The activity surrounding the *Agreement on Early Childhood Development Initiatives* (ECDI) signed between the federal government and the provinces (except Quebec) and territories demonstrates an emerging pan-Canadian vision for children from birth to age six, of course, and such developments can only be applauded. Nonetheless, school-aged children with disabilities are not a central policy focus of governments.

Provincial governments have made gains in coordinating and integrating generic children's policies, but the policy domain is still fragmented and difficult to navigate. Across the country, there is a patchwork of policies, which have developed incrementally and are more often than not "add-ons" to current policy frameworks. Thus, the policy sphere is complex, fragmented, uncoordinated and often underfunded. For parents caring for a child with disabilities, the situation is often one of frustration, disillusionment, and disappointment. The lack of concrete policy attention – and action to achieve it – means that these children may fall through the cracks. To prevent this from happening, parents are forced to take on a variety of stressful roles in an attempt to gain access to necessary services and supports, in addition to providing care for their children.

The paper is divided into seven sections. Section 1 introduces the parameters of the study. Section 2 provides an overview of the current socio-political environment in which children with disabilities and their families live, focusing on the shifting assumptions about disability, the broad trends in the disability policy and children's policy spheres, and demographic trends including ethnic, cultural and socioeconomic factors among children with disabilities. Section 3 details the variety of early childhood development programs across the country. It suggests that, as a package of policies, these initiatives reflect a developing pan-Canadian vision concerning preschool children, including those at risk of developing a disability.

Given the significant changes taking place in the relevant policy spheres (i.e., health, education, social services), Section 4 provides a broad overview and general mapping of the policy environment and administrative arrangements affecting preschool and school-aged children with disabilities and their families. The provinces are grouped into three broad categories according to the extent to which an inclusive policy framework for children with disabilities and their families is in place. For each provincial jurisdiction, an overview is provided of the key ministries with responsibility, key pieces of legislation and key policy areas affecting children with disabilities, their parents and siblings. A summary of federal policies is also provided.

Section 5, the most substantive of the paper, provides an assessment of policies available for children with disabilities (from birth to age 18) and their families, across provincial jurisdictions. Based on the tables and boxes in Appendix A, as well as key informant interviews conducted with policy makers across the country, this section provides a broad, comparative assessment of the *policy and program frameworks* currently in place for children with disabilities, and identifies significant gaps. The section is organized around the three enabling conditions required for positive child outcomes as identified in the *Best Policy Mix for Children* research: adequate income, effective parenting, and supportive community environments.

Adequate Income

An adequate income is the first element needed to create positive child outcomes. This research makes clear, however, that parents of children with disabilities face unique financial challenges and, for most, making financial ends meet is difficult. These costs are often incurred in two forms: (1) from reduced income and benefits due to lost time from paid employment, and (2) from the additional out-of-pocket expenses incurred to meet the daily needs of their child, such as transportation, special clothing, assistive devices and so on.

Thus, under the category of *adequate income*, the analysis groups policies affecting general household income as well as policies targeting the additional costs incurred by households. The report considers policies and programs in the following areas: the tax system, income supplements that help offset the costs associated with raising a child with disabilities, and parental leaves.

The report illuminates that parents are being forced into hard choices about a number of matters. They must often choose between employment and caring for their children because affordable child care and other services are not available. The lack of income support involves choices that affect other children in the family as well, who will also live in poverty when family income is inadequate. In the long run, parents may be mortgaging their own future as well as that of their children, both those living with disabilities and those who are not.

Effective Parenting

The focus of this section is on policies and programs that provide assistance to families for effective family functioning. Thus, the category of effective parenting is broadly understood as a condition enabling positive child outcomes. It is not used to classify service or program goals. Nor is it meant to imply a judgment on the effectiveness of parents caring for a child with disabilities.

In every jurisdiction, governments have created policies and programs to support children with disabilities who are living at home and in their communities. Since the 1970s, there has been a shift away from institutional care, towards community-based strategies. Parents, disability advocates, and professionals have applauded this move but, as this study demonstrates, children and parents are frequently not receiving the scope and level of support required. The section considers policies and programs providing in-home disability supports, in-home and out-of-home respite care, and mental health supports and services.

Supportive Community Environments

The third enabling condition required for positive child outcomes is supportive community environments. The notion of a supportive community environment includes a number of components and involves a variety of policy and investment choices by community groups, employers and governments. At its foundation, however, the notion of a supportive community environment must provide full access and participation for *all* children – including those with disabilities – as well as their parents and siblings. This means more than simply offering inclusive services such as child care, education and recreation, but extends to such things as the construction of a fully accessible built environment so *all* children can go to the shopping centre, go to the movies, and attend swimming lessons at the community pool. A supportive community environment also means providing parents who care for a child with disabilities with non-programmatic supports such as parent networking, training, brokerage, information, and peer support. An important component of full citizenship is ensuring that parents themselves have full access to the communities in which they live and work.

The study limits its analysis to a consideration of supports and services provided by provincial governments. Thus, non-programmatic elements such as those described above are not included in the report. These elements, however, comprise important elements of a supportive community environment. Among those programs provided by provincial governments, the report concludes that there are gaps in the provision of services for children with disabilities and their families. Some advances have been made in supporting the development of preschool children, especially through early childhood development policy and programs, but significant gaps and barriers remain for school-aged children with disabilities and their parents. This report specifically examines access to inclusive child care, education and recreation.

Barriers persist because many generic policy frameworks are not inclusive, and those that are conceived as inclusive continue to *exclude* children because of administrative loopholes, insufficient funding and negative attitudes. The report highlights that this is especially evident in the areas of child care, education and recreation.

Section 6 of the report identifies four broad issues that act as barriers to full citizenship for children with disabilities and their parents. These are: (1) a lack of political will to make school-aged children with disabilities a priority for governments; (2) unclear and contradictory policy goals; (3) policy-practice gaps; and (4) intra- and inter-jurisdictional discrepancies. For children with disabilities and their families, these four patterns are not academic curiosities since they result in exclusion and isolation from work and community life. As a result, children with disabilities and their families have not achieved the full citizenship promised and owed them.

Finally, Section 7 provides a set of conclusions and recommendations. The report concludes that, while most children with disabilities and their parents are living in our communities, they are not active members of these communities. While some provinces have made gains in various areas – including the administrative arrangements in place for delivering services and supports – there is no coherent vision for achieving the best possible policy mix for children with disabilities and their parents, especially school-aged children. Few provinces have such a vision for their own jurisdiction, and no consensus exists as yet for the country as a whole. Nor do all families who care for a child with disabilities have adequate income and supports for effective parenting. Too often, they live in poverty and struggle to obtain the services and supports that they desperately need.

The continued exclusion of children with disabilities from regular child care facilities, educational settings, and recreational facilities and programs, as well as the under-resourced, complex, fragmented set of available specialized services, means that full civil and social citizenship rights are not realized. In short, children with disabilities and their parents do not benefit from full access to work, education, and individual and community supports and services. Most do not, therefore, embrace a strong sense of community belonging. Thus, they are not full citizens. The time has come for governments to deem a priority the needs of *all* of Canada's children, including those with disabilities.

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Enabling Citizenship: Full Inclusion of Children with Disabilities and their Parents

By Fraser Valentine¹

1.0 Introduction

For most of the 20th century, numerous children with disabilities – especially those with developmental disabilities – were hidden from view, often removed from their families and communities, and housed in large institutions. As we move forward into the 21st century, however, children with disabilities are, for the most part, no longer living in institutional settings. Increasingly, they are living at home with their parents or guardians and their families in communities across the country.

In part as a result of the actions of persons with disabilities themselves, progress has been made in advancing our collective consciousness. Slowly, our view of disablement has shifted from a *deficit model*, which understands disability as a “problem” requiring corrective action, to one that sees persons with disabilities as an integral part of the Canadian social fabric. As this study demonstrates, this shift is reflected in policy responses seeking to build stronger personal and familial supports, financial supports, education supports, and community supports.

This shift does not mean, however, that children with disabilities are full and active members of our communities. Their particular needs have sometimes been forgotten as movement has been made in addressing the needs of adults with disabilities. Moreover, despite all the policy attention going to children in recent years, children with disabilities have sometimes been excluded, and the particular needs of parents caring for children with disabilities have also been overlooked. Therefore, despite the advances, many children with disabilities and their parents do not yet enjoy full citizenship rights, especially full civil and social rights.

Full citizenship for children with disabilities and their parents requires, first, the creation of an inclusive generic base of supports for *all* children and their families, such as child care, education, recreational programs and accessible architectural environments. Next, portable and flexible supports targeting the particular needs of children with disabilities and their parents must be put in place. These may include, but are not limited to, in- and out-of-home supports, respite care, education supports, and assistive devices.

1 The author wishes to acknowledge and thank the numerous individuals who assisted in providing information and advice for this report, in particular Caroline Beauvais, who assisted with information gathering on Quebec, members of the CPRN project Advisory Committee, various federal and provincial officials across the country, and individuals involved in the policy research sector. As well, thanks to the external reviewers who made insightful comments on an earlier draft of the report. Finally, thanks to the participants of the CPRN Roundtable (held in Ottawa on May 3 and 4, 2001) for their thorough and thought-provoking contributions.

Ensuring full citizenship also requires that parents and siblings of children with disabilities have the capacity to be citizens. As described in the Preface to this report, this means they must have the resources and opportunity to participate in different areas of life in order to realize their rights, exercise their responsibilities, have access to political institutions, be empowered, and share a sense of belonging to the community. To that end, policy frameworks must acknowledge the extraordinary demands on parents, siblings and families by providing non-programmatic tools designed to help balance the demands of work and family life, such as information sharing, peer support, networking strategies and resources, training, and so on.

As this study demonstrates, the current situation faced by parents caring for a child with disabilities falls far short of full citizenship. In particular, the community supports that most children with disabilities and their families need are not yet understood to be a central component of citizenship rights. Families often have to struggle and fight to get the necessary supports so they and their children can live an active and full life in the community.

While access to special funding, tax credits and community-based supports (e.g., respite care or in-home support) to help families support and care for their children at home may be available, these programs tend to be the opposite of user-friendly. Recent research reveals that community supports often provide access only on a discretionary basis, are often under-resourced, and are frequently delivered through a complex and fragmented set of service delivery frameworks that may include provincial or municipal offices, regional health or social service authorities, and non-profit or for-profit agencies.² Therefore, attention to the situation and needs of families and children with disabilities is still required, if the goal is to include them and enable them to achieve both the full citizenship Canada has identified as its goal for all citizens and the inclusion it has promised all children.

This report is the first of a two-phase research project, both of which are extensions of the approach and methodology used in the CPRN research program on the *Best Policy Mix for Canada's Children*. This earlier research determined that children are “nested” in multiple environments:³

...the child within the family, the family within the larger community of neighborhoods and workplaces, the community as defined by different geographic and political boundaries, the public institutions that provide community infrastructure, and the governments that provide the resources and enabling policies that allows each of these nests to function well. Taken together, these nested environments form society as a whole. These spatial and political environments are also social nests in which children and, in turn, families are nurtured. Each successive nest contributes to the care, growth and development of the other nests enfolded within them.

2 The Roeher Institute has played a leading role in research and policy recommendations concerning children with disabilities and their families, especially through their Children and Family Series of reports. See for instance, *When Kids Belong: Supporting Children with Complex Needs – At Home and in the Community* (Toronto, 2000); and *Agenda for Action: Policy Directions for Children with Disabilities and Families* (Toronto, 2000).

3 Sharon M. Stroick and Jane Jenson, *What is the Best Policy Mix for Canada's Young Children?* (Ottawa: Canadian Policy Research Networks, 2000): 9.

The *Best Mix* approach also recognizes the extensive services provided to individuals and families by non-profit organizations. The research confirms that, while families are the most important in raising children, they do not operate in isolation. Neighborhoods, schools, workplaces, non-profit organizations and governments also play an active and vital role in child development and outcomes. The *Best Policy Mix for Children* final report therefore advances a typology of three “enabling conditions” necessary for children to achieve positive outcomes. These are adequate income, effective parenting, and supportive community environments.⁴

Using this typology, this paper focuses on federal and provincial government policies and investments as they affect preschool and school-aged children with various disabilities and their families. Given the significant changes taking place in the relevant policy spheres (i.e., health, education, social services, and so on), a primary goal of the paper is to provide a broad overview and general mapping of the policy environment affecting children with disabilities and their families who are living in various circumstances across the country. It is beyond the scope of this paper to classify, assess, and compare all policies and programs affecting all children with disabilities and their parents across provincial jurisdictions. Rather, the paper aims to present and organize the broad policy frameworks articulated (or not) by provincial jurisdictions, and assesses the administrative arrangements in place for implementing these frameworks.

The second phase of the research, which is contained in a separate report by Michael Prince, focuses on identifying the governance and accountability structures affecting the policy sphere. It involves mapping ways to better integrate decision-making and service delivery in public policy, and identifying the respective roles of policymakers in the public, private, voluntary and personal/informal sectors.

Drawing on a series of broad policy scans reflected in the inventory tables and boxes provided in Appendix A, this report makes clear that governments have yet to provide a pan-Canadian vision for all children with disabilities and their families. The activity surrounding the *Agreement on Early Childhood Development Initiatives* (ECDI) signed between the federal government, all provinces except Quebec, and the territories does demonstrate an emerging pan-Canadian vision for children from birth to age six. Such developments can only be applauded. Nonetheless, school-aged children with disabilities and their parents are not a central policy focus of governments. Provincial governments have made gains in coordinating and integrating generic children’s policies, but the policy domain is still fragmented and difficult to navigate. Across the country, there is a patchwork of policies, which have developed incrementally and are more often than not “add-ons” to current policy frameworks. Thus, the policy sphere is complex, fragmented, uncoordinated, and often underfunded.

Compounding these factors are the dual forces of decreasing government support to voluntary sector organizations, yet increased expectation and reliance by governments on individuals, families and the non-profit sector to provide supports and resources to children. Participants at a CPRN Roundtable held on May 3, 2001 noted that the compounding forces of decreased funding and increased responsibility have significantly destabilized the sector. As Michael Prince discusses in his report, non-profit organizations play a central role in the delivery of services and supports to persons with disabilities, including children with disabilities and their families.

4 Stroick and Jenson, *What is the Best Policy Mix for Canada’s Young Children?*, 22.

While some provinces such as British Columbia, Alberta and Saskatchewan have moved some distance in coordinating and integrating policies affecting children – including those with disabilities – these initiatives are relatively recent. In addition, there is recognition across the country that policy integration and coordination is necessary but, to date, there is little political will or commitment to create and implement inclusive policies and programs for school-aged children with disabilities and their families. There is no legislative framework in any of the provinces authorizing a coordinated and integrated policy approach for children with disabilities. Instead, programs are the responsibility of, administered by and funded through a variety of disjointed policy instruments and regulatory frameworks.

This review, especially the scans in Appendix A, uncovers a broad policy direction shared by governments, which is to focus policy and programs primarily on providing functional, rehabilitative and therapeutic supports and services to children with disabilities and their families. Such a focus too often overlooks inclusive generic supports – such as child care, educational and recreational facilities and activities – designed to include children with disabilities in our communities. Access to these community supports is taken for granted by many Canadian families, but for children with disabilities and their parents, access is not always readily available. More often than not, children with disabilities are excluded from integrated educational settings through administrative loopholes and an overall lack of funding for special education. As well, children with disabilities are often denied access to generic recreational facilities and programs.

For parents of children with disabilities, the situation is often one of frustration, disillusionment, and disappointment. The lack of concrete policy attention – and action to achieve it – means that these children may fall through the cracks. To prevent this from happening, parents are forced to take on a variety of stressful roles in an attempt to gain access to necessary services and supports, as well as providing care for their children.⁵ These roles are piled onto their everyday work and family responsibilities, thereby creating high levels of stress and a severe time-crunch. The incredible time and resource constraints often leave parents feeling isolated from each other and from their communities. They do not enjoy a sense of community belonging, which, in other words, means they are not able to achieve full citizenship.

5 Roeher Institute, *When Kids Belong*; Roeher Institute, *Count Us In: A Demographic Overview of Childhood and Disability in Canada* (Toronto, 2000); Sharon Hope Irwin, Donna S. Lero and Kathleen Brophy, *A Matter of Urgency: Including Children with Special Needs in Child Care in Canada* (Wreck Cove, NS: Breton Books, 2000).

1.1 The Research Parameters

A Focus on the Full Citizenship of Children with Disabilities and their Parents

This report is framed by the notion that children with disabilities and their parents must be included as full citizens in our communities. Citizenship is a “messy” concept and therefore the boundaries of citizenship are often contested. In this report, however, citizenship is conceived in broad terms, touching on the definition of political community and the conditions of inclusion – and exclusion – in that community.

As Jane Jenson and Martin Papillon state, “citizenship, understood as a relationship between individual and the state, as well as among individuals, is the concrete expression of the fundamental principle of equality among members of the political community.”⁶ This conception, the authors argue, allows one to assess who belongs to and who is excluded from the community, and under what conditions. We must understand citizenship, Jenson and Papillon suggest, as a dynamic relationship between three complementary dimensions: rights and responsibilities, access, and belonging. In a recent CPRN paper, Judith Maxwell captures these dimensions in the following manner:⁷

Citizenship grants *rights* and demands the exercise of *responsibilities*. But citizenship also means *access* to work, education, technology, and social protection. These are the elements that take citizenship beyond a passport to a sense of *belonging*. Therefore, it is important to follow the ways that patterns of access are being altered under the pressure of new economic and social realities and public choices.

This report uses these notions of citizenship to assess the actual patterns of inclusion and exclusion experienced by children with disabilities and their parents and siblings when they seek the access, as well as the supports and services, that their formal rights of citizenship promise them. The limited nature of their citizenship will become visible, as will any improvements that are being made as the model of disability and disablement alters.

Participants at the CPRN Roundtable on May 3, 2001 reinforced the notion that we must not lose sight of the citizenship rights of parents and siblings caring for children with disabilities. Citizenship requires that you take responsibility for yourself. For parents and siblings caring for a child with disabilities, however, these civic responsibilities must be offset through the provision of resources that have as their goal parent and sibling participation. Providing access for parents and siblings to network with each other, as well as to provide peer support and resources, can go some distance in fostering a sense of civic participation and community belonging.

6 Jane Jenson and Martin Papillon, *The Changing Boundaries of Citizenship: A Review and a Research Agenda* (Ottawa: Canadian Centre for Management Development, 2000): 5, available at <http://www.ccmd-ccg.gc.ca/pdfs/conference/finaljenson-papillon/pdf>.

7 Judith Maxwell, *Toward a Common Citizenship: Canada's Social and Economic Choices* (Ottawa: Canadian Policy Research Networks, 2001): 3.

A Focus on Children with Disabilities and their Families in Various Circumstances

When we speak of children with disabilities, what do we mean? This report adopts a *cross-disability framework*,⁸ recognizing that children with disabilities have different and often multiple needs and, therefore, that policies, programs, and resources should be accessible to persons with varied types of disabilities and complex needs. Thus, the report examines policies affecting children with physical disabilities (e.g., paralysis), developmental disabilities (e.g., autism), and behavioural/emotional disabilities (e.g., attention deficit disorder), as well as children with sensory impairments (e.g., blindness, hearing impairment, deafness).

A Focus on Preschool and School-aged Children with Disabilities

To reflect the current initiatives targeting preschool children, as well as the complexity of policies affecting school-aged children with disabilities, the age range of children included in the analysis is from birth to 18 years. The definition takes 18 as the symbolic cut-off point. While other CPRN research has used 15 as the cut-off point because children are obliged to stay in school until they are 16,⁹ we must acknowledge that persons with disabilities face a complex set of barriers in making the transition into the labour force or post-secondary education. Thus, this study sets the cut-off point to include youth and teenagers with disabilities. This report does not include those who have left school to join the labour force, nor policies specifically designed to ease the transition from school to work.

A Focus on Children Living at Home and in their Communities

The goal of this research is to place the achievement of full citizenship for children with disabilities and their parents in a general and appropriate framework for policy analysis. The literature underscores the fact that institutional settings can have harmful effects on children with disabilities, and therefore, do not actively contribute to achieving citizenship.¹⁰ Thus, the focus in this research is on children living in communities. Children living in institutional settings (including hospitals) are not considered in the study. Nor are children and youth at risk, homeless youth, or street youth.

8 A *cross-disability framework* recognizes that people with different disabilities have different needs and, therefore, ensures that programs and resources are accessible to persons with varied types of disabilities. This notion represents a departure from traditional approaches to disability in which the needs of a specific disability type (i.e., individuals with physical disabilities) were met, while other types of disability were ignored.

9 See Rianne Mahon, *School-aged Children across Canada: A Patchwork of Public Policies* (Ottawa: Canadian Policy Research Networks, 2001).

10 For a useful discussion on the harmful effects of the institutionalization of children with intellectual disabilities, see E.M. Craig and R.B. McCarver, "Community Placement and Adjustment of Deinstitutionalized Clients: Issues and Findings," in N.R. Ellis and N.W. Bray (eds.), *International Review of Research in Mental Retardation* (New York: Academic Press, Inc., 1984); and C. Holburn, "Rules: The New Institutions," *Mental Retardation* Vol. 28, No. 2 (1990): 89-94.

Children in the care of the state who receive “child protection” pose a challenge to the parameters of this study. While the capacity and resources necessary to deal with this issue exceeds the study’s boundaries, two overlapping issues are important to consider.

First, children living in foster homes illustrate an overlap between the public sector and private family arrangements, and therefore represent ordinary homes in which people agree to assume responsibility for children in the child protection system. Thus, foster families often face similar issues as birth families as they relate to the care of a child with disabilities. However, as Roundtable participants noted, foster families often have better access to supports and services.

Second, in some provincial jurisdictions, families (including Aboriginal families) are forced to surrender legal custody of their children to the child protection system because the necessary care is not available in their own community. Families are forced to choose between losing their children to “the system,” where they will receive necessary care, or keeping them at home, where their care arrangements are sacrificed.¹¹ No parent should ever be forced to make such a choice.

A Focus on Policies and Programs Affecting Children with Disabilities and their Families

This research examines the types of policies that lie at the intersection between what has traditionally been understood as *family policy* and *disability policy*. These cross-cutting policy domains mean that the report does not concentrate solely on policies related to taxes, labour, health care or public education. Nevertheless, it is recognized that policies from each of these spheres have an impact on the situation of children with disabilities. For instance, care for disabled children is often provided under the health mantle, while their education needs fall under education policy for children with special needs. Thus, a broad policy classification scheme was developed under which a number of discrete policies affecting children with various disabilities, their parents, and their siblings would fall.

This *functional approach* enables the cross-provincial analysis of policies and programs in the areas shown in Chart 1. Each of these is contained in the policy scan found in Appendix A. They are classified according to how they contribute to the three enabling conditions required for positive child outcomes – adequate income, effective parenting, and supportive community environments.

¹¹ On May 9, 2001, a \$500 million class-action law suit was launched against the Ontario government by families caring for children with severe disabilities. They maintain that numerous families have had to surrender legal custody of their children to the child protection system because mandated care arrangements are not available in the community. It is the largest action ever launched on behalf of children with disabilities in Canada.

Chart 1. A Functional Approach to the Analysis

Functional Area	Content of Tables and Boxes in Appendix A	Number
Setting the Context	An Overview of Federal Programs for Children with Disabilities and their Parents in Canada, 2001	Table 1
	Provincial Governments' Coordinating Bodies for Children's Policy and Disability Policy	Table 2
Adequate Income	Tax Measures Affecting Parents of Children with Disabilities (1996-2000)	Box 2
	Extra Income Support for Families with Children with Disabilities	Table 4
	Financial Support for Families Toward the Purchase of Assistive Devices for Children with Disabilities	Table 5
Effective Parenting	Provincial Early Childhood Development Policies and Programs Promoting Child Well-Being and Healthy Development	Box 1
	In-Home Supports for Families with Children who have Severe or Complex Disabilities	Table 6
	In-Home and Out-of-Home Respite Care Available to Families and Children with Disabilities	Table 7
	Mental Health Supports and Services for Children	Table 8
	Special Initiatives for Children with Autism or Autistic-like Tendencies and Their Families	Box 4
Supportive Community Environments	Early Childhood Development Programs for Children with Disabilities or at Risk of Developing a Disabling Condition	Table 3
	Extra Support Targeted for Rural Areas to Address the Needs of Children with Disabilities	Box 3
	Grants or Supports for Child Care Providers to Provide Integrated Child Care for Children with Disabilities	Table 9
	Education Supports Provided to Schools to Accommodate Children with Disabilities	Table 10
	Speech and Language Programs for Preschool and School-Aged Children	Table 11
	Individual Health and Rehabilitation Services for Children with Disabilities	Table 12

1.2 Outline of the Report

The remainder of this report is organized in the following fashion: Section 2 provides an overview of the current socio-political environment in which children with disabilities and their families live, and begins by outlining the shifting societal level assumptions about disablement. Next, the broad trends in disability policy are presented, paying particular attention to the federal-provincial-territorial realms of policy towards children and disability policy. Finally, a demographic overview of children with disabilities is presented, including differences among social groups.

Section 3 details the variety of early childhood development programs across the country, including the recent *Agreement on Early Childhood Development Initiatives*. This section suggests that, as a package of policies, these initiatives reflect a developing pan-Canadian vision concerning preschool children, including those at risk of developing a disability.

Although such a vision or consensus may begin to address the needs of Canada's youngest children, the situation for school-aged children with disabilities is the opposite of inclusive, integrated and coordinated. A pan-Canadian vision for these children and their parents is still missing. Compounding this situation is an unprecedented amount of policy and administrative change in each of the provincial jurisdictions, especially in the areas of health, education and social services. These changes have directly affected horizontal policy domains such as child and family policy and disability policy.¹²

Section 4, therefore, focuses on the policies and administrative arrangements affecting school-aged children with disabilities. The provinces are grouped into three broad categories according to the extent to which an inclusive policy framework for children with disabilities and their families is in place. For each provincial jurisdiction, an overview is provided of the key ministries with responsibility, key pieces of legislation, and key policy areas affecting children with disabilities and their parents.

Using the functional approach to the analysis introduced above, Section 5 provides an assessment of policies available for children with disabilities from birth to 18 and their families, across provincial jurisdictions. This section is organized around the three enabling conditions required for positive child outcomes: adequate income, effective parenting, and supportive community environments. This research agenda did not include extensive and systematic interviews with parents, service-providers, and other professionals. Thus, we do not provide a "first hand" view of the situation facing children with disabilities and their families, which has been reported by other authors.¹³ Instead, based on the tables and boxes in Appendix A, we provide a broad, comparative assessment of the *policy and program frameworks* currently in place for children with disabilities and their families, and identify significant gaps. This evidence-based assessment is undertaken using the following criteria: family-centred, community-based, flexible, portable, integrated, cooperative and inclusive.

Section 6 identifies four broad issues that act as barriers to full citizenship for children with disabilities and their parents. These are: (1) a lack of political will to make school-aged children with disabilities a priority for governments; (2) unclear and contradictory policy goals; (3) policy-practice gaps; and (4) intra- and inter-jurisdictional discrepancies. For children with disabilities and their families, these four types of barriers are not academic curiosities. Rather, they result in exclusion and isolation from work and community life. As a result, children with disabilities and their families have not achieved the full citizenship promised and owed them. Finally, Section 7 provides a set of conclusions and recommendations.

Draft versions of this report and a companion document by Michael Prince were discussed at a two-day roundtable hosted in Ottawa by CPRN on May 3 and 4, 2001. Many of the valuable insights of the participants drawn from the policy, academic and advocacy communities across Canada (see Appendix B) have been incorporated into this final report.

12 Sherry Thompson, with Judith Maxwell and Sharon M. Stroick, *Moving Forward on Child and Family Policy: Governance and Accountability Issues* (Ottawa: Canadian Policy Research Networks, 1999).

13 There is some recent empirical research based on interviews with parents or guardians and caregivers of children with disabilities. See the Children and Families Series of reports by the Roeher Institute as well as the research undertaken by SpecialLink [sic] on inclusion in child care settings.

2.0 Socio-Political Issues and Trends Affecting Children with Disabilities

2.1 Shifting Assumptions about Disability

The ideas associated with disablement have shifted over the past several decades. Many disability scholars have argued that, prior to the 1970s, disability was understood largely as a diagnostic, biomedical category in which the medical profession played a role in “certifying” that an individual with a disability warranted support, and then oversaw their ongoing care.¹⁴ The lives of persons with disabilities were medicalized, and the focus was on rehabilitating or “curing” persons with disabilities who were viewed as “sick.” The medical profession controlled both the meaning of disability and the lives of persons with disabilities.¹⁵ For persons with disabilities – including children – this control meant that they were defined primarily by the medical category of their disability and by whatever demands were made on the state or society on their behalf by parents, medical professionals, researchers or most recently in North America, televised charity fundraising events.¹⁶

Since the 1970s, however, new sets of ideas about disability have entered the mainstream discourse. Persons with disabilities have challenged widely held views about the identity and role of persons with disabilities as being passive, sick, asexual, and apolitical. They have done so in three ways: (1) by asserting their right to organize autonomously; (2) by asserting their right to equal treatment as adults with full citizenship and, therefore, to all the rights and capacity for responsibility that citizenship implies; and (3) by arguing that disability is *socially constructed* and often reflects the fears, biases and aversions of so-called “normal” individuals more than the lived experiences of persons with disabilities.¹⁷ In 1985, this “citizenship-rights approach” was firmly entrenched in Canada with the guarantees of equality for persons with mental and physical disabilities in the *Canadian Charter of Rights and Freedoms*.

14 See, for instance, Diane Driedger, *The Last Civil Rights Movement: Disabled Peoples' International* (New York: St. Martin's Press, 1989); and Michael Oliver, *The Politics of Disablement* (London: MacMillan Press, 1990).

15 The medical model informed much, if not all, of the medical research and practices since the late-19th century. Many myths about persons with disabilities can be attributed to the theories so-called experts (particularly medical experts) have developed. Historically, medicine has constructed an image of a person with a disability as compliant, inadequate and inept. This has placed undue emphasis on clinical diagnosis in the medical model. As a result, this understanding of disability has led to a partial and inhibited view of persons with disabilities. At a broader level, the medical model affects all persons who engage with the medical profession simply because the patient/doctor relationship has been founded on the validity of the medical model. See Gerben DeJong, “Independent Living: From Social Movement to Analytic Paradigm,” *Archives of Physical Medicine and Rehabilitation* Vol. 60, No. 10 (October 1979): 435-46.

16 It is important to note that during this period, the rehabilitation and reintegration processes were often not extended to all kinds of disabilities, in particular to persons with cognitive disabilities. Nor did these processes focus on the economic needs or political concerns of persons with disabilities and their families.

17 Fraser Valentine and Jill Vickers, “Released from the Yoke of Paternalism and Charity: Citizenship and the Rights of Canadians with Disabilities,” *International Journal of Canadian Studies* Vol. 14 (Fall 1996): 155-77; Marcia H. Rioux and Michael Bach (eds.), *Disability is Not Measles: New Research Paradigms in Disability* (Toronto: Roeher Institute, 1994); Roeher Institute, *Disability, Community and Society: Exploring the Links* (Toronto, 1996).

This *rights-based approach* is increasingly evident in government documents, and policy responses are beginning to support the notion that persons with disabilities, including those with sensory impairments, have a place in society as contributing citizens. Public policy is slowly recognizing that disability is a product of both individual impairment and the social environments in which we all live and work. Some policy frameworks are beginning to recognize that disability is not static. Instead, disability is viewed as a process or a “continuum of disability” that can be more or less present based on the availability of accommodations, aids, supports and devices over an individual’s life. As Sherri Torjman explains:¹⁸

The term “persons with disabilities” therefore includes physical, mental and psychiatric impairments. It refers to persons whose disabling condition was present at birth and those whose condition arose at some point in their lives as the result of an accident, injury or normal aging. The actual disability may be mild or profound, temporary or permanent. Its consequences may be very different – affecting physical functioning and stamina, cognition and memory, or visual and auditory communication. Some disabilities can be readily accommodated at home or in the workplace while others cannot. Some disabilities are constant while others are progressively degenerative. Still other conditions have periods of remission; given individuals may have periods of normal activity followed by periods of inability to function.

The shift towards a rights-based approach and the growing recognition of the continuum of disability have begun to result in policy frameworks that move away from trying “fix” the problems of individuals toward creating policies that have as their goal making our communities more inclusive for all people of all ages and abilities. This shift also means that individuals and groups are increasingly turning to the judicial branch to pursue rights-based claims in a variety of policy spheres. It is still premature to determine the full impact of this approach to both the rights of individuals and the policy sphere. We can, however, discuss broad trends in two policy spheres.

2.2 Broad Trends in the Disability Policy and Children’s Policy Spheres

The last few years have been a time of change in the design of disability policies, as organizations of persons with disabilities and other policy actors frustrated by inaction on the part of governments pushed harder for the recognition of the rights of disabled citizens to inclusion and full citizenship. These shifts explain, in part, the commitment among governments to de-institutionalize children with intellectual disabilities and integrate them into community settings.¹⁹

18 Sherri Torjman, “Canada’s Federal Regime and Persons with Disabilities,” in David Cameron and Fraser Valentine (eds.), *Comparing Policy Making in Federal Systems: The Case of Disability Policy and Programs* (Kingston: Institute of Intergovernmental Relations, forthcoming).

19 See, for instance, Government of Canada, Minister Responsible for the Status of Disabled Persons, *Obstacles: 1987 Report Update* (Ottawa: Minister of Supply and Services, 1987); Government of Alberta, Alberta Legislative Assembly, *Claiming My Future: A Person with a Mental Disability – Today and Tomorrow*, Report of the Brassard Review Committee (Edmonton: Alberta Legislative Assembly, 1989); and Canadian Association for Community Living, *Replacing Institutions: A Challenge to End Segregation – A Call to Action to the Government of Canada* (Toronto, 1988).

Further, as discussed below, the development of provincial early intervention initiatives (see Table 3 and Box 1), integrated child care settings (Table 9), education supports (Table 10) and home-based care and supports (Tables 6 and 7) are examples of concrete policy and program directions that move away from viewing disability as disease, and recognize that a child's well-being must include social and environmental factors.

Despite these examples, children with disabilities, especially school-aged children, have not been a primary focus for policy innovation and development among governments. The impact of the fiscal restraint of the 1990s was that governments focused their attention on fostering labour market attachment. For working-age persons with disabilities (those aged 18 to 64), these efforts have resulted in new policy frameworks such as bilateral agreements for Employment Assistance for Persons with Disabilities, and the creation of programs such as the Opportunities Fund. Unlike the case of working-age persons with disabilities, however, governments have devoted little attention to the particular needs of children with disabilities and their families, especially for school-aged children.

This remains the situation, despite the fact that the *Social Union Framework Agreement* process targeted for concrete action the policy spheres of both children and disability. As early as 1996, the Federal-Provincial-Territorial Council on Social Policy Renewal began to work collectively on these two priority issues. Later that same year, these two policy priorities were included in a report received by First Ministers at their annual meeting. At the federal level, in the same year, the Federal Task Force on Disability Issues, chaired by Andy Scott and known as the Scott Task Force, was established jointly by Human Resources Development Canada, the Department of Finance, Revenue Canada, and the Department of Justice Canada. It was charged with reporting on the future role of the federal government as it relates to the Canadian disability community. The Scott Task Force undertook a comprehensive review of and consultation on issues affecting persons with disabilities in five key areas: national civil infrastructure/citizenship; legislative review; labour market integration; income support; and the tax system. While some of the report's recommendations affected children with disabilities and their families, they were not a central area of concern and were largely overlooked.²⁰

In 1997, the federal government issued reports detailing the way in which it was seeking to implement the recommendations of the Scott Task Force, and was working with its provincial and territorial counterparts on the report *In Unison: A Canadian Approach to Disability Issues – A Vision Paper*, released in October 1998. This key document lists principles for ensuring full citizenship to the approximately 16 percent of Canadians living with disabilities, and builds on past collaborative initiatives such as the Scott Task Force and the *Mainstream Review* in 1992. In July 1999, the federal government issued its own strategy document, *Future Directions to Address Disability Issues for the Government of Canada: Working Together for Full Citizenship*. It is clear that the federal, provincial and territorial governments, in their joint vision and framework, recognize the importance of removing barriers to full participation faced by Canadians with disabilities.²¹

20 Government of Canada, Federal Task Force on Disability Issues, *The Will to Act: Equal Citizenship for Canadians with Disabilities* (Ottawa: Minister of Public Works and Government Services, 1996).

21 In recent years, the federal government has made progress in some areas, especially in the tax system. As well, several provinces have made steady progress in areas identified in the strategy. In particular, bilateral federal-

Children with disabilities and their parents, however, have never been anywhere near the centre of this vision or framework. Their issues and concerns are not addressed, for instance, in any of the seven priorities identified in the *Future Directions* document.

In response to this silence, a collection of national disability organizations jointly released *A National Strategy for Persons with Disabilities: The Community Definition* in November 1999. This report, endorsed by every significant national disability advocacy organization in the country,²² sought to “flesh out, in the form of tangible actions, time-lines and the designating of responsible government departments, what the Government’s paper says in lofty sentiments.”²³ The disability community pointed out that: “*In Unison* and related documents respond primarily to issues affecting persons with disabilities of working age (18-64). A comprehensive disability strategy must also address issues regarding children with disabilities and their families.”²⁴ Although the disability community directed its response to the federal government, it also called on provincial, territorial and municipal governments to consider similar proposals.

It is important to note that, to date, the lead disability organization on issues relating to children with disabilities has been the Canadian Association for Community Living (CACL). With the support of the Roeher Institute, CACL has been at the forefront of advocating for policy change on behalf of children with disabilities and their parents. Most of the other national disability organizations concern themselves with issues affecting working-age Canadians. The Council of Canadians with Disabilities, however, has been an intervenor in Supreme Court cases concerning children with disabilities and their parents.

As mentioned above, during this same time period and in the same social policy forum, Federal-Provincial-Territorial social service ministers were also advancing their agenda for addressing children’s issues. In particular, they agreed to the creation of the National Child Benefit (NCB), and the inauguration of the National Children’s Agenda (NCA). The most recent development is the *Federal-Provincial-Territorial Agreement on Early Childhood Development Initiatives*, announced in September 2000. These policy statements consistently claim to address the needs of all children and all families. Unfortunately, the first version of the NCA vision statement belied this claim.

provincial agreements have enhanced employment assistance for persons with disabilities. See Michael J. Prince, “Citizenship by Installments: Federal Policies for Canadians with Disabilities,” in Leslie Pal (ed.), *How Ottawa Spends 2001-2002* (Toronto: Oxford University Press, forthcoming).

22 The report was endorsed by the following organizations: Council of Canadians with Disabilities (CCD), Canadian Association of Independent Living Centres (CAILC), Canadian Association for Community Living (CACL), Canadian Paraplegic Association (CPA), Canadian National Institute for the Blind (CNIB), Canadian Hard of Hearing Association (CHHA), Aboriginal Reference Group on Disabilities, Neil Squire Foundation, Canadian Council on Rehabilitation and Work (CCRW), DisAbled Women’s Network (DAWN), Assembly of Manitoba Chiefs (AMC), National Educational Association of Disabled Students (NEADS), and the Learning Disabilities Association of Canada (LDAC).

23 Council of Canadians with Disabilities, *A National Strategy for Persons with Disabilities: The Community Definition* (1999): 5, available at <http://www.pcs.mb.ca/~ccd/nation~4.html>

24 *A National Strategy for Persons with Disabilities*, 6.

In the summer of 1999, *A National Children's Agenda – Developing a Shared Vision* was released for consultation. Disability organizations quickly discovered that the document virtually ignored children with disabilities. In response, CACL mobilized to have children with disabilities included in the NCA. In a series of documents entitled *Don't Exclude Our Children*, CACL called for explicit attention to children with disabilities in the NCA. Further, in *A National Strategy for Persons with Disabilities: The Community Definition*, national disability organizations called for “a national disability strategy that ensures that the issues affecting children with disabilities are included as part of the National Children's Agenda.”²⁵

These efforts did result in an amended NCA statement that was more inclusive of children with disabilities and their families. In June 2000, a *Public Report: Public Dialogue on the National Children's Agenda* was released. The document acknowledges that some of the new terminology and framing of issues came in response to participants in the consultations who called on the NCA to “include all children so that parents don't have to continuously fight for equal access to programs for children with special needs.”²⁶ It is too early to generalize on the full impact of the new terminology but, as this study demonstrates, some provinces – notably, British Columbia, Alberta, Saskatchewan and Quebec – are developing and implementing inclusive policy frameworks, some of which have been influenced by the NCA.

It is important to note that because both the NCA and disability policy fall largely within provincial jurisdiction, the Government of Quebec does not formally accept these Agreements and actions. Nevertheless, Quebec supports the basic goals in both policy frameworks. The province's early childhood policies and programs are quite consistent with the comprehensive policy framework agreed to by all the provinces and territories.²⁷

In summary, while governments have made meaningful progress in each separate policy sphere on disability and children, there is a lack of integration of children in the broader *disability* agenda, and the needs of children with disabilities and their families are often overlooked in the broader *children's* agenda. This “invisibility” of children with disabilities and their parents in these two policy spheres means that they are not a priority for governments. A contributing factor to this invisibility is a lack of reliable, comprehensive statistical data.

2.3 Demographic Trends

While the literature shows that children with disabilities are potentially more vulnerable than other children and tend to “fall between the cracks” of health, social services, education and recreation systems intended to support healthy child development,²⁸ we continue to have little comprehensive quantitative data about this societal grouping. A partial picture does emerge, however, from a series of national surveys.

25 *A National Strategy for Persons with Disabilities*, 5.

26 Government of Canada. National Children's Agenda, *Public Report: Public Dialogue on the National Children's Agenda – Developing a Shared Vision* (Ottawa, 2000): 10.

27 Quebec's basic policy foundation and approach to disability issues has remained constant since 1984, when it developed *A part égale/On Equal Terms*. When the provincial social service ministers released *In Unison*, the government of Quebec issued a press release making it clear that Quebec has in place its own distinct disability policy and that the province will remain the sole master of its domain in this regard.

28 Canadian Institute of Child Health, *The Health of Canada's Children: A CICH Profile*, 3rd ed. (Ottawa, 2000).

Research based on the 1996-97 *National Population Health Survey* (NPHS) has determined that approximately 565,000 children and youth from birth to 19 years of age had an activity limitation or a disability, which comprises 7.7 percent of all children living in households.²⁹ These figures are similar to the 7.2 percent identified by the 1991 *Health and Activity Limitation Survey* (HALS), which is the most recent data collected specifically on disability.³⁰

Using a broader definition of disability including both activity limitations and “special needs,” an analysis of the 1996 *National Longitudinal Survey of Children and Youth* found that 436,000 children (9.3 percent) were identified as having one or more special needs. Additionally, when children with emotional problems and learning disabilities were included, 14.6 percent of children aged 6 to 11 years were identified as having special needs.³¹

In their national study on the health of Canada’s children, the Canadian Institute of Child Health (CICH) reports that there is limited national data on the mental health and mental well-being of children and youth. There is no standardized information from sources such as provincial and territorial child welfare systems. Nevertheless, they report that the rates of behavioural and emotional problems for children aged 4 to 11 is “disturbingly high,” with one in ten children exhibiting behaviour consistent with hyperactivity disorder, conduct disorder, or an emotional disorder.³² Higher rates of these disorders were reported for boys than girls. Approximately, one in four boys were identified with one or more problems, compared to less than one in five girls. This research also confirms that socioeconomic factors are an important determinant of mental health.

The Roeher Institute, in its Children and Family Series, has compiled much of the available data on children with various disabilities.³³ Its research reinforces the idea that the experience of disability varies for every child and every family. There are many different types of disabilities involving a child’s vision, hearing, mobility, development and learning, which are experienced with different levels of severity.³⁴ The Roeher Institute finds that:

- Between 5 and 20 percent of Canadian families have children with disabilities.
- The most common type of long-term condition among young children aged birth to 14 years is a learning disability, affecting approximately 17 of every 1,000 children reporting.
- Among children with disabilities, 15 percent (more than 80,000 children) have a moderate or severe level of disability.

29 Canadian Institute of Child Health, *The Health of Canada’s Children*, 3rd ed., 229.

30 The federal government canceled the HALS survey in 1996 as a part of its Program Review process.

31 Canadian Council on Social Development, *The Progress of Canada’s Children into the Millennium: 1999-2000* (Ottawa, 1999).

32 Canadian Institute of Child Health, *The Health of Canada’s Children*, 3rd ed., 200.

33 See, in particular, Roeher Institute, *Count Us In*; and Roeher Institute, *When Kids Belong*.

34 It is important to note that policy-makers often overlook low incidence disabilities among children, especially blindness. At the CPRN Roundtable held in Ottawa on May 3, 2001, participants noted that only 1 in 10,000 Canadian babies is diagnosed with legal blindness of some kind, while 1 in 1,000 Canadian babies is born with Down’s Syndrome, for example.

As well, the Canadian Institute of Child Health found that more than 200,000 children from birth to 15 years have long-term health problems or chronic conditions aside from asthma, allergies and bronchitis, and more than 160,000 are limited or prevented from participating in school, play or other typical activities because of their long-term conditions.³⁵ Data from the CICH also confirms that children with disabilities are not a homogeneous group. In fact, the CICH reports that the rate of disability varies by age group and gender. The rates of disability are higher for older versus younger children. This is due, in part, to the fact that many disabilities among children – especially those with learning disabilities – are not diagnosed until the child is school-aged, even though these disabilities are often present from birth.³⁶ Further, among children 10 years of age and under, boys have a higher rate of disability than girls. Among children over age 10, the gender differences diminish, and then reverse. The highest rate of disability was reported for female youth aged 15 to 19 years.³⁷

While these data help paint a picture of children with disabilities in Canada, authors are quick to point out that the reliability of the data must be questioned. First, as noted above, sources of data with a national population base for children with disabilities aged from birth to 18 years is limited. The last comprehensive national study on disability was the *Health and Activity Limitation Survey* (HALS) in 1991, and it did not specifically collect data on individuals under 15 years of age.³⁸ Since that survey was only focused on activity limitations, it did not include other special needs children (i.e., those with behavioural and emotional conditions).

The national surveys that include questions on disability or the limitation of activities – including the *National Population Health Survey*, the *National Longitudinal Survey of Children and Youth*, and the survey on *Health Behaviour in School-Aged Children* – also have limitations, largely because they have not been designed as disability surveys. In the *National Population Health Survey*, for instance, the size of the child sample is relatively small, making it difficult to undertake in-depth analyses. Similarly, the *Health Behaviour in School-Aged Children* survey cannot present a complete picture because it only considers chronic conditions and long-term illnesses. As Sharon Hope Irwin, Donna S. Lero and Kathleen Brophy note in their national study on inclusive child care, each of these surveys views disability through a “medicalized prevalence framework,” which necessarily overlooks the complexity of disability as a human condition.³⁹

The Canadian Institute of Child Health has called for a “comprehensive survey, focusing on the health and well-being of children and youth with disabilities and the details of their day-to-day lives.” This data is “urgently required,” they continue, “to better understand the relationship between different disabilities and various economic, social and personal factors.”⁴⁰

35 Canadian Institute of Child Health, *The Health of Canada's Children: A CICH Profile* (Ottawa: Canadian Institute of Child Health, 1994).

36 Canadian Institute of Child Health, *The Health of Canada's Children*, 229.

37 Canadian Institute of Child Health, *The Health of Canada's Children*, 229.

38 The Government of Canada eliminated funding to the HALS survey in 1995, as a part of the Program Review process. In March 2000, Statistics Canada announced that it will undertake an updated *Health and Activity Limitation Survey* in 2001. This new survey will include focused questions on children with disabilities.

39 Irwin, Lero and Brophy, *A Matter of Urgency*, 14.

40 Canadian Institute of Child Health, *The Health of Canada's Children*, 228.

It is important to note that new national surveys focusing on children are under development. The 2001 *Health and Activity Limitation Survey* and the federally supported *National Longitudinal Survey of Children and Youth*, which is tracking the development and well-being of children from birth to early adulthood, will help provide us with a more complete picture. In particular, the NLSCY is collecting information about factors such as family, friends, schools, and communities that influence a child's physical, behavioural and learning development.⁴¹

2.4 Ethnic, Cultural and Socioeconomic Factors among Children with Disabilities

There is very little national data on disability and race, cultural differences, or socioeconomic status. Nevertheless, as the Roeher Institute notes, "like all other children, those with disabilities are racially and culturally diverse."⁴² Thus, using recent national data compiled by the Canadian Council on Social Development on children from minority communities, a partial picture emerges. This data suggests that 7.5 percent of children speak neither French nor English as a first language, 5 percent were born in another country, and 5 percent are First Nations or Métis.⁴³

The available data on First Nations children with disabilities is limited. These gaps are evident for a number of cross-cutting factors. In particular, First Nations people are not a homogenous group. Instead, they are comprised of various nations with distinct values, customs and beliefs. As Michael Prince notes, this has led to varying understandings of "disability" within First Nations communities, which have affected data collection.⁴⁴

Despite this, we do know that First Nations peoples are twice as likely to be disabled as their counterparts.⁴⁵ Compounding a higher disability incidence rate and discrimination, First Nations and other Aboriginal peoples face jurisdictional disputes depending on whether or not an individual is granted "status" according to federal law. The federal government assumes responsibility for Inuit peoples and for First Nations peoples who are status Indians living on reserve, while provincial governments are mandated to provide services to non-status Indians and Métis peoples. Moreover, First Nations peoples often encounter issues of geographic isolation and lack of community supports and services in remote areas of the country.⁴⁶

Finally, using data from the National Population Health Survey, the Roeher Institute concludes that, while children with disabilities may live in families in various economic circumstances, these children are "more likely to be poor than other children."⁴⁷

41 The Canadian Institute on Child Health has been instrumental in assisting in the development of a set of preliminary indicators of inclusion for the NLSCY. For more information, see Karen Kidder and Dawn Walker, "Indicators of Inclusion," *International Scan of Issues: Children with Disabilities and their Families: A Congress Discussion Document*, 6th International Congress of the Inclusion of Children with Disabilities in the Community (no date).

42 Roeher Institute, *Count Us In*, 3.

43 Canadian Council on Social Development, *The Progress of Canada's Children into the Millennium*.

44 Michael J. Prince, *Governing in an Integrated Fashion: Lessons from the Disability Domain* (Ottawa: Canadian Policy Research Networks, 2001).

45 Assembly of First Nations, *First Perspective: An Approach to First Nation Disability Issues*, Discussion Paper (Ottawa: Assembly of First Nations, 1998).

46 Torjman, "Canada's Federal Regime and Persons with Disabilities."

47 Roeher Institute, *Count Us In*, 5.

They found that nearly 17 percent of children with disabilities live in families who depend on government income support, compared with only approximately 8 percent of non-disabled children. These findings are supported by the Canadian Council on Social Development, which reports that poor children are over 2.5 times more likely than children living in high-income families to have vision, hearing, speech or mobility impairments.⁴⁸

Our discussion now shifts to a consideration of the current policy landscape affecting preschool and school-aged children with disabilities.

3.0 Developing A Vision: Early Childhood Development Initiatives

When the federal government unilaterally introduced the Canada Health and Social Transfer (CHST), replacing the cost-sharing arrangements under the Canada Assistance Plan (CAP) and the *Established Payments Financing Act* for health, post-secondary education and social assistance policies and programs, it seemed to many people that national-level policy goals would no longer be possible to achieve. The establishment of the social policy renewal process, and especially the signing of the *Social Union Framework Agreement* in 1999, however, introduced new mechanisms into the policy process.

There is little doubt that new measures such as the National Child Benefit (NCB) and the National Children's Agenda (NCA) have benefited preschool children and their families.⁴⁹ Federal, provincial and territorial governments have taken concrete policy action, improved policy coordination, and increased funding targeted at children from birth to age 6.⁵⁰ In particular, the *Agreement on Early Childhood Development Initiatives* (ECDI) announced on September 11, 2000 – in which the federal government will invest \$2.2 billion over the five years starting in 2001-02 – reflects a recognition that all levels of government need to work together to support families and local communities.⁵¹

48 David P. Ross and Paul Roberts, *Income and Child Well-Being: A New Perspective on the Poverty Debate* (Ottawa: Canadian Council on Social Development, 1999).

49 Susan Phillips and Havi Echenberg have argued that the National Children's Agenda cannot succeed as simply a government-to-government exercise. Rather, it is inherently complex, involving policies and processes that are cross-sectoral, intergovernmental, horizontal and vertical. As such, the NCA is not a single policy area, program or funding mechanism, but instead is a policy framework necessarily involving a variety of actors. Thus, they propose a model for engaging the voluntary sector in the NCA. See Susan Phillips, with Havi Echenberg, *Simon Says 'Take a Giant Step Forward': Advancing the National Children's Agenda*, Discussion Paper prepared for the National Children's Alliance, available at <http://www.nationalchildrensalliance.com/nca/pubs/simon/index.htm>

50 The National Children's Agenda grew out of the First Ministers' request to the Federal-Provincial-Territorial Council of Ministers on Social Policy Renewal to engage the public in developing a shared vision for enhancing the well-being of Canada's children. The five national Aboriginal organizations worked with the Council to produce *A National Children's Agenda – Developing a Shared Vision*.

51 While the government of Quebec did not sign the ECDI agreement, it is important to note that their early childhood policies and programs are consistent with the comprehensive policy framework agreed to by all other provinces and territories.

Provincial and territorial governments have agreed to use the increased funding from the ECDI to undertake a coordinated effort to: (1) promote healthy pregnancy, birth and infancy; (2) improve parenting and family supports; (3) strengthen early childhood development, learning and care; and (4) strengthen community supports.⁵² Although the ECDI is a relatively new Agreement that provincial governments have yet to fully implement, we can expect increased provincial investments in these areas. In its March 2001 *Speech from the Throne*, for instance, the Saskatchewan government re-announced a \$73 million commitment over five years towards Early Childhood Development programs aimed at children in high-risk communities. An important emphasis of the Saskatchewan plan will be to prevent Fetal Alcohol Syndrome, which begins to limit the development of children before they are even born.⁵³ In Nova Scotia, the 2001-02 Budget commits \$9 million to programs targeting mothers, babies, and child care.⁵⁴ Provincial government investments in early childhood development programs are summarized in Table 3 and Box 1.

Some voluntary sector organizations have raised concerns about the ECDI. While they applaud the Agreement and the new funding accompanying it because it represents concrete recognition of the importance of investing in children and their families, they point out that the funding is insufficient and the areas of investment are vague. Given that funds flow to the provinces through the CHST – a block funding mechanism – it is difficult for Canadians to monitor how provincial governments will allocate funds.⁵⁵

The ECDI Agreement does, however, make clear commitments on public reporting. It affirms that First Ministers commit their governments to: (1) report annually to Canadians on their investments and their progress in enhancing programs and services; (2) develop a shared framework, including jointly agreed comparable indicators to permit each government to report on improving and expanding early childhood development programs and services; and (3) make regular public reports on outcome indicators of child well-being, using an agreed set of common indicators (to be developed by September 2002).⁵⁶

We can see how the ECDI might affect ongoing policies and programs by looking at the area of non-parental child care. Prior to the last decade, most preschool children with disabilities were placed in segregated programs or parents were expected to bear sole responsibility for their care, either by not participating in the labour force or by making private arrangements that were often expensive and cumbersome.⁵⁷ Then, some provincial governments became more active in the area of early childhood development policy frameworks, well before the ECDI Agreement was signed.

52 For more information, see *Early Childhood Development* (2000), available at http://socialunion.gc.ca/nca/ecd-back_e.html

53 Government of Saskatchewan, *Speech From the Throne on the Occasion of the Opening of the Second Session of the Twenty-Fourth Legislature of the Province of Saskatchewan* (2001), available at http://www.executive.gov.sk.ca/throne_speech/march_2001.htm

54 Government of Nova Scotia, *2001-2002 Budget* (2001), available at <http://www.gov.ns.ca/finance>

55 Marcel Lauziere, "The Early Childhood Development Initiative: Challenge for the Voluntary Sector," *Perception* Vol. 24, No. 3 (December 2000).

56 See *First Ministers' Meeting Communiqué on Early Childhood Development*, available at http://socialunion.gc.ca/news/110900_e.html

57 Irwin and Lero, *In Our Way*.

As Box 1 describes, provinces have developed a range of techniques and cross-departmental bodies responsible for focusing attention and resources on children during the early years⁵⁸ (see also Table 2). Moreover, as Table 9 shows, all provincial governments also provide grants to child care providers who choose to furnish integrated child care for children with disabilities. Although research shows that inclusive child care policy continues to have significant gaps (as does child care policy for all children), it is nevertheless an area in which the provinces have developed a relatively common and consistent approach.⁵⁹ Nevertheless, gaps persist because legislation does not mandate inclusion. Moreover, the system suffers from an overall lack of funding, a shortage of trained staff, and negative attitudes towards inclusion among some child care providers.

Despite these problems, innovation is evident. In some provinces, the development of inclusive child care pilot projects demonstrates the promise of greater inclusion for children with disabilities. New Brunswick has taken the lead, using funds from Ottawa's Child Care Visions program (funded through the Department of Human Resources Development Canada) to develop a cross-provincial inclusive child care pilot project.

Keeping the Door Open: Enhancing and Maintaining the Capacity of Centres to Include All Children is a partnership program spearheaded by the New Brunswick Association for Community Living that involves child care divisions in the governments of New Brunswick, Prince Edward Island, and Saskatchewan. The program provides centre-based funding towards the development of a collaborative action plan aimed at making changes to create an inclusive centre-based environment for all children, including those requiring additional supports. The focus is on shifting *programs* to meet the needs of all children, rather than forcing *children* to meet program needs.

Saskatchewan has also been active in creating child care programs that foster the creation of supportive community environments for *all* children, including those with disabilities. The Community Solutions program, which is a part of the Saskatchewan Action Plan for Children, is a pilot project developed by the child day care division in the Ministry of Social Services. It provides project-based funding for child care initiatives that promote and support the inclusion of children with disabilities and their families through community-based partnerships. The program has been successful in bringing together various local and regional agencies (district health boards, school boards, community organizations, and so on) to work collectively at supporting the child care needs of children with disabilities and their parents.

58 For a complete discussion of these governance structures, see Mahon, *School-aged Children Across Canada*, 45-49.

59 For a comprehensive examination of child care policies, especially as they relate to inclusion, see Irwin, Lero, and Brophy, *A Matter of Urgency*.

The Play to Learn program, for instance, is located in the northern Saskatchewan community of Meadow Lake. It has brought together First Nations and non-First Nations communities to develop a program to provide a continuum of early childhood services in the community of Meadow Lake.⁶⁰ The result has been the creation of a new service delivery framework – Meadow Lake and Area Early Childhood Services – which manages and delivers a continuum of services including in-home early childhood intervention, centre-based preschool services, and centre-based child day care services.

The federal government is also involved in a variety of initiatives and programs affecting preschool children and their families. They are summarized below:

- The Community Action Program for Children (CAPC) is the responsibility of the Childhood and Youth Division of Health Canada. It provides long-term funding to selected community groups to establish and deliver services that respond to the developmental needs of children from birth to 6 years of age who are at-risk (children living in low-income families; teen-parent families; those at risk of experiencing developmental delays or social, emotional or behavioural problems; and those who are abused or neglected). CAPC funds prevention and early intervention programs, delivers services through parent or family resource centres or child development centres, and provides parenting education and infant stimulation.
- The Canada Prenatal Nutrition Program is also the responsibility of the Childhood and Youth Division of Health Canada. It is a comprehensive community-based program that supports pregnant women who face conditions of risk that threaten their health and the development of their babies. The program provides resources for community-based groups to offer support such as nutrition, knowledge and education, social support, and assistance to gain access to services. The program is delivered through Health Canada regional offices, and managed jointly by the federal, provincial, and territorial governments.
- The federal government has supported a number of Fetal Alcohol Syndrome/Fetal Alcohol Effects (FAS/FAE) initiatives. In 1996, Health Canada, with 18 other signatories, released a *Joint Statement on the Prevention of FAS/FAE in Canada*. In addition, a National Advisory Committee was formed to develop recommendations to effect an integrated, coordinated and sustainable Canadian response to FAS/FAE. Federal collaboration and coordination are sought through an Interdepartmental Working Group on Substance Abuse, which houses a Sub-Committee on FAS/FAE. In the 1999 Federal Budget, the government committed \$11 million over three years to enhance activities in this area. Some of these funds were directed to Health Canada, which has initiated a series of research studies on FAS/FAE, including a cross-Canada survey on alcohol use in pregnancy. As well, in the fall of 2000, Health Canada hosted a national forum to develop a National Action Plan for FAS/FAE.

60 The collection of organizations, agencies and communities involved in the program are the Northwest Health District, Meadow Lake School Division, Flying Dust First Nation, North West Friendship Centre, Meadow Lake Tribal Council, Positively Parenting, Meadow Lake Association for Community Living, and the Ministry of Social Services.

In summary, the NCA and ECDI initiatives are making a difference in the lives of families with preschool children. There is, however, more work to do if our goal of ensuring full citizenship for all children and their families is to be achieved. As Rianne Mahon identified in *School-aged Children Across Canada: A Patchwork of Public Policies*, children aged 6 to 15 are not a strong focus of the NCA and, while this age group is the focus of some public policy, it is a “veritable patchwork of policies and programs, reflecting the often divergent courses being charted by provinces as well as the fact that responsibility for children is spread over a range of ministries and agencies, often with differing philosophies about the goals for children.”⁶¹

Not surprisingly, then, for school-aged children with various disabilities, the situation is far more serious. It is to this subject that we now turn our attention.

4.0 Policy Scans: School-aged Children with Disabilities

We are beginning to see the introduction of government-wide coordinating bodies in the children’s policy sphere, which have had some limited impact on policies affecting children with disabilities and their families.⁶² At the same time, six provincial governments have developed independent, government-wide, disability-specific policy advisory bodies (see Table 2). In general, the mandate of these bodies is to provide the government with policy and program advice concerning persons with disabilities.⁶³ With the exception of Quebec, children with disabilities and their families do not figure prominently in this work.⁶⁴ In June 2000, the Manitoba government designated the Minister of Family Services and Housing as the Minister Responsible for Disabled Persons. Children with disabilities are included in the Minister’s mandate.

These coordinating bodies have difficulties in overcoming years of incremental policy development in the disability policy sphere. Moreover, governments do not operate in a vacuum. They must set priorities based on a variety of factors, including deficit and debt control. Thus, the power of coordinating bodies and disability-specific advisory bodies to set policy priorities is weak.

61 Mahon, *School-aged Children Across Canada*, iii. It should be noted, however, that the NCA Vision document includes children up to 18 years and sets “fostering strong adolescent development” as one of its focus areas. See *Developing a Shared Vision*, 13.

62 In almost every provincial jurisdiction, the policy and administrative arrangements in the areas of health, education and social assistance have undergone considerable change and, in many cases, this is an ongoing process. It is within this context that this section attempts to capture the key features in each province.

63 In 1995, while the NDP was still in office, the Ontario Advisory Council on Disabilities Issues undertook a policy discussion on issues affecting children with disabilities and their families. The Council published four reports based on this two-day discussion. See Ontario Advisory Council on Disability Issues, *Children’s Issues: Proceedings of a Two-Day Forum* (Toronto: Publications Ontario, 1995).

64 In Alberta, for instance, the Premier’s Council on the Status of Persons with Disabilities is developing the Alberta Disability Strategy. This policy framework embraces the notion of full citizenship for persons with disabilities and aims to bring the province in line with the commitments made in the federal-provincial-territorial *In Unison* report. The Council has identified education and learning as fundamental elements of the provincial strategy but their approach is generic and, as such, issues of concern for school-aged children with disabilities and their families are not given priority.

Across the country, policies affecting school-aged children with disabilities and their families are under the jurisdiction of a variety of legislative frameworks and ministries. In addition, supports and services for children and youth with disabilities are provided through a range of organizations including regional or local ministry offices, health authorities, social service authorities, contracted agencies, and voluntary organizations. In short, the policy sphere is the opposite of integrated and coordinated. For families, the result is often confusion and frustration.

In recent years, significant provincial reforms to education, health, and social assistance have directly affected the policies, supports and services used by children with disabilities and their parents. To track the current situation, this section provides an overview of policy frameworks and administrative arrangements in place in the provinces and the federal government that affect school-aged children with disabilities and their parents. Table 2 and Box 1 also present material upon which the discussion in this section is based.

Each jurisdiction is grouped into one of three categories according to whether or not it has an inclusive policy framework for children with disabilities and their families, as shown in Chart 2. The criteria for identifying the presence of an inclusive framework include: a mission or vision statement, a strategic plan, operating principles, a legislative framework, and a policy implementation scheme including a service delivery plan.

Chart 2. A Classification of Inclusive Policy Frameworks

Jurisdiction	Classification
British Columbia Alberta Quebec Saskatchewan	An inclusive policy framework is in place for children with disabilities and their families.
Manitoba Ontario Nova Scotia Newfoundland	An inclusive policy framework appears to be under development for children with disabilities and their families.
New Brunswick Prince Edward Island Federal Government	A sectoral policy framework is used for children with disabilities and their families.

4.1 Provinces with an Inclusive Policy Framework

British Columbia

In response to the report of the Gove Inquiry Into Child Protection in 1995⁶⁵ – which recommended a fundamental restructuring in the way services are provided to children and families – British Columbia created a single ministry responsible for all legislative frameworks, policy development, administration, and coordination of service delivery for children and families. The ministry’s mandate includes an inclusive policy approach for children with various disabilities and their families. This approach goes beyond integrating diagnostic services and disability-related in-home and out-of-home supports. It also includes education and mental health supports.

In September 1996, the provincial government created the Ministry of Children and Families by drawing together policies, programs and services from five separate ministries including Social Services, Health, Education, Women’s Equality, and the Attorney General. The government’s intent was to establish an integrated, effective and responsive ministry that would emphasize prevention and early support in order to maximize children’s healthy development. At the same time, the ministry’s organizational and policy frameworks were designed with the recognition that positive outcomes for children are best achieved through a mix of policies.

Since the ministry was established, a central goal for officials has been the development of a new policy framework for children with disabilities, bringing together the previously fragmented mandates, policies, standards, guidelines, and models from the separate ministries. While still in draft form, the result of this process is the new *Policy Framework for Services for Children and Youth with Special Needs*, announced in January 2001. This proposed policy framework has, as its foundation, an approach to supports and services that is evidence-based, family-centred and individualized, and is operationalized through an overall system-level integration that emphasizes promotion, prevention, and early support. Further, the new policy framework proposes the adoption of a broad definition of “special needs,” reflecting the broad mandate of the ministry. Special needs are defined as:⁶⁶

A child or youth (from birth to 19 years of age) who requires extra educational, medical and social/environmental supports to enhance or improve their health, development, quality of life and community integration. This definition includes children and youth with impairments that limit their ability to participate in their daily activities at home, in school and in their communities. These impairments are in one or more of the following areas: cognition, communication (speech, language, hearing), sensory/motor, social/emotional/behavioural, self-help (adaptive), and/or exceptional health needs.

65 The Gove Inquiry Into Child Protection was established by the government to examine and make recommendations on fragmented social services and child protection. Subsequent to the Commission’s report, the government established the Office of the Transition Commission, which established a framework for a better service delivery structure for health and social service delivery.

66 Government of British Columbia, *Draft Policy Framework for Services for Children and Youth with Special Needs* (Victoria: Special Needs Group for Children, Ministry of Children and Families, 2001). This definition is based on the World Health Organization’s classification of impairments, activities and participation, and modified to align with other provincial ministries’ definitions.

This broad, standard definition for all programs, supports and services means that the ministry will develop a consistent approach for determining eligibility. Thus, the proposed eligibility criteria under the new policy framework will be need-based, which allows for services and supports to be tailored to reflect the needs and priorities of the child and family.

Finally, a single service delivery model is included in the new policy framework. While services will continue to be delivered through a variety of ministry offices, agencies and organizations, the goal of the new policy framework is a province-wide, standardized and coordinated service delivery system. The family is responsible for making the first contact with service-providing agencies. Subsequent to this contact, however, the service provider with whom they first connect will begin to pull together an appropriate network of services based on an individualized plan developed according to child and family priorities. The aim of this new approach is to place the onus on the service community to mobilize to meet family needs – rather than having the family negotiate the complexity of the service delivery system.

This proposed policy framework for children with disabilities and their families responds to many of the concerns raised by disability advocates, parents and professionals, especially in its inclusive approach to policy development. Further, it represents a provincial vision, strategic plan, and implementation framework for an inclusive set of policies and programs affecting children with disabilities and their families.

The election of the BC Liberal Party on May 16, 2001 puts the future of these initiatives on hold. In their election platform, however, the Liberal party committed to “increase the emphasis on early childhood intervention programs for families with special needs children.”⁶⁷ In establishing Cabinet priorities following the election, Premier Gordon Campbell created a Ministry of State for Early Childhood Development, and has indicated that the Ministry for Children and Families will now be known as the Ministry of Children and Family Development. The four key areas of responsibility for the renamed ministry, which have not yet been fully articulated, are adoption, child protection, community living for adults, and major boards and commissions.

Alberta

The government of Alberta has implemented an inclusive policy framework for children with disabilities and their families, largely through a “carrot and stick” approach. Created in May 1999, the Ministry of Children’s Services is responsible for the key policy frameworks affecting children with disabilities and their families, but excluding education supports. To this end, the government views the ministry as a partnership among families, communities, regional authorities, municipalities, and the provincial government. Thus, the ministry achieves coordination (not integration) through agreements with its various branches including the Office of the Children’s Advocate, regional Child and Family Services Authorities, Family and Community Support Services, the Youth Secretariat, the Department of Children’s Services, as well as with other ministries, school boards, Regional Health Authorities, Persons with Developmental Disabilities Boards, and local governments.

67 BC Liberal Party, 2001 Election Platform, “A New Era for British Columbia,” available on-line at: http://www.bcliberals.com/Campaign_2001/Platform.shtml

Unique to Alberta, the ministry does not deliver any supports or services, but instead is responsible and accountable for its respective entities. The ministry oversees the development and implementation of business plans, annual reports, performance results, and the supporting management information that contributes to the government's overall fiscal and business planning processes. Responsibility for managing services and resources for children and their families (with community involvement) has been transferred to 18 autonomous Child and Family Services Authorities (CFSAs).

From the outset, the government built an inclusive approach into its policy framework and service delivery system. In particular, the development and planning of the CFSAs was guided by what the ministry terms the "four pillars." These are: community-based services, early intervention services, improved services for Aboriginal children and families, and integrated services "facilitating the barrier-free access to holistic services for children and families."⁶⁸

Each CFSA has its own government appointed CEO and Board of Directors who are responsible for preparing a regional business plan identifying goals, strategies and outcome measures. The government maintains that this decentralized service delivery model allows for programs and services to respond to community needs and priorities. Nevertheless, the ministry has developed a framework of Provincial Standards for Services for Children and Families, which details a set of province-wide expectations that must be met by each CFSA. Under this framework, each CFSA is expected to meet these standards and demonstrate that service providers are also meeting them. Ensuring that supports and services are inclusive of children and families "of all abilities and backgrounds" is a key element of the Standards.

It is still premature to evaluate the new policy framework and its decentralized service delivery system but, in its design, it reflects a "best policy mix" approach to fostering positive child outcomes. Questions must be raised, however, about the autonomy accorded to CFSAs in setting regional and local priorities. It is possible that across the province, individual CFSAs will develop, offer and fund an uneven mix of services and supports while still meeting provincial standards. This has the potential to create gaps for children with disabilities and their families.

Quebec

Quebec, like British Columbia and Alberta, has someone speaking to children's issues at the Cabinet table. Further, the *Ministère de la Famille et de l'Enfance* (Ministry of Child and Family Welfare)⁶⁹ has built an inclusive and integrated approach to disability issues within the ministry. Quebec has also integrated children's issues within its special office for disability issues (Office des personnes handicapées du Québec), which has been responsible for coordinating and integrating all programs and services for persons with disabilities since its establishment in 1978.

68 See *An Overview of Child & Family Services Authorities* (Edmonton: Ministry of Children's Services, Government of Alberta), available at: http://www.gov.ab.ca/cs/cfsa/cfsa_main.htm

69 In its own documentation in English, the ministry translates its name as Ministry of Child and Family Welfare. We will use this translation as well.

The Ministry of Child and Family Welfare is responsible for advising the government and other ministries, for coordinating multisectoral interventions, and for ensuring there is overall consistency in government action concerning child and family matters, including those affecting children with disabilities. Most health and social service supports, including pre- and post-natal services, early childhood intervention services, and supports for school-aged children with disabilities, are delivered through the province's network of *Centres locales de services communautaires* (CLSCs).

Unlike any other province, CLSCs (along with government ministries and agencies) determine eligibility for disability-related programs and services by the *presence* of a disability, regardless of the cause or the level of family income. This provision is based on the notion of the rights of citizenship. Citizens with disabilities have a *right* to special supports, regardless of any other circumstances. The Quebec model is the closest that any jurisdiction in Canada comes to embodying the ideal of full and equal citizenship through the provision of disability-related supports.

Saskatchewan

The government of Saskatchewan pioneered the strategy of developing and implementing a collaborative cross-departmental policy framework for children and youth. Unlike British Columbia, Alberta and Quebec, which have created children's ministries with Cabinet representation, Saskatchewan's policy framework for children and families is achieved through a coordinated interdepartmental Cabinet committee of nine departments. This Committee (and its supporting intra-governmental bodies) coordinate the development and implementation of the Saskatchewan Action Plan for Children. The Action Plan involves a number of actors both inside and outside government, including: a series of regional intersectoral committees; the Saskatchewan Council on Children, which advises the government on children's policy; and the Children's Advocate's Office, which acts as a government services watchdog for children.

Developed in the early-1990s, the Action Plan was created collaboratively across government departments and with community involvement. The result is a long-term policy framework for children with a vision, beliefs, and principles that guide community and government actions and directions. Supporting the idea of a "best policy mix" approach, Saskatchewan's policy framework concentrates on prevention, collaboration and community-based approaches to achieve a more holistic way of providing services to children and families. A central principle of the Action Plan is an inclusive approach, which ensures that children with disabilities and their families are included in the government's overall policy framework for children.

Since it was launched, the Steering Committee has secured close to \$70 million for child-centred initiatives. While official data are not available, provincial officials report that some of this funding has benefited children with disabilities and their families. As well, the Committee has raised the profile of issues affecting children with disabilities and their families in the province. In particular, the Action Plan's cross-departmental approach is an important and positive step forward to including the needs of children with disabilities and their families across policy and program streams.

Despite these important advances, Saskatchewan has not moved as far as British Columbia, Alberta or Quebec. While the Action Plan emphasizes cross-departmental and government-community collaboration, the reality is that there is no single ministry responsible for children with disabilities and their families. Like all other provinces, there is no single piece of legislation that governs the care of children with disabilities. Instead, policies are elaborated through generic legislation such as the *Saskatchewan Child and Family Services Act*, the *School Act*, and the *Health Act*. Thus, parents are forced to coordinate and access needed services from various departments, ministry offices, regional health authorities, hospitals and community organizations.

4.2 Provinces with an Inclusive Policy Framework that is Under Development

Manitoba

In Manitoba, the policy framework for children with disabilities and their parents is in transition. In the recent past, Manitoba has had individual programs and services that demonstrated a commitment in this area, but it did not have an overall strategic plan for this policy sphere. In particular, there was little evidence of the political will necessary to build an inclusive policy framework that integrates the concerns of children with disabilities and their families into an overall service and program delivery framework.

There is no single entry point for parents to gain access to services for their disabled children in Manitoba. Services and supports for children with various disabilities are the responsibility of three ministries – Manitoba Family Services and Housing, Manitoba Health, and Manitoba Education, Training and Youth. While the government does not have an overall inclusive policy framework for children with disabilities and their families, it is able to offer limited service and program coordination by locating a range of supports targeted to children with various disabilities in a single ministry branch. The result is that parents can more easily access multiple services for children because they are offered through the same funding and policy envelope.

Three recent developments, however, put Manitoba on the verge of creating a truly inclusive policy framework. First, in December 2000, the newly elected NDP government launched Healthy Child Manitoba in its *Speech from the Throne*.⁷⁰ Using the model adopted in Saskatchewan, the province-wide initiative focuses attention on supporting children and parents in the community. A new Cabinet Committee chaired by the Minister of Family Services and Housing, and comprised of ministers responsible for Aboriginal and Northern Affairs; Culture, Heritage and Tourism; Education; Training and Youth; Health; Justice; and the Status of Women coordinates the initiative. Unlike the Saskatchewan model, however, this Committee is not charged with developing an inclusive, coordinated, and integrated policy framework across the government for children. Further, the Initiative does not have children with disabilities and their families as a priority area.

70 Government of Manitoba, *Speech from the Throne at the Opening of the Second Session of the Thirty-Seventh Legislature of the Province of Manitoba* (2000), available at <http://www.gov.mb.ca/throne.html>

Second, on June 1, 2000, the government designated the Minister of Family Services and Housing as the Minister Responsible for Persons with Disabilities. The minister's responsibilities include improving communication with the disability community to identify issues affecting persons with disabilities, coordinating policies across government departments to reduce barriers and create more accessible programs and services, promoting positive attitudes, and raise awareness of disability issues. Children with disabilities are included in the Minister's responsibilities, although to date their particular concerns do not seem to be a high priority.

Finally, the Minister Responsible for Persons with Disabilities released a White Paper proposing a new province-wide disability strategy on May 4, 2001.⁷¹ *Full Citizenship: A Manitoba Provincial Strategy on Disability* calls for a more inclusive society and announced plans to improve employment opportunities and supports for people with disabilities, including children. The strategy document sets out an Action Plan that has as its goal the full citizenship of Manitobans with disabilities, with proposed mechanisms to measure the progress of developing a truly inclusive society. The government is holding province-wide public consultations on the strategy and a public report is expected once this process is complete.

Ontario

The Ontario government's record on disability and children's issues is not strong. First, since 1995, the government has promised the disability community that it would enact province-wide "barrier removal legislation" known as the *Ontarians with Disabilities Act*. Despite repeated assurances (one in the April 1999 *Speech from the Throne*) and a public consultation, to date, the government has failed to act. Second, concerning children's policy, a junior Minister of Children was appointed in 1997, which was followed by the creation of a Children's Secretariat.⁷² Its responsibility, however, has been largely to implement the province's early childhood intervention strategy and compile a directory of children's services. The Secretariat does not serve as a coordinating body for policies, programs and services affecting children.

While the Ontario government has implemented measures to coordinate service delivery supports for children with developmental disabilities, there is little evidence of an inclusive policy framework that integrates the concerns of *all* children with disabilities and their families into an overall service and program delivery framework.

Understanding the policy sphere for children with disabilities in Ontario is difficult at best. Given that the province has a large population that is linguistically, culturally and geographically diverse, the policy sphere is the largest and most varied in the country. Compounding these demographic realities, the government of Ontario has, since 1995, undertaken an unprecedented level of reform in health, social services, education, and municipal government policy. The force for policy change in the province has been deficit control, which drove the simultaneous restructuring of health, education and municipalities.⁷³

71 A copy of the strategy document is available on-line at: <http://www.gov.mb.ca/access/>

72 The Secretariat is very small, with a staff of only 15 and an operating budget of \$2.4 million annually.

73 Kate Bezanson and Fraser Valentine, *Act In Haste ... The Style, Scope and Speed of Change in Ontario*, The Speaking Out Project (Toronto: Caledon Institute of Social Policy, 1998).

In this climate, policies affecting children with disabilities and their families have not been a priority, but the regime shifts within these policy domains have necessarily had an impact on policies affecting children with disabilities. Such policies are the responsibility of several actors. The key policy frameworks are found within the Ministries of Community and Social Services, Health and Long Term Care, and Education and Training. In addition, however, regional and municipal governments, regional health authorities, Community Care Access Centres (CCACs), hospitals, specialty clinics, community agencies, and non-profit and for-profit organizations are all involved in the policy sphere. Thus, the overall system of care for children with disabilities is non-specific, forcing parents to independently navigate the complexity of the system to secure the necessary supports and services for their children.

While children's policy and disability policy do not receive attention around the Cabinet table, they have garnered some attention within the bureaucracy. In 1997, the Ministry of Community and Social Services released a new service delivery framework for children and adults with developmental disabilities. The initiative Making Services Work for People (MSWP) has as its primary goal to reform, restructure and coordinate services, making them more effective, cost-efficient, and accessible. It commits to the development of a "local system of services" subject to provincial requirements, enabling parents to access a more consistent and coordinated range of services for their children. Disability advocates and organizations agree that these administrative reforms will mean the development of coordinated and integrated supports at the local level, thereby reducing the complexity and number of service delivery access points. While the overall reform initiative was welcomed by professionals, parents, and disability advocates, some key elements of the initiative have been called into question by concerned advocates.⁷⁴

Cross-ministerial coordination has also been a goal of the Ontario government. The Office of Integrated Services for Children was established in January 2000 by the Deputy Ministers of the Ministry of Community and Social Services and the Ministry of Health and Long-Term Care, and charged with the responsibility of integrating children's services across four ministries: Health and Long Term Care; Community and Social Services; Education and Training; and Citizenship, Culture and Recreation. Through a structure of six branches, the Office's role is to ensure integrated policy development, service delivery and accountability mechanisms.⁷⁵ Its priority focus, however, is on families with children at risk, from the prenatal stage to 8 years of age. Policies affecting school-aged children with disabilities and their families are not a priority in the Office's mandate.

74 For a detailed critique, see Ontario Association for Community Living, *Making Services Work for People: Impact Analysis – Discussion Paper* (1998), available at <http://www.acl.on.ca/mswp/impact.html>

75 The responsibilities of the division are carried out through the following six branches: (1) Early Years and Healthy Development Branch; (2) Early Years Challenge Fund Branch; (3) Early Years Task Group Branch; (4) Integration Strategies for Children's Services Branch; (5) Services for Children with Special Needs Branch; and (6) Child Welfare and Young Offenders Branch.

Nova Scotia

In recent years, the Nova Scotia government's policy priorities have focused on deficit reduction, social assistance reform, and labour market strategies. Moreover, unlike New Brunswick and Newfoundland, which are projecting surpluses in 2002, Nova Scotia's 2001-02 Budget anticipates a deficit of approximately \$91 million.⁷⁶

Policies affecting children with disabilities and their families have not figured prominently around the Cabinet table. The National Child Benefit and the *Agreement on Early Childhood Development Initiatives* have resulted in some focused attention on developing a coordinated policy and service delivery framework for children from birth to 6 years of age. At the generic children's policy level, there is evidence within the bureaucracy that the need for a more coordinated and integrated approach is recognized and under construction, but the development of an inclusive policy framework that integrates the concerns of school-aged children with disabilities and their families is not yet evident.

The Child and Youth Action Committee (CAYAC) was established in 1996 by the Ministers of Justice, Health, Education, Community Services, and the Youth Secretariat. This coordinating Committee brings together senior level bureaucrats from six ministries to develop integrated service delivery protocols for children and youth. Their work does not focus on policy development or policy coordination, however, but on service delivery. In particular, the Committee has been given the responsibility to integrate regional service delivery for mental health services for children and youth, as well as for services to children with special needs. The Committee has focused on developing strategies to provide equitable levels of service across the province because the disparity between services in urban versus rural areas is a significant barrier for children and youth in the province, especially for those with disabilities.

In a recent final report of the Mental Health Review Advisory Committee, however, CAYAC's commitment to interdepartmental coordination is called into question. The report states:⁷⁷

It seems that the support for CAYAC, from the various Departments involved, has been variable and inconsistent with greater commitment from some than from others. This being the case, there has been criticism of CAYAC that it has the right idea but has not been able to achieve much. Indeed, the members of the Committee itself have sometimes felt hampered in their efforts to achieve change.

76 Government of Nova Scotia, *Budget Address, Province of Nova Scotia for the Fiscal Year 2001-2002* (2001), available at <http://www.gov.ns.ca/finance/budget2001/address.htm>

77 Mental Health Review Advisory Committee, *Mental Health: A Time For Action*, submitted to the Deputy Minister of Health (Halifax: Ministry of Health, 2000): 15.

Newfoundland and Labrador

There is no single legislative or policy framework mandating the provision of supports and services for children with disabilities and their families in the province. Instead, a number of statutes, which are the responsibility of various ministries, affect children with various disabilities and their families. Like many other provinces, Newfoundland has been plagued by poor service coordination and a lack of collaboration among various ministries and service delivery actors. Since the mid-1990s, however, the province has taken concrete action to develop an integrated service delivery framework.

In 1995, Newfoundland began developing and implementing a coordinated interdepartmental service delivery strategy for children and youth. The Model for the Co-ordination of Services to Children and Youth is a cross-department strategy involving the Ministries of Education; Health and Community Services; Human Resources and Employment; and Justice. Through service coordination, collaboration and integration, the model seeks to provide appropriate assessment and early identification in supporting a child's full participation in family, school and community life. Since there is no single entry point into the system, the service delivery framework model assists families in coordinating the necessary network of support providers.⁷⁸

The model is still in the implementation phase, but it has gone some distance towards integrating the various services and supports required by children with disabilities and their families. Despite this, service availability is uneven across the province, especially between urban and rural areas.

4.3 Provinces Employing a Sectoral Policy Framework

New Brunswick

In 1994, the government of New Brunswick created the Minister of State for the Family, along with a separate Family Policy Secretariat. The result was the development of a broad family policy framework in 1995 entitled *Foundations for the Future: A Proposed Family Policy in New Brunswick*, which focused on economic security and a balancing of work and family responsibilities. However, this proposed policy framework was not inclusive of the needs of children with various disabilities and their families. Then, when the Liberal government won the provincial election in 1999, the priorities of this policy framework were abandoned or integrated into the Ministry of Family and Community Services.

Like other provinces, the government of New Brunswick has implemented a cross-departmental Early Childhood Development policy framework with a single service delivery entry point. There is no evidence, however, of an inclusive, cross-departmental policy framework targeting school-aged children with disabilities and their families.

⁷⁸ The model also forms the basis of the coordinated and collaborative service delivery framework in the province's Early Childhood Development Initiative, *Healthy Beginnings: Supporting Newborns, Young Children and their Families*.

Instead, a sectoral approach is in place in which policies affecting children with disabilities and their families are the responsibility of several ministries. These policies are administered and delivered through regional ministry offices, hospitals, specialty clinics, contracted agencies, and community organizations.

Prince Edward Island

The government of Prince Edward Island has not initiated a comprehensive, system-wide process aimed at developing an inclusive, integrated, and coordinated policy framework for children with disabilities and their families. Through its Healthy Child Development Strategy, the government has developed a policy framework and five-year strategy to support children from birth to the early school years. In addition, in its most recent *Speech from the Throne* on November 23, 2000, the government committed to establishing a Premier's Council on Healthy Child Development to advise on the implementation of the recommendations of the Healthy Child Development Strategy and to monitor and report on outcomes. To increase coordination and cooperation for services for children, the government further committed to establish an Early Childhood Secretariat, which will support the Premier's Council and work closely with non-governmental and community agencies to support key early childhood development initiatives.⁷⁹

Within the bureaucracy, the government has also begun to move forward on increasing the coordination of supports and services for school-aged children with disabilities and their parents. In July 2000, a coordinator of disability supports and services was appointed within the Ministry of Health and Social Services. Most supports and services affecting school-aged children with disabilities are accessed through the Family Support Program, which is located in the Child, Family and Community Services Division of the Ministry of Health and Social Services. An internal comprehensive review of provincial supports and services has been completed, and the ministry is now in the process of implementing program realignment. The results of this process are not yet known.

A key challenge in Prince Edward Island is a lack of health care specialists. As a result, the province must pay for children and families to travel to Halifax or Montreal to access services. This places a heavy burden on both the provincial government and the families involved.

4.4 The Federal Government

The provision of supports and services to children with disabilities and their families is fundamentally a matter of provincial authority.⁸⁰ Nevertheless, the policy sphere for children with disabilities and their families is one area where the jurisdictions of both levels of government overlap. Table 1 lists the key federal initiatives that are aimed at children, including those with disabilities, and their families.

79 Government of Prince Edward Island, *Speech from the Throne, 2nd Session, 61st General Assembly* (2000), available at <http://www.gov.pe.ca/leg/speech/2000/index-fall.php3>

80 The only exception to this picture lies in the supports and services provided to Aboriginal peoples on reserve, where the federal government retains policy and program authority. The conditions of service delivery vary within and across provinces, however, because the federal government has negotiated a variety of agreements with First Nations' communities and provincial governments.

The provinces provide health, social services and education and, at the same time, they help to realize federal mandates for strengthening citizenship and equality. Indeed, the calls from disability advocates for the federal government to protect and promote the “citizenship rights” of persons with disabilities have been embraced by a variety of government reports and documents, as described in Section 2 above.

These dual policy goals, however, are not always on parallel tracks. Moreover, as detailed here, the results of provincial health, education, and social services restructuring mean that municipal and regional levels of government are playing an increasingly influential role in structuring the delivery of services to children with disabilities and their families. This has further inhibited the ability of governments to achieve clear and focused policy goals, especially for children with disabilities, for whom the policy sphere is defined by complexity, fragmentation and generally poor coordination.

There is no designated federal minister responsible for this policy area, but the Minister of Human Resources Development Canada (HRDC) is deemed to be the lead minister to which most disability-related issues are directed. HRDC also houses the Office for Disability Issues and has been actively involved in the Social Union discussions. Nevertheless, a variety of other federal ministries are involved in the policy sphere including Finance, Justice, Heritage, Transportation, Industry, and Communications.

Within this general context, the federal government does play a significant role in certain areas: (1) fiscal transfers to the provinces; (2) the National Children’s Agenda; (3) Aboriginal children living on-reserve; and (4) targeted initiatives. Each of these key areas is discussed below.

Federal Fiscal Transfers to the Provinces

As noted previously, the federal government implemented the Canada Health and Social Transfer (CHST) in 1996. The CHST provides cash and tax transfers to the provinces, which can be used for health, post-secondary education, social assistance, and social services. This mechanism of fiscal federalism, therefore, plays an important role in both the children’s and disability policy spheres. That said, the CHST is a block transfer, which means that provinces can invest in the areas they deem appropriate.⁸¹ The result has been that disability policy, and especially policy affecting children with disabilities and their families, receive a low priority among other policy domains, especially those of health care and post-secondary education.

81 Provincial cash and tax transfers were reduced by \$3 billion in 1996-97 and by \$4 billion in 1997-98. In 1999, the federal government announced increased CHST funding of \$11.5 billion over five years (\$2.5 billion for 2000). In 2000, \$30.8 billion was transferred to the provinces and territories. The 1999 Budget introduced measures to eliminate disparities among provinces in per capita CHST entitlement (cash transfers plus tax transfers). By 2001-2002, all provinces and territories will receive the same amount on a per capita basis.

National Children's Agenda

As discussed in Section 2 of this report, the recently announced *Agreement on Early Childhood Development Initiatives* between the federal, provincial and territorial governments is the most recent and significant development in the National Children's Agenda. It marks an important step forward in the creation of collaborative measures for Canada's youngest children, including those with disabilities and those at risk of developing a disability.

First Nations Children Living On-Reserve

The service-delivery function to First Nations' children with disabilities is primarily the responsibility of the federal government. Children with disabilities living on reserves are the responsibility of the Department of Indian Affairs and Northern Development. For children living off reserve, however, the responsibility is far from clear. A series of issues make this a confusing policy area. These range from problems of comparability and portability of services between those living on- and off-reserve, the limited nature of services on reserves, and confusion concerning off-reserve entitlements to services and supports. The result for First Nations' children with disabilities, however, is clear. Across the country, there is a chronic lack of supports and services for children with disabilities. There are reports that some children are forced into the child protection system and therefore separated from their families as a last ditch effort to access the supports and services they require.

In recent years, the federal government has responded to this situation. As Michael Prince details in the companion report to this document, Health Canada is a strategic government department in relation to Aboriginal and First Nations peoples, their health policy and services, and to Aboriginal and First Nations children with disabilities. In 1995, the Aboriginal Head Start Initiative was launched to help improve child development and school readiness among Indians, Métis, and Inuit living in urban centres and large Northern communities. Total program funding was \$83.7 million over four years (between 1995-1996 and 1998-1999) and \$22.5 million a year ongoing. The Initiative includes early family support, school readiness, life skills, school follow-up, parent support, and community coordination for Aboriginal children and their families.

Following the recommendations of the Royal Commission on Aboriginal Peoples, as well as commitments made by the government in both *Gathering Strength: Canada's Aboriginal Action Plan, Securing Our Future Together* and the 1997 *Throne Speech*, it was announced in October 1998 that the Initiative would be expanded to include Aboriginal children living on-reserve, through the Aboriginal Head Start On-Reserve Program. Funding for the program was set at \$100 million over four years and \$25 million a year ongoing. In the 2001 *Throne Speech*, the government committed to "expand significantly the Aboriginal Head Start Program, to better prepare more Aboriginal children for school, and help those with special needs."⁸² As well, to provide guidance and policy direction for the development of the First Nations and Inuit component of both the Canada Prenatal Nutrition Program (CPNP) and initiatives related to Fetal Alcohol Syndrome and Fetal Alcohol Effects (FAS/FAE), a National First Nations and Inuit CPNP/FAS/FAE Steering Committee was formed in 1999.

82 Government of Canada, *Speech from the Throne to Open the First Session of the 37th Parliament of Canada* (2001), available at http://www.sft-ddt.gc.ca/sftddt_e.htm

Targeted Initiatives

The federal government also undertakes a variety of targeted initiatives related to children with disabilities and their families. It plays a central role in funding research and knowledge generation and dissemination in the area of disability policy. This includes investments such as the 2001 *Health Activity Limitation Survey*, the *National Longitudinal Survey of Children and Youth*, and a variety of project-based research initiatives. In addition, the federal government is actively involved in collaborative measures aimed at information dissemination. For instance, the Federal-Provincial-Territorial Working Group for Benefits and Services for Persons with Disabilities, with the support of Human Resources Development Canada, has launched a new web site dedicated to providing quick information on government-related disability programs and services across Canada. Disability WebLinks [sic] (see <http://www.disabilityweblinks.ca>) contains information and links on disability related topics, ranging from employment and education programs to tax programs and financial supports offered by the federal, provincial and territorial governments.

The federal government has also made investments towards the establishment of a number of Centres of Excellence. One of a network of Centres established by the federal government, the Centre of Excellence for Children and Adolescents with Special Needs operates under the administrative leadership of Lakehead University, in partnership with the Government of Nunavut, the University of Northern British Columbia, Memorial University, and Mount Saint Vincent University. The Centre focuses specifically on rural and remote communities and, in particular, on children and youth with special needs living in Canada's North. The Centre investigates models for the prevention and early identification of special needs in rural and remote communities. It will also consider the most appropriate ways to diagnose and treat these children, given challenges such as professional availability, cost, geography and distance.⁸³

Finally, the Federal-Provincial-Territorial Working Group on the Mental Health and Well-Being of Children and Youth was established in 1986. It has a mandate to promote mental health and wellness, improve mental health outcomes, monitor the mental health status of children and youth, monitor services for this population, and identify critical issues in service provision and integrated service delivery. The Working Group's 13 members meet on a yearly basis and regularly submit recommendations to Health Canada (e.g., status reports, position documents) through the Federal Coordinator who is located in the Child, Youth and Family Health Unit of the Childhood and Youth Division of Health Canada. The Working Group's primary functions are to consult intergovernmentally on child and youth mental health issues, provide advice and strategic directions to the federal government, provide opportunities for information sharing, and identify and analyze critical issues and emerging trends in the policy sphere.

In summary, this section has described the policy directions and governmental machinery in the provinces and the federal government related to children with disabilities and their families. Some jurisdictions provide a more integrated and inclusive approach than others, but gaps remain in all of them. The analysis will now shift to an assessment of the existing mix of provincial policies and programs for children with disabilities and their parents.

83 For more information, see http://www.hc-sc.gc.ca/hppb/childhood-youth/centres/e_special.html

5.0 Limited Citizenship: Assessing the Patterns of Inclusion and Exclusion in Existing Policies for Children with Disabilities and their Parents

Federal and provincial governments have made repeated commitments to develop policy frameworks supporting the full citizenship and participation of Canadians with disabilities, including children with disabilities.⁸⁴ In November 1999, however, 13 national disability organizations released a report identifying a trend among governments to approach disability issues in a “piece meal and uncoordinated fashion, favouring ‘disability initiatives’ and ‘special projects’ which do not have sufficient scope or depth to achieve the equality promised in the *Canadian Charter of Rights and Freedoms*.”⁸⁵ The scan of existing provincial policies and programs for children with disabilities and their families presented in Appendix A reinforces this conclusion.

In addition, the CPRN Roundtable participants poignantly reminded us that the first explanation for the limited citizenship of children with disabilities, their parents and siblings stems from negative attitudes and stereotypes. In short, children with disabilities are often not valued in our communities. The impact of a child not being valued, and therefore not belonging to the community, reverberates throughout the entire family. It inhibits their ability to participate as full and active members of the community and therefore limits their capacity to be full citizens.

Aside from the impact of these stigmatizing attitudes, the policy and program scans located in Appendix A uncover three interdependent factors hampering access to full citizenship for children with disabilities, their parents and their siblings:

- First, despite a shift away from “pathologizing” individuals, the policy and program scans contained in Appendix A uncover a broad pattern of providing primarily functional, rehabilitative, and therapeutic supports to children with disabilities and their parents.
- Second, the development of inclusive, generic policy frameworks, especially in education, recreation, and child care, remain underdeveloped. Further, in those instances where policies do respond to family needs, such as in-home supports and respite care, they are often underfunded, inflexible and difficult to access.
- Third, the ability of parents raising a child with a disability to secure an adequate income is often difficult. Parents confront barriers to their participation in the paid labour market because income and community supports are not readily available, forcing them to drop out of the labour market and assume full responsibility of caring for their children. Thus, their own capacity to participate in the labour market, assume responsibility for their family, and access adequate income is undermined.

84 These commitments are most evident in the Federal-Provincial-Territorial *Mainstream Review* (1992); the *In Unison* report (1998); and in the most recent federal government *Future Directions* report (1999). As discussed in the next section, these commitments have expanded into the international realm.

85 *A National Strategy for Persons with Disabilities: The Community Definition*, 2.

Drawing on the tables and boxes in Appendix A, this section undertakes an evidence-based assessment of current provincial policies and programs available for children with disabilities and their parents, and identifies current gaps. Provisional judgements of provincial policies and programs are made based on the following set of principles: family-centred, community-based, accessible, flexible, portable, integrated, cooperative and inclusive.⁸⁶

The typology of *three enabling conditions* necessary for children to achieve positive outcomes – adequate income, effective parenting, and supportive community environments – is used to organize the material in the following sections. As the *Best Policy Mix for Children* research confirms, when all three conditions are in place, children and families are well-placed to claim their rights to full citizenship status.

5.1 Adequate Income

For most parents of children with disabilities, making financial ends meet is difficult. Parents face significant costs related to their children's disability. Recent Canadian research suggests that these costs are incurred in two forms: (1) from reduced income and benefits due to lost time from paid employment; and (2) from the additional out-of-pocket expenses incurred to meet the daily needs of their child, such as transportation, special clothing, medications, medical supplies, assistive devices, adapted technology (voice synthesizers, Braille printers, and so on), home and vehicle modifications, special diets, tutors, child care, homemaking supports, and so on.⁸⁷ These findings are reinforced by recent research on child care barriers to labour market attachment faced by parents of children with disabilities. Sharon Hope Irwin and Donna Lero found that:⁸⁸

While all families face significant issues in managing paid work and family responsibilities, our research indicates that parents of children with special needs are not on a common, level playing field with others. These parents face many additional challenges, often with few appropriate, ongoing supports. To date, their needs have not been recognized – let alone addressed.

While we often refer to “parents caring for a child with disabilities,” the literature shows that in both two-parent and lone-parent families, it is most likely women who are providing the vast majority of care for their child or children.⁸⁹ Often they have willingly left or have been forced to leave the paid labour market to provide the necessary at-home care for their child. This means that women are often carrying a significant personal burden and absorb many of the costs associated with the provision of care. Compounding the emotional toll are income-related factors. If a parent drops out of the paid labour market to provide care, for instance, then they are by definition ineligible for benefits under the *Canadian Pension Plan*.

⁸⁶ These criteria build on a reform proposal by Sherri Torjman for a national disability personal supports fund. See Sherri Torjman, *Proposal for a National Personal Supports Fund*, (Ottawa: Caledon Institute of Social Policy, 2000). The criteria were also discussed and elaborated at the CPRN Roundtable held on May 3, 2001 in Ottawa.

⁸⁷ Roeher Institute, *Beyond the Limits*; Roeher Institute, *Finding a Way In*; and Irwin and Lero, *In Our Way*.

⁸⁸ Irwin and Lero, *In Our Way*.

⁸⁹ See, for instance, M. Bulmer, *The Social Basis of Community Care*, (London: Allen and Unwin, 1986); and J. Finch, “Community Care: Developing Non-Sexist Alternatives,” *Critical Social Policy* Vol. 9, (1984): 6-18.

Each of these findings is significant. Parents of children with disabilities face unique financial challenges. Governments have responded with a limited number of mechanisms including tax policies and income supplements, as well as parental and family leaves. As discussed below, however, there is room for improvement.

There are a range of policies considered in this section that can be understood as belonging to one of two broad categories: (1) policies that affect general household income, such as tax policy; and (2) policies that target the additional costs incurred by households caring for a child with a disability. There is a difference between the nature of these two kinds of policies but, in this functional analysis, they are grouped under the single category of adequate income.

The Tax System and Children with Disabilities

As noted previously, while many other policy areas have been scaled-back, over the past decade, the government has extended and created new disability-related tax measures recognizing the significant costs associated with raising children.⁹⁰ Each of these measures in the income tax system are targeted to help offset family costs associated with the care of their child (see Box 2 for a chronology of recent changes to the tax system).

To help offset the costs for children with disabilities, the tax system includes a Medical Expense Tax Credit (METC), which helps offset the some of the costs associated with disablement through credits for itemized medical expenses, as well as a Disability Tax Credit (DTC), which benefits individuals with physical or mental impairments.

The METC is available to all taxpayers with above-average medical costs and provides combined federal and provincial tax relief for about 25 percent of eligible medical costs.⁹¹ In 1997, the federal government broadened the allowable expenses covered in the METC to include:⁹²

- Twenty percent of the cost of a van that is adapted for the transportation of an individual using a wheelchair (to a maximum of \$5,000)
- Fifty percent of the cost of an air conditioner necessary to help an individual cope with a severe chronic ailment, disease or disorder (to a maximum of \$1,000)
- Expenses incurred for moving to accessible housing
- Reasonable expenses relating to alterations to the driveway of the principal residence of an individual with a severe and prolonged mobility impairment, to facilitate access to a bus

90 For a useful overview of tax policy affecting children with disabilities, see Sherri Torjman, *Will the 'Children's Budget' Include Kids with Disabilities?* (Ottawa: Caledon Institute of Social Policy, 1999).

91 One taxpayer, Mr. Fred Weeks, attempted to challenge the allowable expenses for medical tax credit under the *Income Tax Act* because it excluded certain disability-related expenses. His claim that the credit is “under exclusive” because many medical expenses are not covered was unsuccessful before the Tax Court and the Federal Court of Appeal. He is currently seeking leave to appeal to the Supreme Court of Canada.

92 Department of Finance, “Helping Canadians with Disabilities,” *Building the Future for Canadians: Budget 1997* (Ottawa: Department of Finance, 1997), available at <http://www.fin.gc.ca/budget97/pamphe/disapae.html>

- Sign language interpretation fees, and
- An increase in the limit on part-time attendant care expenses, from \$5,000 to \$10,000.

In contrast with the METC, the Disability Tax Credit does not cover costs incurred within the home setting. Rather, it provides a “flat-rate” credit against federal income tax, payable to those who qualify. The federal government’s most recent measures affecting all persons with disabilities, including children with disabilities, which took effect on January 1, 2001, altered the DTC (see Box 2). The amount used for calculating the Disability Tax Credit rose to \$6,000 from \$4,293. In addition, the amount used for calculating the supplement to the Disability Tax Credit for children with severe disabilities was increased to \$3,500. This change responded to critiques by disability organizations that the DTC did not reflect the real costs associated with disability.

The increases in the allowable tax credit amount helps parents secure an adequate income, but there remains room for improvement. In particular, the disability community has argued that the federal value of the DTC should be refundable so that it benefits people who earn very low incomes, and that provincial and territorial governments should not consider tax credit amounts received as income. This call is supported in the recommendations of the Scott Task Force.⁹³

The tax system also provides a deduction for parents for non-parental child care. In 2000, the federal government changed the Child Care Expense Deduction (CCED) in the *Income Tax Act*, allowing parents caring for a child with disabilities to partially cover one of the necessary costs of participating in the labour force or school. Under these changes, families caring for a child with disabilities at home can deduct expenses of up to \$10,000 for a child who qualifies for the disability amount.⁹⁴ Caroline Beauvais and Jane Jenson note that while the CCED is an important instrument to “level the financial playing field” for families, it does not cover all child care costs incurred by families in order to participate in the paid labour market.⁹⁵

The National Child Benefit provides the policy framework for child benefits. It consists of: (1) the basic Canada Child Tax Benefit; (2) a National Child Benefit Supplement; and (3) provincial investment commitments. The National Child Benefit, including the Canada Child Tax Benefit (CCTB) is a generic program targeted at low-income families but, given the demographics of children with disabilities, we can assume that the CCTB is available to many families who have children with disabilities.

The CCTB is a tax-free monthly payment made to eligible families to help them with the cost of raising children under 18. The benefit is paid to the parent who is primarily responsible for the care of the child. Payments are targeted according to income and phased out at higher income levels. The CCTB includes a basic annual benefit of \$1,020 for each child and an additional benefit called the National Child Benefit Supplement (NCBS) for very low-income families.

93 The Task Force recommended the creation of a new disability expense tax credit combining the best features of the DTC and the METC. See *The Will To Act*, 97-99.

94 The eligibility criteria states that the child must be under 16 years of age to qualify. The changes made in 2000, however, remove the age limit for children that are “mentally or physically infirm.” For more information, see <http://www.ccrea-adrc.gc.ca/E/pbg/tf/t778eq/README.html>

95 Caroline Beauvais and Jane Jenson, *Two Policy Paradigms: Family Responsibility and Investing in Children* (Ottawa: Canadian Policy Research Networks, 2001): 11.

The NCBS is available to all low-income families, regardless of their source of income. The maximum yearly amounts of the supplement are \$605 for families with one child, \$1,010 for families with two children, plus a further \$330 for each additional child. Qualifying families whose net income is under \$20,921 will get the full amount of both the CCTB and NCBS.⁹⁶

The government also provides GST/HST exemptions towards the purchase of medical devices such as wheelchairs and walkers, as well as guide dogs for blind persons, and hearing-ear dogs for hearing impaired persons. Recreation programs offered by a public sector body to persons with disabilities are also exempt from the GST/HST (this includes camps, community centre programs, and so on). Finally, the government provides a GST/HST rebate towards the purchase or modification of specially equipped motor vehicles.

Income Supplements

An important set of instruments to help parents offset the costs associated with raising a child with disabilities are cash subsidies. As Table 4 shows, six provinces have programs providing extra income support for families who have children with disabilities. There is no convergence, however, on the nature of the programs, eligibility criteria, or level of benefits.

In British Columbia and Saskatchewan, programs provide extra income support for families to purchase medical or respite supports. These programs target only those families who cannot access “mainstream programs” because of extraordinary circumstances such as geographic isolation or severely disabled or medically complex children. British Columbia’s At Home Program provides financial support for the medical and respite needs of families who have children with severe disabilities being cared for at home. Eligibility is determined using functional criteria of dependence on the caregiver, based on four government-defined activities of daily living (i.e., bathing, toileting, dressing, and feeding). In Saskatchewan, extra income support is provided to families living in rural areas through the Outreach Program. This program targets only those families who cannot access respite services provided through the provincial Resource Homes, which are located in Regina and Saskatoon.

Three provinces provide extra cash subsidies to families in financial need. In Ontario, families with an annual gross household income of \$60,000 or less, with a child under 18 years who is living at home, are eligible for cash subsidies ranging from \$25 to \$375 per month under the Assistance for Children with Severe Disabilities program. Eligible expenses include transportation and lodging costs, parental relief, day care or babysitting, special diets, speech therapy, and vision, dental, drug and hearing aids. If the family’s income is above the set limit, assistance will not be given. Ontario also provides extra income support to families through the Special Services at Home program. This program provides the parents of children with developmental or physical disabilities with funding to purchase a range of supports, including respite, which are not available in their community. The program is not a legislated entitlement program and operates on a fixed allocation of funding through the *Developmental Services Act* and the *Child & Family Services Act*.

96 For details about the purposes and functioning of the NCB, see Beauvais and Jenson.

In Newfoundland, the Special Child Welfare Allowance Program provides financial assistance to families who have a child 18 years or under with disabilities. The program is designed to help offset the costs of required supports. The ministry determines eligibility through a household financial assessment but, unlike Ontario, which calculates eligibility based on gross household income, Newfoundland's assessment is based on a formula that includes a consideration of household income, family size, and the complexity of the supports required.

Manitoba's Children's Special Services Branch will provide some financial relief to families in need for some of the out of ordinary costs of raising a child with disabilities.

Quebec is the only jurisdiction that provides a universal cash subsidy to all families raising a child with disabilities. The *Allocation pour enfant handicapé* (Allowance for a Child with Disabilities) provides a monthly allowance of \$119.22 to all families with a child who is 18 years and under, and assessed as having a physical, mental or developmental disability. This subsidy is only available, however, for families whose children have temporary and/or fluctuating levels of disablement for a minimum foreseeable period of one year.

Convergence is evident among a second set of programs providing cash subsidies to families towards the purchase of assistive devices, medical equipment and supplies.⁹⁷ As Table 5 describes, every province has such a policy but divergence is evident in the manner in which the programs are implemented and in the level of benefits provided to families. Three issues are central to this discussion:

- First, three provinces (British Columbia, Nova Scotia, and Prince Edward Island) have programs targeting children with disabilities, while all other jurisdictions include children in their generic assistive devices programs. There is concern that the particular needs of children have the potential to be overlooked in the generic programs.
- Second, Quebec is the only jurisdiction that provides full cost recovery for the purchase of a wide range of supports including assistive devices, medical equipment and supplies, and home and vehicle modifications. All other jurisdictions only partially cover the costs of equipment, and the level of coverage varies from device to device. In Alberta, for instance, the Alberta Aids to Daily Living Program provides 75 percent of funding towards the purchase of certain devices, but only up to \$500 per family per year. Thus, for some families, significant costs are incurred.
- Finally, in some jurisdictions, there is a lack of cross-ministry program coordination resulting in confusion for families about who will extend reimbursement expenses. In Manitoba, for instance, there is often confusion about whether the Ministry of Family Service and Housing or the Ministry of Health will pay for a device. This occurs because some devices are funded through Children's Special Services in the Ministry of Family Services and Housing (i.e., communication devices), while many other devices (i.e., medical supplies and equipment) are funded through the Ministry of Health. Parents are often lost in this puzzle.

⁹⁷ Some provinces provide financial assistance only towards the purchase of *assistive devices* through the programs discussed in this section, but not for *medical supplies and equipment*. In these instances, families access support towards the purchase of medical supplies and equipment through in-home support programs, which are described in Appendix A, Table 6.

Although governments have made advancements in the provision of income supports to families raising a child with disabilities, more must be done. At the CPRN Roundtable discussion on May 3, 2001, participants confirmed that policies are often inflexible and non-portable. The rigidity of these policies presents ongoing difficulties for children and their parents, but it is especially evident during the numerous transition points in a child's life. It is at the moments in every child's life when their development changes that different supports are required. For parents of children with disabilities, these transition points are more pronounced and often demand significant changes in supports and services. Existing policies, however, are often not designed to respond to these transition points.

In summary, parents are being forced into hard choices about a number of matters. They must often choose between employment and caring for their children because affordable child care and other services are not available. The lack of income support involves choices that affect other children in the family, who will also live in poverty when family income is inadequate. In the long run, parents may be mortgaging their own future as well as that of their children, both those who are living with disabilities and those who are not. The effects of inadequate income will reverberate, for example, when pensions are calculated.

Parental Leaves

Supports available under provincial *unpaid* parental leave policies for birth and adopting parents have varied considerably across the country.⁹⁸ With the extension of paid parental leaves to a full year in 2001, provinces have been reforming their labour legislation to adapt to the new conditions.⁹⁹

For parents of children with disabilities, however, the provisions of parental leave do not meet all of their needs. Aside from the inflexible benefit periods, the criteria for parental leave are restrictive and often do not respond to the needs of parents with children who have ongoing care requirements or medical needs. British Columbia is the only jurisdiction that extends parental leave by up to five weeks (for a total of 40 weeks) for parents caring for a child with a physical, psychological or emotional condition.

The federal government extended *paid* maternity and parental benefits available under the *Employment Insurance Act* from six months to a full year, and the leave available to adoptive parents will triple, from 10 weeks to 35 weeks, as of January 2001. To receive benefits, however, parents must qualify under the rules of the Employment Insurance (EI) regime, and they only receive 55 percent of insurable earnings up to a maximum of \$413 per week. This could mean a significant loss of income for families if they do not receive a "top up" benefit through an employee collective agreement, for instance. Moreover, many do not qualify for benefits at all (due to insufficient hours of part-time work or self-employment, for example).

98 Unless otherwise noted, the substance of this section is taken from the CPRN Discussion Paper, *Two Policy Paradigms: Family Responsibility and Investing in Children* (2001) by Caroline Beauvais and Jane Jenson.

99 For details, see Beauvais and Jenson.

This extension of support is a step forward for parents but critics argue that more needs to be done. In particular, they assert that sick leave regulations in the *Act* should be made more flexible to allow parents of children with complex medical needs to take paid time off work to care for their children. The inflexibility of the rules attached to parental leave does not respond to the needs of parents who have children with complex medical needs or disabilities. Thus, they are forced to take time off work, often exhausting their paid sick leave and holiday time to care for their children. Moreover, as noted, the new EI regime excludes many workers, which significantly limits the ability of parents to access parental leaves.¹⁰⁰

Some provinces have begun to innovate in the area of *family* leaves, which has the potential to benefit parents caring for children with disabilities. As Caroline Beauvais and Jane Jenson note, family leave is a form of absence from employment that recognizes ongoing needs throughout a child's life. This can be used when a child is sick, to meet with teachers, and so on. British Columbia, Quebec and New Brunswick offer the most flexible family leaves, permitting family members to use them for a wide variety of purposes. Saskatchewan, however, is the province that has been most committed to extending family leave. To date, the program offers 12 weeks for medical emergencies only, but is seeking to make the program more flexible.

Although no concrete plans have been formally announced, in the 2001 *Speech from the Throne*, the Government of Canada also committed to move forward on this issue:¹⁰¹

The Government of Canada will take immediate action with its partners to improve the support available to parents and caregivers in time of family crisis. No Canadian should have to choose between keeping their job and providing palliative care to a child. The Government will take steps to enable parents to provide care to a gravely ill child without fear of sudden income or job loss.¹⁰²

The government has yet to concretely define this commitment. It appears to use the provision of palliative care provided to a child by parents or caregivers only as an example and, therefore, the commitment could include parents caring for a child with disabilities or complex medical needs. As the Roeher Institute notes in its study on low-income parents raising children with disabilities, all parents of children with disabilities require flexible unpaid and paid parental leave policies.¹⁰³ Juggling the demands of work and family are challenging for everyone, but these challenges are perhaps ever greater for parents of a child with a disability. If they are unable to secure necessary supports – especially time off work – then these challenges become insurmountable. Yet parental and family leave policies rarely acknowledge and respond to the fact that children with disabilities are often more vulnerable to sickness, may require frequent operations or appointments with medical specialists (i.e., physicians, physiotherapists, speech pathologists, and occupational therapists) and with social workers, community support workers and education professionals.

100 The Canadian Labour Congress reports that less than half of women who give birth are eligible for an EI benefit, a statistic that has remained constant since 1988. See Canadian Labour Congress, *Analysis of UI Coverage for Women* (Ottawa: Canadian Labour Congress, 2000), available at <http://www.clc-ctc.ca>

101 For details, see Beauvais and Jenson.

102 Government of Canada, *Speech from the Throne to Open the First Session of the 37th Parliament of Canada* (2001), available at http://www.sft-ddt.gc.ca/sftddt_e.html

103 Roeher Institute, *Finding a Way In*.

5.2 Effective Parenting

An adequate income is the first element needed to create positive child outcomes. The second is providing supports and services to enable effective parenting. Thus, our focus in this section is on policies that provide supports to families enabling them to live an ordinary life in the community.¹⁰⁴ At this point, a cautionary note is necessary. At the CPRN Roundtable, participants reminded us that parents of children with disabilities often feel blamed by society for their child's disabling condition. Of course, this societal blame is unfounded, but the results for parents and their children are real. As they try to live an ordinary life raising their children, they constantly get pushed back by negative attitudes and stereotypes that lead to exclusion from the community.

In this context, the category of effective parenting is broadly understood as a condition enabling positive child outcomes. It is not, therefore, used to classify service or program goals. Nor is the category meant to imply a judgement on the effectiveness of parents in caring for a child with disabilities. Instead, our focus is on existing policies and programs that provide assistance to families for effective family functioning. Finally, it is important to note that existing policies do not necessarily respond to all the concerns of parents caring for a child with disabilities. In particular, this section does not comprehensively discuss non-programmatic elements such as case management, information sharing, assistance through transitions, or networking. These factors play a key role in providing family support and enabling parents to live ordinary lives in the community. Our focus in this report, however, is on existing policies and programs.

In every jurisdiction, governments have created policies and programs to support children with disabilities living at home and in their communities. Since the 1970s, there has been a shift away from institutional care, towards community-based strategies. Parents, disability advocates, and professionals have applauded this move but the literature consistently demonstrates that children and parents frequently are not receiving the scope and level of support required.

In Section 3 of this report, we saw the diversity of provincial policy frameworks for children with disabilities and their families. This diversity is further reflected in the wide range of provincial programs designed to provide in-home supports and in-home and out-of-home respite care to families caring for a child with disabilities. The range of programs provided by the provinces in each of these areas is summarized in Tables 6 and 7. British Columbia, Ontario, and Quebec offer the greatest number of programs supporting children living at home, while the other provinces each have a single program coordinating the delivery of all supports and services. In some instances, a second, smaller program is in place providing special support services to rural areas, for instance (see Box 3).

¹⁰⁴ The conception of families in this section includes foster families. While foster homes illustrate a link between the public sector (through the child protection system) and private family arrangements, foster families nevertheless function as ordinary households, and therefore are should be understood as a family unit.

In-Home Disability Supports

As Table 6 describes, every province has at least one program designed to provide in-home supports to families who are raising a child with disabilities. As a response to criticisms from parents who often felt that professionals dominated decisions relating to the care of their children, some provinces (British Columbia, Manitoba, Ontario, and Newfoundland, for instance) are using a “family-centred” approach for determining the appropriate type and level of support required by the child and family. This approach privileges the needs of the child and family over strictly defined therapeutic or medical goals. Still, in other provinces (New Brunswick and Nova Scotia, for example), eligibility for certain aspects of these programs continues to be determined through income tests.

Despite some convergence toward programs that support children with disabilities who are living at home (see Section 3), there continues to be divergence on a number of elements including the administrative responsibility for programs (as well as the service delivery function), eligibility criteria, and the type and level of support provided to the family. A few provincial examples illustrate the issues:

- Manitoba’s program is an example of a “child and family centred” approach. The Children’s Special Services Branch of the Child and Family Services Division in the Ministry of Family Services and Housing is responsible for the policies, programs and services affecting the provision of in- and out-of-home supports for all children with disabilities and their families. The current policy framework is focused on the integration of children with disabilities into all aspects of community life. To that end, the range of the available supports for children and families includes counselling, information and referral, respite care, therapy services, supplies and equipment, home modifications, transportation, and training. Although the coordination and administration of these supports is contained within one branch of a single ministry, the delivery of these supports and services continues to be fragmented across a variety of service providers including local and regional ministry offices, regional health authorities, hospitals, specialized centres, school districts, contracted agencies, and community organizations. The division assigns a regional Children’s Special Services worker to assist families in navigating the complexity of the service delivery system. Nevertheless, the complexity can present difficulties and frustration for families trying to gain access to supports for their children. Further, the availability of services varies across the province, especially between urban and rural settings.
- Alberta’s program, Handicapped Children’s Services (HCS), which is the responsibility of the Ministry of Children’s Services, illustrates a unique approach among the provinces. The program does not provide services to families, but instead provides individualized funding and information and referral services so the family can access supports available in their community, primarily through a network of provincial Child and Family Services Authorities (CFSAs). To receive support at the regional level, every family must sign a *Handicapped Children’s Services Agreement*, which outlines the nature of services to be provided, length of time (to a maximum of one year, after which the Agreement must be renewed), as well as the family’s contribution (financial or otherwise).

While the program permits parents to purchase a wide range of supports and services, it operates under the assumption that the necessary supports are readily available at the community level. The recently established Provincial Standards, which guide the operation of CFSAs, will go some distance in ensuring that a comparable level of supports and services is available throughout the province. Nevertheless, the “demand-side” approach necessarily means that urban/rural discrepancies for example, have a greater potential to emerge.¹⁰⁵

- New Brunswick exemplifies a third style. All non-insured government programs – including those for children with disabilities – are subject to income testing. While the criteria have been relaxed in recent years, the government expects families to make some financial contribution based on net household income and ability to pay. If a family’s household income precludes their ability to pay, however, they are not denied services or supports. The Community Based Services for Children with Special Needs program is located within the Support and Maintenance Unit in the Ministry of Family and Community Services. Like other provinces, the program is designed to assist children with various disabilities from birth to age 19 years to live in community settings. The program targets children with severe physical, mental, intellectual, or emotional/behavioural disabilities and, in particular, children with multiple disabilities.

New Brunswick’s program also illustrates another common feature of disability policy across the country. Like many policies and programs targeting persons with disabilities, it has grown incrementally. It was established in 1986 to respond to the needs of children with developmental disabilities and their families when a provincial hospital for children was closed through a de-institutionalization program. Over the years, however, additional program areas have been added to the program to enable it to serve a greater number and diversity of children. However, the program’s budget has remained more or less constant. In addition, in 1997, rehabilitation professions were removed from the program, forcing parents whose children require the services of physiotherapists, occupational therapists, psychologists, and nurses to access them through the health care system, often in institutional settings. Because the program’s resources are stretched, there are long waiting lists. Such is the peril of incremental changes in policy, in which unanticipated consequences can create additional hardships.

In-Home and Out-of-Home Respite Care

In simple language, respite care allows the parent or caregiver to take a break from the demands of looking after a child with disabilities. An individual may come into the home to care for the child, or the child may be taken to a community-based institution for a short period of time. While respite care is consistently identified as underdeveloped across the country, it is also recognized as an essential support to enable families to continue to care for their child at home, in their own community. It is an area, however, hampered by policy and program gaps. Before proceeding, one caveat about respite care must be noted.

105 Some supports for children with disabilities, in particular assistive devices and home care support, are accessed through the Ministry of Health and its related Regional Health Authorities (RHAs). Data on children accessing home care is not available, however, because of the small numbers served by the program. Funding to RHAs, like CFSAs, is in one envelope and it is the responsibility of each Authority to coordinate local health services, based on the assessed needs of children with disabilities and their families in their geographic area.

Numerous CPRN Roundtable participants reminded us that respite programs should not be understood as a single solution for families. Instead, the need for respite care programs stems from the fact that families do not have access to required family supports. Indeed, the development of flexible and portable family-centred care and non-programmatic family supports such as networking, peer support, training, and assistance through transitions, would lessen the need for respite care programs. Nevertheless, respite care programs are evident across the country. As Table 7 shows, every province except Newfoundland has a community-based respite care program for families who are caring for a child with disabilities.¹⁰⁶ In British Columbia, Alberta, and Ontario, specific respite care programs have been created, while the other provinces integrate respite care supports into existing programs, especially in-home support programs (described above). A few provincial examples illustrate the different approaches:

- Saskatchewan is a good example of those provinces that integrate respite care supports into existing program areas. The Family Support program, for instance, provides a range of community-based services to parents raising a child with disabilities, but respite care has become the program's primary support mechanism. These supports are primarily delivered through two resource homes that are located in Regina and Saskatoon. Thus, access to the program is difficult for rural families. As described in Table 7 and Box 3, the Outreach Program is designed to respond to rural needs by providing funding to families to help offset the costs associated with purchasing these services at the local level. Some additional services are provided in rural areas through a network of group homes.
- Nova Scotia also integrates respite care supports into the in-home support program but, unlike Saskatchewan, some of these supports are subject to income-tests. The Services for Physically and Developmentally Challenged Children Program provides a range of supports to children from birth to 18 years who have been assessed and referred by a physician. Aside from being need-tested, the provision of some services are income-tested, wherein the program and family both pay for services based on a sliding scale formula. The program provides two categories of support – a range of support services such as respite care and supplies, as well as funding towards the purchase of extra supports. In addition, there is no consistent level of service provision across the province, especially for respite care, which greatly affects families living in rural areas. Nova Scotia does not have a targeted program for rural families.
- British Columbia and Ontario have created separate respite support programs. As Table 7 describes, British Columbia has three programs providing respite care supports to families. The Respite Services Program provides intermittent rest or relief for families with a child who has been assessed by a professional (i.e., doctor, psychologist, or social worker) and has a mental disability or autism. The At Home Program provides direct cash subsidies for parents of children with complex or multiple disabilities to purchase respite services. Finally, the Nursing Support Program provides professional nursing support services or respite services enabling children to participate in selected community settings, such as school and non-parental child care.¹⁰⁷ However, program overlap is not permitted.

¹⁰⁶ Respite care supports in Newfoundland are underdeveloped. If families are in urgent need of support, they must rely on institutional facilities.

¹⁰⁷ In other words, families receiving respite supports through the At Home and/or Nursing Support programs are not eligible for supports offered through the Respite Services program.

Respite care is a program area that needs immediate national attention. Despite some integration and coordination of services, respite care services are underfunded across the country. In 1997, Sherri Torjman of the Caledon Institute of Social Policy concluded that “while there is a great need for respite care to help families in caregiving roles ... the financial support is far from adequate and is actually declining.”¹⁰⁸

Recently, some jurisdictions have begun to respond to this crisis. In May 1999, the Ontario government announced \$17 million in annualized funding for respite care for children with multiple special needs. In 1999-2000, \$7 million was allocated to provide up to \$3,500 per child for families caring for a “medically fragile and/or technologically dependent child.” The government has promised that the remaining \$10 million will be spent in 2000-01 to create the Out-of-Home Respite Initiative, which will provide respite services for “children with multiple special needs requiring the greatest amount of care.”¹⁰⁹ Such announcements, however, must be considered within the context of policy and administrative change in Ontario and other provinces. As a recent study by the Roeher Institute notes, “it is safe to say that cutbacks to the medical system, agencies, and services, in general, have had a direct and serious impact on children with disabilities.”¹¹⁰ Thus, it is unclear if this targeted spending initiative is simply responding to gaps created by the overall cuts in health and social services through the 1990s.

Beyond their funding limitations, respite care programs have been criticized for their narrow and rigid eligibility criteria. Often, respite care policies do not take into consideration that, from time to time, families face emergencies. So, while the respite care program may be developed and delivered in a collaborative fashion – involving the family, the child, and the professional – it often does not allow for emergency or unexpected respite support. The reality is simply that it is not always possible for families to predict when they will need short-term respite services. Across the country, most respite care programs do not take this into consideration. For instance, programs do not allow families the flexibility to hire a family friend or relative to provide respite support. Introducing this type of flexible and portable support would go some distance in enabling families to lead ordinary lives in the community.

As well, most respite care programs have fixed eligibility criteria, which excludes a number of children and families who need support. Manitoba illustrates this situation. Ministry staff have found that a significant number of children with disabilities such as Fetal Alcohol Syndrome, alcohol related birth defects, and Attention Deficit Hyperactivity Disorder – *without* a developmental delay – do not meet the program’s eligibility criteria. These children and families are, in other words, ineligible for supports provided by the program, especially respite care, child development, and therapy supports. Ministry staff have identified this gap as a priority and a review is underway examining the types of services required, and the potential costs.

108 Sherri Torjman, *Desperate for Respite* (Ottawa: Caledon Institute of Social Policy, 1997), available at <http://www.caledoninst.org/full69.htm>

109 See Government of Ontario, Ministry of Community and Social Services, *\$10M Out-of-Home Respite Initiative*, available at <http://www.gov.on.ca/CSS/page/news/sept1200fs.html>

110 Roeher Institute, *Finding a Way In*.

Mental Health Supports and Services

Among all individuals with disabilities, those with mental health conditions face the greatest amount of stigma.¹¹¹ Individuals with mental health problems often face personal and systemic attitudes of rejection, exclusion, isolation and prejudice. For children and youth, these stigmatizing attitudes have a direct impact on their ability to learn and socialize in school, participate in recreational activities, and enjoy the full benefits of community life. Like all families caring for children with disabilities, families caring for a child with a mental health concerns require a variety of supports. Assessment and intervention services, in-home supports, respite care, and education supports are especially important to ensure positive child outcomes. This package of supports, however, is not necessarily available in all jurisdictions.

Further, as participants at the CPRN Roundtable noted, children with mental health conditions usually come from families who have a parent or parents with similar types of conditions. The compounding nature of this situation means that a different set and range of interventions and approaches are required to meet both the child's and the family's needs. In particular, a family-centred approach – rather than the more medically defined child-centred approach – is necessary to ensure positive outcomes for the entire family unit.

This review confirms that mental health supports and services for children and youth with disabilities and their families are inconsistent across the country. As Tables 6 and 7 illustrate, some jurisdictions allow families caring for children with mental health problems to apply for supports provided through in-home support and respite care programs. As noted above, however, these programs are often underfunded, rendering these supports unevenly available. Nevertheless, most provincial governments have also created a specialized mental health program. As Table 8 describes, every province except Newfoundland has a program extending at least partial community-based mental health supports and services to children and youth with disabilities. Among these programs, however, there is virtually no consistency. Instead, the type, level and scope of support varies within jurisdictions and across the country. Thus, these provincial programs are best characterized on a spectrum.

At one end, British Columbia has recently announced a new community-based strategy known as the Provincial Child and Youth Mental Health Plan. In an attempt to achieve greater integration and coordination, the government transferred responsibility for children's mental health services from the Ministry of Health to the Ministry of Children and Families. Further, the mission of the new policy framework is to ensure that child and youth services are "family-centred" and to promote and protect the healthy development of children and youth while recognizing their lifelong attachment to family and community. At the other end of the spectrum is Newfoundland, which does not have a program offering community-based services. Instead, children and youth with mental health conditions must access supports through a family physician or provincial hospital. The Ministry of Health has recently announced that it will hire a mental health consultant to coordinate all mental health programs, including those directed towards children.

111 The report does not include children with mental illness. Participants at the CPRN Roundtable observed that this group of children and their parents require a distinct set of interventions and approaches, which are beyond the scope of this investigation.

Prince Edward Island falls somewhere between the two ends of the spectrum. Until recently, it did not have community-based supports for children and youth with mental health conditions. Recent changes have been implemented to expand the availability of community- and school-based mental health supports. In response to recommendations from a Children's Mental Health Forum, the ministry established a multisectoral, province-wide Children's Mental Health Coalition and provided funding for the first phase of a Children's Mental Health Initiative. The Initiative will focus on developing a regional network of mental health clinicians in order to initiate a comprehensive approach to addressing children's mental health issues. The network is supported by a multi-agency coordinating committee comprised of government ministries (Health, Education and Justice) and regional or community non-governmental organizations.

Alberta has also been developing a new policy framework for children's mental health services. A provincial Children's Mental Health Design Committee, co-led by the Alberta Mental Health Board and the Ministry of Children's Services, has been established. It has identified regional priorities and established a three-year action plan to improve children's mental health services in the province. The action plan, known as the Children's Mental Health Initiative, was accepted by the government in the spring of 1999. It identified short-term recommendations for implementation including new funding and activities for incorporation in the broader provincial mental health board business planning process, as well as a series of long-term recommendations. In fiscal year 1999-2000, the government announced \$5 million of new funding for regional Alberta Mental Health Board offices. This funding is targeted to priorities identified in the early stages of the initiative but is to be refined according to regional needs.

Children and youth mental health policy is also under review in Nova Scotia. In May 2000, the Mental Health Review Advisory Committee to the Minister of Health released its report, *Mental Health: A Time for Action*. Among its recommendations, the Committee identified children and youth mental health services as a priority. The Committee found that confusion and a lack of cooperation between the Ministries of Community Services and Health were causing significant problems for children and families. While the Ministry of Community Services is mandated by legislation to ensure that treatment services are provided where there is an identified need, the *Family and Children's Services Act* does not mandate ministry staff to provide any treatment or supports. Thus, the ministry turns to the mental health services branch of the Ministry of Health for assessment and treatment services. The Committee reports that this has led to considerable "discrepancy between the expectations of the Department of Community Services for mental health assistance for children and the mental health program's ability to provide services."¹¹² The Minister responsible received the Committee's report but, as yet, has not released a response to its recommendations.

Although, administrative arrangements have created barriers for children and families, the lack of availability of services at the community level poses an even greater barrier. Ontario illustrates this problem. The Children's Mental Health Services program is the joint responsibility of the Ministries of Health and Long Term Care (MOH) and Community and Social Services (MCSS).

112 Mental Health Review Advisory Committee, *Mental Health: A Time For Action*, submitted to the Deputy Minister of Health (Halifax: Ministry of Health, 2000): 12.

The MOH retains responsibility for in-patient and out-patient care in general and psychiatric hospitals, and children's mental health services (provided in OHIP-funded hospitals and by physicians) are funded by the MOH under the *Mental Health Act*. Children's mental health programs are funded under the *Child and Family Services Act* as child and family intervention or child treatment services. Approximately 90 Children's Mental Health Centres (CMHCs) provide child and family intervention services, which are designed to alleviate a range of social, emotional, or behavioural problems experienced by children up to age 18 and their families. Children and families are referred to these services by schools, family physicians, police, children's aid societies, young offenders programs, and others in the community.

Parents are also able to directly access most of these services for their children. Long waiting lists, however, make it difficult to access these services in a timely manner. In 2000, Children's Mental Health Ontario – a nonprofit, independent organization representing Children's Mental Health Centres – reported that 7,000 children and families were on waiting lists for service. The average waiting period was six months.¹¹³ The government has sought to respond to this situation. In the 1999 budget, for instance, the government announced a \$10 million allocation in the 1999-2000 fiscal year to enhance children's mental health services and increase access. Critics argue that more funding is necessary.

Despite these complexities, in some provinces, children with autism or autistic-like tendencies have become a priority. Autism is a congenital developmental disorder present at birth, which is characterized by problems in three areas – social development, communication, and behaviour. It is often very difficult for families with an autistic child to manage their complex needs. As Box 4 describes, British Columbia, Manitoba, Ontario, Nova Scotia, Prince Edward Island and Newfoundland have responded with special initiatives directed at assisting families with an autistic child or a child with autistic-like tendencies.

Citing various federal and provincial studies and initiatives, Rianne Mahon notes in the CPRN study *School-aged Children across Canada: A Patchwork of Public Policies* that improved mental health services for children has been an area of concern since the 1980s.¹¹⁴ Despite this attention, however, we continue to have an incomplete picture of children's mental health. The Canadian Institute of Child Health reports that there is insufficient national and provincial data available on the mental health and well-being of school-aged children. Researchers found that data is "hidden" in difficult to access, non-standardized systems such as school systems and hospitals. As a result, the Institute suggests that there is very weak "evidence picture" of the mental health and well-being of school-aged children.¹¹⁵ These gaps are creating barriers for the children and families who need supports and services.

113 Children's Mental Health Ontario, *Issues & Information* (2000: 3), available at <http://www.cmho.org/Issues.shtml>

114 Mahon, *School-aged Children across Canada*, 33.

115 Canadian Institute of Child Health, *The Health of Canada's Children*, 3rd ed., 224.

5.3 Supportive Community Environments

The third enabling condition required for positive child outcomes is supportive community environments. Sharon Stroick and Jane Jenson observe that:¹¹⁶

Good parenting is easier in supportive community environments, where health and development resources are available for infants and toddlers, where recreation and cultural programs for young children are accessible, and where children are safe to play and participate in enriching activities.

The notion of a supportive community environment includes a number of components and involves a variety of policy and investment choices by community groups, employers and governments. At its foundation, however, a supportive community environment must provide full access and participation for *all* children – including those with disabilities – and their parents and siblings. This means more than simply offering inclusive services such as child care, education and recreation, but extends to such things as the construction of a fully accessible built environment so *all* children can go to shopping centres or movies, attend swimming lessons at the community pool, and so on. A supportive community environment also means providing parents caring for a child with disabilities with non-programmatic supports such as parent networking, training, brokerage, information, and peer support. An important component of full citizenship is ensuring that parents themselves have full access to the communities in which they live and work.

Resource and space constraints do not permit a consideration of non-programmatic elements in this report.¹¹⁷ Instead, an assessment of supportive community environments is limited to supports and services provided by provincial governments. A review of Tables 9 through 12 demonstrates that, for preschool and school-aged children with disabilities, there is a gap in the provision of supportive community environments. Some advances have been made in supporting the development of preschool children with disabilities, especially in early childhood development policy and programs (see Box 1 and Table 3), but significant gaps and barriers remain for school-aged children with disabilities and their parents. As Tables 11 and 12 document, school-aged children have access to language and health programs in most provinces, yet two of the major areas that affect school-aged children and their citizenship are still not achieving sufficient attention.

We will look at access to inclusive education and recreation as key areas here. In addition, parents of preschool and school-aged children still confront problems accessing non-parental child care. We will find that barriers persist because many generic policy frameworks are not inclusive, and those that are conceived as inclusive continue to *exclude* children because of administrative loopholes, insufficient funding and negative attitudes. As discussed below, this is especially evident in the areas of child care, education and recreation.

¹¹⁶ Stroick and Jenson, *What is the Best Policy Mix for Canada's Young Children?*, 91.

¹¹⁷ For a useful discussion and analysis of peer support networks in supporting children with disabilities, see Deborah Gold, "We Don't Call It a 'Circle': The Ethos of a Support Group," *Disability & Society* Vol. 9, No. 4 (1994): 435-452.

Inclusive Child Care

In this report, child care is understood as a multi-faceted service providing three key elements: (1) a labour adjustment strategy; (2) respite for parents; and (3) a developmental opportunity for children. It is estimated that, in 1996, most Canadian child care centres supported some children with disabilities, some of the time. However, inclusion was achieved only on a centre-by-centre and child-by-child basis.

The decision to include or exclude a child is the responsibility of the individual day care provider. There is neither a standardized eligibility process, nor an appeals process. Thus, children are excluded from integrated child care settings on a discretionary basis.¹¹⁸ This finding is supported by research, which found that, in 1991, 12 percent of children aged 4 years and under who had disabilities were refused access to inclusive child care settings.¹¹⁹

Finally, the programs in place privilege access to inclusive child care for preschool children with disabilities. Very few programs provide services for older children who may require before- or after-school care.¹²⁰ Thus, parents are forced to incur additional expenses and attempt to secure private care arrangements. The federal government does provide some relief through the Child Care Expense Deduction, but for parents of children with disabilities more must be done.

In their comprehensive study of inclusive child care in Canada, *A Matter of Urgency*, Sharon Hope Irwin, Donna S. Lero and Kathleen Brophy found significant variation across the country concerning the inclusion of children with special needs in child care settings. In addition, they found a general lack of training among child care providers. As they note, this is perhaps not surprising, given that there is no legislative framework that requires child care providers to include children with disabilities. To begin redressing this gap, their report calls on federal-provincial-territorial governments to “develop and adopt policy frameworks and adequate funding programs related to the inclusion of children with special needs and their families with goals, targets, timetables, and follow-up mechanisms that can be used to assess progress.”¹²¹

To date, however, governments have relied on voluntary measures and provide only modest incentives to child care providers through financial grants. As Table 9 reveals, every province offers grants to child care providers who choose to integrate children with disabilities into their facilities and programming. The funds available through these programs, however, do not come close to meeting the actual costs involved. In British Columbia, for instance, the Supported Child Care Program provides a monthly a maximum grant of \$107 to assist in financing extra supports for integration. In Prince Edward Island, the Special Needs Grant provides extra funds to child care providers, enabling them to hire extra staff to support the inclusion of children with disabilities. The benefit level provided, however, is capped at \$10 per hour. Given the poor salaries often paid, concerns have been raised about the level of training among staff caring for children with disabilities.

118 Irwin and Lero, *In Our Way*.

119 Roeher Institute, *Labourforce Inclusion and Parents of Children with Disabilities* (Toronto, 1999).

120 See Mahon, *School-aged Children across Canada*, 23.

121 Irwin, Lero, and Brophy, *A Matter of Urgency*, 168.

Often, child care facilities are not physically accessible. This is perhaps not surprising given that none of the provinces have legislation mandating architectural accessibility for these facilities. Further, only Quebec and Manitoba provide funding for architectural modifications of child care facilities. Quebec's program, *Subvention pour l'intégration d'un enfant handicapé* (Subsidy for the Integration of a Child with Disabilities), provides a maximum of \$1,629 for child care providers towards the costs associated with structural modifications that foster inclusion. In contrast, Manitoba's Community Places program provides 50 percent of costs (to a maximum of \$50,000) towards the upgrading of child care facilities in making them accessible for children with disabilities.

Inclusive Education

Most parents view inclusive public education for children with disabilities in regular classrooms as an entitlement associated with full citizenship rights.¹²² The concept of inclusive education requires students with disabilities to be educated in regular classroom settings with their same-age peers, with the provision of appropriate supports and services that are responsive to the student's individual needs in the least restrictive environment. Diversity in the classroom is not viewed as an obstacle, but instead as an opportunity to enrich school settings. Writing in the mid-1980s, Robert Gall summarized special education in Canada in the following manner:¹²³

While some collective progress toward the provision of full and appropriate educational rights for special needs children can be observed nationally, the sporadic and piecemeal nature of this evolution begs for explanation. While the physical integration of special needs students into many facets of regular Canadian school life is becoming accepted, such achievements have been accomplished at a snail's pace and are largely devoid of commitment. Related issues such as early childhood education and teacher training are considered regional, not national, problems. A variety of practical problems, including attitudinal barriers and administrative resistance, continue to hinder the Canadian ideal of unrestricted equality of educational rights.

Although Gall was writing more than 15 years ago, his assessment applies equally to the contemporary period. Despite the fact that at the international level, Canada – along with the United States – has been a leader in advancing the notion of inclusive education, recent studies on special education indicate that special education policy and practice are inconsistent across the country. This creates a situation that imposes significant hardships upon many Canadian children and their families. In short, too many children are being excluded from regular classroom settings because of attitudinal, administrative, and funding barriers. Indeed, interpretations of inclusive education vary across the country. These variations mean that there is no standard for inclusive education – its meaning changes in different provinces, in different school boards, and in different schools. Some recent evidence illustrates this point.

122 Roeher Institute, *Beyond the Limits*, 7.

123 Robert Gall, "Special Education in Canada: An Analysis of Major Contemporary Developments," in N.J. Marlett, R. Gall and A. Wight-Felske (eds.), *Dialogue on Disability: A Canadian Perspective* (Calgary: University of Calgary Press, 1984): 28-29.

The Canadian Coalition on the Rights of the Child reports that “the implementation of the commitment to integrated education varies across the country.”¹²⁴ A joint study by the Canadian Association of School Administrators and the Canadian School Boards Association found that various new legislative frameworks that embrace inclusion and integration have been put in place in several provinces, but the extent to which inclusion is achieved varies from school system to school system, and province to province.¹²⁵ In their study of the well-being of children and youth, the Canadian Institute of Child Health concluded that “families with children with disabilities are facing cutbacks in teaching assistant and teacher-training for inclusion – and shorter school days for children with disabilities.” Moreover, “cutbacks in related services funded under Health and Social Services have further reduced access to education for children with disabilities.”¹²⁶

Children may, in fact, be included in regular classroom settings, but often they are not provided with the appropriate supports and services that are responsive to the students’ individual needs. In other words, a child with low vision may be in a regular classroom, but not have adequate access to Braille instruction due to a shortage of itinerant teachers.

The Roeher Institute, in its recent study of mothers caring for children with disabilities, identifies a disjuncture between provincial-level special education policy statements and local-level practice in school settings. Three situations illustrate this finding:

- Parents were dissatisfied with their child’s education because of a perceived lack of responsiveness and commitment to inclusion policies on the part of the teachers, administrators or school districts. This translates into a lack of physical and human resources for supporting children in the classroom.
- Parents must consistently advocate on their children’s behalf to secure the needed supports and acceptance. On average, parents spent 14 hours per week advocating for and coordinating supports, providing supports themselves, and providing transportation related to their children’s education.
- Parents contend that positive attitudes among education professionals towards full inclusion and integration are necessary for success.

Provincial examples illustrate these situations, especially the disjuncture between special education policy and practice.¹²⁷

124 Canadian Coalition on the Rights of the Child, *How Does Canada Measure Up?* (Toronto, 1999). This report is a monitoring update on Canada’s record in meeting its obligations under the *United Nations Convention on the Rights of the Child*.

125 Canadian Association of School Administrators and the Canadian School Boards Association, *Toward Inclusion: Improving Education for Students with Special Needs* (Ottawa, 1998).

126 Canadian Institute of Child Health, *The Health of Canada’s Children*, 3rd ed., 248.

127 Although Nova Scotia is not used as an example in this section, in its 2001-2002 Budget, the government committed an extra \$3 million for special education. See <http://www.gov.ns.ca/finance>

In Alberta, the Ministry of Learning's special education policy framework supports the inclusion and integration of children with special needs in the classroom. Local school authorities, however, rely on an assessment provided by the individual principal in determining if a child is included in regular or segregated classrooms. Given the tremendous funding constraints faced by school boards, and an overall lack of supports available in educational settings, the possibility for excluding children with disabilities from regular classrooms is great.

Ontario's special education policy also allows many school boards to exclude children with disabilities, forcing them into specialized, segregated settings. The *Education Act* and its accompanying regulations do not demand the inclusion of children with disabilities in regular classroom settings. Instead, the *Act* requires that school boards provide students who have special needs with special education programs and services that are deemed "appropriate to their needs." The government argues that it has responded to the needs of local schools boards by increasing funding to special education over the past two fiscal years. This funding increase has been eclipsed, however, by broader changes to education in the province – in particular, overall funding reductions. From 1995 to 1997, the government removed \$1.4 billion from the entire education and training system. Studies demonstrate that these reductions have indeed affected special education programs.¹²⁸ For example, in September 1999, the Ontario government told parents of children with disabilities to keep their children at home until the necessary teaching assistants were hired.¹²⁹

The newly introduced education funding formulas in Ontario, including the formulas applied to special education programs, have also been cited as a problem area.¹³⁰ A new funding formula requires each school board to submit an Intensive Support Amount to the ministry for each child with a disability. These applications are then used to determine the level of support provided to the school board.

Studies have shown, however, that difficulties are arising from the complex funding formula that supports the special education system, and that time and resources are now being directed toward administrative requirements rather than classroom teaching.¹³¹ In addition, there are reports that parents are concerned that the model is medically-based, resulting in negative, deficit views of children that meet the narrow funding eligibility criteria.¹³²

128 Anne O'Connell and Fraser Valentine, *Centralizing Power, Decentralizing Blame: What Ontarians Say About Education Reform*, The Speaking Out Project (Toronto: Caledon Institute of Social Policy, 1998), available at: <http://caledonist.org>. The parent advocacy organization, People For Education has reported that there are some 35,000 children on waiting lists for special education services in Ontario elementary schools. See People For Education, *The Tracking Report 2000: The Effects of Funding and Policy Changes in Ontario's Elementary Schools* (Toronto: People For Education, 2000), available at: <http://www.peopleforeducation.com/tracking.html>

129 Canadian Institute of Child Health, *The Health of Canada's Children*, 3rd ed., 248.

130 For an overview of changes in education policy, see O'Connell and Valentine, *Centralizing Power, Decentralizing Blame*, 1998.

131 Jim Bradt and Noreen Hardwick-Leclerc, *Special Education in Ontario: Do We Care Where We're Going?* (Ottawa: Caledon Institute of Social Policy, 2000); Jim Bradt and Noreen Hardwick-Leclerc, *Special Education Funding in Ontario: Bugged Down in Claims* (Ottawa: Caledon Institute of Social Policy, 2000).

132 Roeher Institute, *Finding a Way In*, 31.

In January 2000, the Ontario government announced several initiatives for improved quality and accountability in special education. In particular, the government has implemented Individual Education Plans, which seek to encourage more student-parent-advocate input into education planning. This approach is viewed as a key to accountability, ensuring that supports are provided, curriculum is modified as needed, and resources are in place. The government is currently setting provincial standards for Individual Education Plans, as well as auditing existing student plans.¹³³

Prince Edward Island illustrates another situation in this area. The province has only recently begun to shift its special education philosophy from a segregated system to an integrated system in which students with special needs are included in regular classrooms. A Minister's Directive on Special Education provides the policy framework for special education services. It mandates that school boards deliver educational supports and services to children with special needs. That said, the Directive provides an imprecise definition of "special needs," which has led to confusion among school boards concerning eligibility criteria, resulting in uneven service delivery for students. In September 1988, the Department of Education received the *Final Report of the Review of Special Education Committee*. The Committee mandate was to revise and update the special education policy framework. To that end, it made some 40 recommendations. The province has made no formal response to the Committee's report but, in its most recent Annual Report, states that "work has commenced on the development of draft policies, preliminary definitions, and foundation philosophies."¹³⁴

New Brunswick has the strongest inclusive special education policy in the country. Unlike other jurisdictions, which permit school boards to exclude children "where appropriate," New Brunswick requires, by law, the inclusion of all children with disabilities into regular classroom settings. Special Education is the responsibility of the Student Services Unit of the Curriculum Branch in the Ministry of Education. The ministry is mandated through legislation to offer educational opportunities to every individual in the province between the ages of 6 and 20 years. To facilitate integration, students with special needs are eligible for programs and services that are funded by the ministry, administered by School Authorities and Regional School Districts, and delivered by local school boards.

Some additional supports in school settings are available to students in the public education system who have physical, perceptual, behavioural, communication or intellectual disabilities through the Support Services Education Program, established in 1988. The Ministry of Family and Community Services, the Ministry of Health and Wellness, and the Ministry of Education collaborate to provide health-related supports such as occupational therapy, physiotherapy, speech and language therapy, nursing care, and social work services. Finally, extra resources for students who are deaf or hard-of-hearing and for students who are blind or visually impaired are available through the Atlantic Provinces Special Education Authority.

133 The ministry announcement and background information on Individual Education Plans is available at <http://www.gov.on.ca/eng/document/nr/00.01/improve.html>

134 Department of Education, *Annual Report, 1999* (Charlottetown: Ministry of Education, 2000): n.p., available at <http://www2.gov.pe.ca/educ/reports/educ/english.asp>

As Table 10 shows, the provision of education supports by schools to accommodate children with disabilities is a common approach across the country. Yet, as Tables 11 and 12 illustrate, some types of supports and services (which a child may use in an educational settings) are accessible only through programs located in different ministries. Some families must access speech and language programs as well as rehabilitation services through programs provided by ministries of education or health or social services. Compounding the administrative complexities, these supports do not necessarily guarantee full or even partial inclusion. Instead, they focus primarily on therapeutic or rehabilitative interventions (i.e., speech therapy, occupational therapy, physiotherapy). In most cases, these are the responsibility of education ministries, but are delivered through regional health authorities or regional ministry offices. The exception is in British Columbia, which is the only jurisdiction that provides integrated education supports for schools from other than a ministry responsible for education.

Thus, in British Columbia, three programs providing school-based services and supports are the responsibility of the Ministry of Children and Families (occupational therapy services, physical therapy services and audiology services¹³⁵). The result for parents of children with disabilities is that educational supports are an *integrated* component of the overall policy framework.

The Atlantic Provinces Special Education Authority (APSEA) is unique in the country. It involves an inter-provincial cooperative agreement to provide education supports to children with low-incidence sensory impairments. Established in 1975 by a joint agreement among the Ministers of Education in New Brunswick, Nova Scotia, Prince Edward Island and Newfoundland, APSEA provides educational services, programs and opportunities for persons from birth to 21 years of age who are residents of Atlantic Canada and who are deaf, deaf and blind, hard of hearing, blind, or visually impaired. It is governed by – and overall policy and planning is the responsibility of – a 12 member Board of Directors, with three members from each province.¹³⁶ Under the Agreement, school boards are recognized as the direct educational service providers for all school-age children. When school boards require assistance in providing for children with low-incidence sensory impairments, APSEA supports a service delivery system that assists in meeting the educational needs of those children. Thus, services vary from province to province. Services for preschool children with a diagnosed or suspected hearing loss, for instance, are only available under APSEA in New Brunswick and Nova Scotia.

The complexity of special education policy and the disjuncture between policy and practice have not gone unnoticed by numerous provincial jurisdictions. In the year 2000 alone, for instance, no less than five provinces (British Columbia, Alberta, Saskatchewan, Manitoba, and Prince Edward Island) undertook comprehensive reviews of special education policies and programs. Tracking government action on these recommendations, however, is challenging. Two examples help to illustrate this situation.

135 The Ministry of Health provides 20 percent of the funding for the audiology services program, while the Ministry of Children and Families is responsible for the program, which is administered by Regional Public Health Clinics.

136 The Deputy Minister of Education from each province is a permanent member of the Board. The two additional members from each province are appointed by the Lieutenant Governor-in-Council for two year terms.

In September 1998, the Saskatchewan government established the Special Education Review Committee to examine special education policy and programming. The Committee's final report, *Directions for Diversity: Enhancing Supports to Children and Youth with Diverse Needs*, was submitted in January 2000 and publicly released in April 2000. The Committee recommended that the government fully adopt the philosophy of inclusive schools, accelerate integrated services, support the development of comprehensive services, increase resources, and enhance accountability measures. In response to the Committee's report, the Ministry of Education released *Strengthening Supports* in October 2000. The government committed to the development of a comprehensive policy for supporting children and youth with diverse needs. Although still in development, the government has made it clear that the policy will articulate a vision, guidelines for effective practices, strategies to enhance family and community partnerships, and strategies for enhancing board capacity in determining program effectiveness.

Similarly, in March 1999, British Columbia's Minister of Education announced the formation of a Special Education Review Team to examine and make recommendations on special education policy in the province. In its final report, the Review Team made 40 recommendations and concluded that, while there is strong support for the policy of inclusion, the policy is not uniformly understood or implemented by school boards or districts, and that coordination among service providers needs to be improved.¹³⁷ The government is in the process of developing a response to the report, as well as implementation plan.

In summary, there is universal commitment among the provinces to the inclusion of children with disabilities in regular classroom settings, yet a variety of administrative loopholes allow school boards or local school officials to deem children "inappropriate" for inclusion and integration. The result is impeded access for children to regular education, which reinforces the exclusionary practice of placing children with disabilities in specialized, segregated settings. Further, in several provinces, this situation has been exacerbated by changes to and funding reductions in generic education policies and programs. All of these changes have resulted in an imprecise picture of the current situation facing children with disabilities and their parents.¹³⁸ Nevertheless, there is good evidence suggesting that where legislation is in place, as in New Brunswick, greater integration is achieved.

137 Linda Siegel and Stewart Ladyman, *A Review of Special Education in British Columbia* (Victoria: Ministry of Education, 2000).

138 Academic scholarship is essential in filling in some of the knowledge gaps, but contemporary research on special education remains unavailable. The journal *Education Exceptionality Canada* is publishing a special edition in the Summer 2001 (edited by Professor Vianne Timmons, Faculty of Education, UPEI), highlighting each province's and territory's approach to services for children with special needs.

Inclusive Recreation

Providing access to recreational facilities and including children with disabilities in leisure activities is central to fostering full citizenship. As the Roeher Institute notes, this kind of inclusion can take a variety of forms. Good examples are participating in community activities such as bowling, swimming, soccer, music, dance lessons, karate, and gymnastics; participating in groups like Scouts and Guides; and accessing facilities such as libraries, community recreation centres, and youth centres. Another important element is the ability of children with disabilities to attend summer camp, day camp, swimming lessons, and the like.¹³⁹

Given that recreation facilities and programs are the responsibility of municipal governments, measuring the inclusiveness of such facilities and programs is difficult. To do so would require a complete national inventory. Nevertheless, provincial governments can play an important role in supporting recreational inclusion goals. Thus, we can look to provincial-level programs supporting recreational inclusion as an indication of the situation. Unfortunately, there is little progress to report.

The policy and program scans in Appendix A do not include recreational programs for children with disabilities because none of the provinces have a designated program. Some provinces such as Manitoba have programs (funded using provincial lottery earnings) to help offset the costs of modifications to create physical accessibility for recreational facilities. The Community Places program, for instance, provides 50 percent of the costs (up to a maximum of \$50,000) towards the upgrading of playground structures and recreational facilities to make them accessible to children with disabilities. While this program addresses a vital component of full inclusion, there is no provincial program that fosters or supports the development of inclusive recreational programming. Thus, such supports are available on a piecemeal basis, which varies considerably both within a single provincial jurisdiction and across the country.

It is important to note that many provincial governments do provide funds to support voluntary organizations providing recreational activities and programs to children with disabilities. While many of these programs are only offered in segregated settings such as disabled swimming lessons, horseback riding and day camps, non-profit organizations play an important role in this sector. CPRN Roundtable participants noted, however, that increasingly, it is a role under stress as governments reduce funding support to the voluntary sector. Moreover, participants noted that, in many instances, parents have no choice but to place their children in segregated recreational settings because it is the only option available in their community. This situation bolsters the availability of segregated programs and reinforces the sense that children with disabilities are not valued as full and active members of our communities.

139 Roeher Institute, *Beyond the Limits*.

6.0 Barriers to Full Citizenship

Canada has committed itself to fostering full citizenship rights for persons with disabilities through a variety of domestic and international instruments. The *Canadian Charter of Rights and Freedoms* and the *Canadian Human Rights Act* form the foundation of this commitment. At the international level, the Government of Canada made a firm commitment to the rights of all children, including those with disabilities, when it signed the *United Nations Convention on the Rights of the Child*.

This Convention is an international legal instrument, which establishes standards for the realization of children's civil, political, economic, social, and cultural rights. The Convention was adopted by the United Nations in November 1989 and has received significant support from the world community. Canada ratified the Convention in 1991 and, in so doing, bound all governments and members of Canadian society to the principles, goals and standards set out in the document.

The Convention also recognizes the additional supports required by children with disabilities, above and beyond those promised to non-disabled children. Article 23 of the Convention states:¹⁴⁰

Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph two of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.

Canada has set a high standard. It demands nothing less than full citizenship for children with disabilities and their families. The concept of full citizenship extends *rights* to individuals (and groups) and demands *responsibilities* in return. At the same time, it involves making these rights and responsibilities real and realizable by ensuring *access* to work, education, technology, and social protection. It is only in this way that citizenship will include a meaningful sense of *belonging* and we can then say that full citizenship exists. The policy and program scans in Appendix A confirm, however, that there is significant work to do in realizing this goal for children with disabilities, their parents and siblings.

140 United Nations, *United Nations Convention on the Rights of the Child*, G.A. Res 44/25, Annex 44, U.N. GAOR Supp. (No. 49) at 167, U.N. Doc A/44/49 (1989).

Positive child outcomes, and therefore the grounding for full citizenship, are achieved through a combination of three enabling conditions: adequate income, effective parenting, and supportive community environments. Using these criteria, this review demonstrates that, while some provinces have made gains, there is no coherent vision within each or across all jurisdictions for achieving the best possible policy mix and, thereby, enabling the full citizenship of children with disabilities and their parents. In addition, there is no focused attention paid to the particular needs of parents caring for a child with disabilities.

This study reveals that four areas in the children's policy and disability policy sphere need immediate attention. These are: (1) the lack of political will to make school-aged children with disabilities a priority for governments; (2) unclear and contradictory policy goals; (3) policy-practice gaps; and (4) intra- and inter-jurisdictional discrepancies. Each of these challenges will be discussed in turn.

6.1 Making School-aged Children with Disabilities a Priority for Governments

This research confirms that school-aged children with disabilities and their families are not a priority for governments. Although some provinces – in particular British Columbia, Alberta, Quebec and Saskatchewan – have made recent gains, in general, there is a patchwork of sectoral policies, programs, funding mechanisms, and services that are complex, fragmented, largely uncoordinated, and underfunded.

The result for children with disabilities and their parents is a frustrating situation of gaps and overlaps in services, and of care provisions that often vary within provinces and certainly across the country. Moreover, certain necessary ingredients for achieving full citizenship are often not considered as a component of the policy sphere and are therefore overlooked. This is especially evident concerning the access and belonging of parents caring for a child with disabilities. All parents require support from generic systems, but parents of children with disabilities require additional supports that are flexible and portable and have as their goal full participation and inclusion in the community. Currently, this is not the case. As the previous section described, unpaid and paid parental benefits and family leaves require immediate attention, as does the fact that children with disabilities are much more likely than other Canadian children to live in poverty. This is because their parents may have difficulty holding a job and caring for them, or because of the extra costs required to adequately provide for a child with disabilities.

Further, the exclusion of children with disabilities and their families from generic child care, as well as from inclusive education and recreation, hinders their achievement of full citizenship. Inclusive and integrated approaches in each of these areas do not exist everywhere as yet. Access to child care, educational settings and recreational facilities and programs are all central components of a full and healthy life. Aside from creating inclusive legislative frameworks, the realization of this goal depends on the provision of adequate funds – including funds directed to school boards and municipalities, as well as funds provided to service-providing agencies in the voluntary and private sector.

6.2 Unclear and Contradictory Policy Goals

Across the country, and even within a single jurisdiction, the mix of programs addressed to children with disabilities and their families is based on unclear and contradictory policy goals. Some policy frameworks, primarily those located in ministries of health, understand disability as an individual pathology requiring treatment, rehabilitation and passive care. These medical diagnoses of disability subsequently determine who is deemed as legitimately “disabled” and, therefore, entitled to certain programs and services. This is especially evident in the financial support available to families toward the purchase of assistive devices (Table 5), education supports (Table 10), speech and language programs (Table 11), and individual health and rehabilitation services (Table 12).

Another set of policy frameworks are primarily located in ministries of social services, and they tend to frame disability as a human condition and experience requiring accommodations and supports to enable active participation in community life. These more inclusive approaches are evident in policies and programs for early childhood development (Table 3 and Box 1), in- and out-of-home supports (Table 6), respite care (Table 7), and grants for child care providers to provide inclusive child care (Table 9). Yet these programs are often underfunded, resulting in long waiting lists, and often suffer from problems with service delivery coordination and integration.

The incremental development of the disability policy sphere explains, in part, the presence of contradictory policy goals. This situation, however, is much more than an academic curiosity. For a child with a disability and his or her parents, these contradictory policy goals present a significant barrier to the *access* dimension of full citizenship. The problem is particularly evident in the variety of “disability definitions” attached to policies and programs.

Although the federal government and the provinces officially employ the disability definitions set out by the World Health Organization,¹⁴¹ these definitions are not applied in a uniform and consistent manner. As governments have sought to reduce deficits through program cuts and restrictions, a common approach has been to narrow program eligibility criteria through the adoption of restricted disability definitions.¹⁴² These changes, however, have been made on a program-by-program basis. Thus, parents often confront a wide range of program eligibility criteria and definitions in seeking support for their children. In this situation, desperate parents may force the child to fit program criteria in order to receive help.

141 In 1975, the World Health Organization (WHO) developed a new conceptual framework within which to understand disablement in the age of the contemporary welfare state. Published in 1980, the *International Classification of Impairment, Disabilities and Handicaps: A Manual for Classification Relating to the Consequences of Diseases (ICIDH)* was produced to act as a guideline for domestic disability policy-making. In fact, many industrialized states have adopted the ICIDH classifications and incorporated them into some of their policies and programs. For a complete discussion and analysis, see Jerome E. Bickenbach, *Physical Disability and Social Policy* (Toronto: University of Toronto Press, 1993): 30-60.

142 Ontario used this strategy when they created the Ontario Disability Support Plan (ODSP). See Harry Beatty, “Ontario Disability Support Program: Policy and Implementation,” *Journal of Law and Social Policy* Vol. 14 (1999): 1-68. See also Kate Bezanson and Susan McMurray, *Booming for Whom?: People in Ontario Talk about Income, Jobs and Social Programs*, The Speaking Out Project (Toronto: Caledon Institute of Social Policy, 2000).

Quebec is the jurisdiction that comes closest to employing a citizenship model as it relates to the provision of disability-related supports. Although there is no legislated framework, most of the eligibility criteria for disability-related programs and services – including those for children with disabilities – are determined by the *presence* of a disability, regardless of cause or level of family income. The result is that programs are designed to suit the needs of individuals, rather than eligibility criteria determining access and level of support.

British Columbia is also making strides in this direction and has moved forward in addressing the high degree of variability in disability definitions and eligibility criteria. As discussed previously, the government has proposed a new children’s policy framework that represents a significant advance in this area. The province has integrated all children’s policies and programs within a single ministry, and uses an inclusive approach. Further, the evidence-based, family-centred, individualized framework employed uses a ministry-wide, common definition of “special needs children and youth” for some 18 program areas.

6.3 Policy-Practice Gaps

The methodology for this study did not include interviews with families of children with disabilities. Our review nevertheless confirms that policy-practice gaps are evident throughout the policy sphere. Other empirical studies confirm that while a provincial policy framework may endorse a coordinated and inclusive approach, families often report their experience is very different. More often than not, the responsibility falls to parents to advocate for and coordinate the necessary package of supports for their disabled children across a range of governmental and non-governmental bodies.

Three interrelated factors help explain the persistence of the policy-practice gaps evident in this sphere. First, community supports – especially child care, education and recreation policy and programs – remain difficult to access. Generic programs are rarely truly inclusive, even when they promise to be. Nor are the necessary steps, in terms of funding and program design, a top priority. The result is that inclusive approaches in generic policy spheres remain underdeveloped and undervalued. Further, the instability of the non-profit sector – which plays an important role in the provision of services and supports to children with disabilities and their families – has also contributed to increased policy-practice gaps.

Second, in most provinces, the administrative arrangements in place for delivering specialized supports to children and families such as in-home support and respite care are fragmented, uncoordinated, inflexible and complex. Our comparison reveals that four provinces (British Columbia, Alberta, Quebec and Saskatchewan) have developed inclusive and integrated policy frameworks; four others (Manitoba, Ontario, Nova Scotia and Newfoundland) have recognized the need to integrate policies across ministries and are beginning to take action; and two provinces (New Brunswick and Prince Edward Island) have done little in this regard. Among the second group of provinces, some have developed mechanisms to assist in coordinating the delivery of services to children and families but have taken little action to develop truly inclusive policy frameworks. Even in provinces in which an integrated and coordinated policy framework is in place, children and families encounter gaps in service delivery. This variation is a barrier for children and their families.

Third, this policy sphere and its supporting administrative arrangements are chronically underfunded. Across the country, parents encounter waiting lists, a lack of supports, and burned out professionals. Respite care is an area that is particularly deficient in this regard.

These gaps are not new. In 1997, CPRN undertook a systematic cross-provincial inventory of services that affect children with disabilities and their families. The authors found that:¹⁴³

There is a resounding ... need to coordinate and integrate services for children with special needs. Every single ministry and department is said to be working on collaborating with providers (including the families) and on improving the coordination of services, but there are still gaps and overlaps in almost every province.

More recent research conducted by the Roeher Institute examining home and community supports for children with disabilities confirms that this is an ongoing problem.¹⁴⁴

The focus group participants indicated that, despite the need for them, coordination supports were often unavailable, unresponsive to the particular needs of persons with disabilities and their families, delivered in ways that put coordinators in conflicts of interest, or designed with very restrictive eligibility requirements.

Finally, in consultations with families across the country, the Canadian Association for Community Living found evidence of similar policy-practice gaps, especially in the area of respite care. They conclude:¹⁴⁵

A resounding message from families is that they need respite to ease the pressure on their families. Currently, respite is inflexible and often times, respite caregivers are untrained. Since home care for children is unavailable in many parts of the country, families are using respite to provide personal care for their children.

Why do these gaps persist? As Michael Prince details in the companion report to this research, a partial explanation is that health and social service restructuring has resulted in the creation of a new level of governance. Regional health and social service authorities have introduced a new layer of administration for parents of children with disabilities. To secure and coordinate services, many parents must deal with ministry staff at the central and regional levels, as well as staff of regional authorities. In addition, in some provinces, Alberta in particular, the legislative framework permits regional authorities to determine which, and at what level, services will be offered to citizens. Thus, not all services are necessarily available in all regions of the province. With this scenario, children with disabilities are likely to continue to fall through the cracks.

143 Virginia E. Hayes, Marcus J. Hollander, Elsie L.C. Tan, and J. Eden Cloutier, *Services for Children with Special Needs* (Victoria: Canadian Policy Research Networks, 1997): vi.

144 Roeher Institute, *When Kids Belong*, 22.

145 Canadian Association for Community Living, *Don't Exclude Our Children* (Toronto: Canadian Association for Community Living, n.d.): 3.

6.4 Intra- and Inter-Jurisdictional Discrepancies

Socioeconomic and geographic factors present themselves as serious barriers for families caring for a child with disabilities. Difficulties are pronounced among Aboriginal peoples living on- and off-reserve as well as for low-income families, especially those living on social assistance.

In their Children and Family Series, the Roeher Institute has undertaken some preliminary research on parents living on social assistance who have children with disabilities. They conducted in-depth qualitative interviews in Alberta, British Columbia and Ontario with a purposive sample of 24 families, reflecting the nation's plurality. The research found that these families face substantial barriers in daily living – in housing, income, child care, education, therapies, health care, recreation, transportation, and personal supports. The report concludes.¹⁴⁶

This preliminary research reveals a group of people who face substantial barriers in daily living, whose lives have been changed by circumstances largely beyond their control, and who struggle in a political environment that is increasingly unsympathetic to *all* parents on social assistance, regardless of their individual situations. These are families whose voices are seldom heard, and whose circumstances and struggles are systemically made invisible. They also proved to be an innovative and passionate group of parents, juggling the complex responsibilities involved in caring for their children, advocating for their children, and surviving in difficult circumstances and financial hardship.

The lack of availability of supports and services in rural areas is also a barrier for families. As the Canadian Association for Community Living found in its national survey of families who have children with disabilities:¹⁴⁷

Any number of disability and health related needs were identified by families in different communities. There is inconsistent and sometimes inadequate provision and coverage of health care and disability related services in communities across the country. Whether certain services or devices are available to families, and whether families paid for them out of pocket depended more on where families lived than on the needs of their child or their ability to pay.

As Box 3 describes, Saskatchewan, Manitoba, Ontario and Quebec have created specialized programs providing extra support to families living in rural areas. In Ontario, for instance, the Integrated Services for Northern Children Program is the joint responsibility of the Ministries of Health, Community and Social Services, and Education. Local offices of the Ministry of Community and Social Services administer the program. The program targets all children with physical, developmental, and mental disabilities who are living in northern communities, and provides an integrated network of physical, mental health, and special education services. These programs begin to address the complexities of caring for a child with disabilities in a rural area, but more must be done.

146 Roeher Institute, *Finding a Way In*, 45.

147 Canadian Association for Community Living, *Don't Exclude Our Children*, 4.

Canada is a country characterized by a vast territory, sparse population, and harsh climate for much of the year. Our geography and climate are a part of who we are as Canadians. Our policies must respond, therefore, to these realities.

7.0 Conclusions and Recommendations

Citizenship promises *rights* and demands *responsibilities*. For full citizenship to be realized, however, individuals and families need real *access* to those rights as well as to work, education, technology, and social protection so they are able to exercise their responsibilities. With this will come inclusion and a true sense of *belonging*.

Full citizenship for children with disabilities, their parents, and their siblings requires two elements. First, that *all* children, parents and siblings have access to an inclusive base of generic supports and services. Full citizenship demands the easy access to inclusive supports, services and community settings. Ensuring this level of access only, however, does not enable full citizenship for children with disabilities and their parents. An extra step is required. The provision of a package of portable and flexible supports targeting the particular needs of children with disabilities and their families must be readily accessible in local communities. Policy frameworks must acknowledge the extraordinary demands placed on parents, siblings and families by providing them with tools to help balance the demands of work and family life, such as information sharing, peer support, networking strategies and resources, and training. This study confirms that, while most children with disabilities and their parents are living in our communities, they are not active members of them.

A *Best Policy Mix for Children* is one in which positive child outcomes for children are achieved through a mix of policy responses that create three enabling conditions: adequate income, effective parenting, and supportive community environments. Using these criteria, this report demonstrates that, while some provinces have made gains in various areas – including the administrative arrangements in place for delivering services and supports – there is no coherent vision for achieving the best possible policy mix for children with disabilities, especially school-aged children, and their parents. Few provinces have such a vision for their own jurisdiction, and no consensus exists as yet for the country as a whole. Nor do all families who care for a child with disabilities have adequate income and supports for effective parenting. Too often they live in poverty and struggle to obtain the services and supports that they desperately need.

The continued exclusion of children with disabilities from regular child care facilities, education settings, and recreational facilities and programs, as well as the under-resourced, complex, fragmented set of available specialized services means that full civil and social citizenship rights are not realized. In short, children with disabilities and their parents do not benefit from full access to work, education, and individual and community supports and services. Most do not, therefore, embrace a strong sense of community belonging. They are not full citizens. The time has come for governments to deem a priority the needs of *all* of Canada's children, including those with disabilities.

7.1 Recommendations

Ensure that all children – including those with disabilities – have access to full citizenship:

Create a generic base of supports for *all* children – including those with disabilities – and their families ensuring full access and participation in the community. To ensure such access for children with disabilities and their parents, create an additional layer of portable and flexible supports targeting their particular needs.

Ensure that parents caring for children with disabilities have the capacity to be citizens:

All parents need access to resources and supports to enjoy the benefits of full citizenship, but for those with children who have disabilities, there is a need for additional resources to ensure their full participation in community life. Enact policies that help alleviate the extraordinary demands on parents and siblings caring for a child with disabilities and assist in balancing the daily demands of work and family life. This may include policies that target information sharing, peer support, networking strategies and resources, and training.

Expand the National Children’s Agenda to include school-aged children with disabilities:

It is time for the development and implementation of a national Action Plan for Children with Disabilities and their Parents. The Action Plan should not be segregated from the NCA, but instead should take an inclusive and integrated approach. Children’s and disability advocates have been calling on governments to set the needs of children with disabilities and their families as a priority, and school-aged children are particularly in need of this kind of policy recognition. The Canadian Association for Community Living, the Roeher Institute, the Canadian Alliance for Children’s Healthcare, and SpecialLink [sic] have all demonstrated a need for action on this file. Governments have responded with incremental gestures, but there is no pan-Canadian vision or national commitment to effect meaningful change in the lives of children with disabilities and their families.

Ensure that families caring for a child with disabilities have adequate income support:

Amend both the Disability Tax Credit and the Medical Expense Tax Credit to reflect the real costs associated with disability. Expand the eligibility criteria of the Disability Tax Credit to enable more families to qualify. Make these tax credits refundable so that they benefit low-income families. Make unpaid and paid parental leave more flexible, to allowing parents to respond to their children’s daily needs, which vary over the life cycle.

Enable parents to optimally provide effective parenting to their disabled children through the development of flexible and portable supports:

Reduce the reliance on respite care through the development of flexible and portable in-home and out-of-home disability supports. Relax the eligibility criteria for existing in-home and out-of-home supports enabling parents to have more flexibility in caring for their children in a variety of community settings. Develop family-centred policies and programs ensuring that the needs of the entire family are addressed, not simply the needs of the child with disabilities. Ensure that families have access to non-programmatic family supports such as networking, peer support, training and assistance through transitions. In those instances where respite care is necessary, increase its funding, flexibility and availability.

Adopt an inclusive and integrated approach in all generic community environments (i.e., recreation, transportation, education, and so on) to ensure that children with disabilities can participate fully in community life: Enact mandatory legislation with potent regulatory supports on a voluntary but universal basis. This would require the development of a broad national perspective on special education including a national consensus on service implementation. Modify and construct accessible schools and child care facilities, and expand and increase funding for education supports. Require municipalities to develop and support accessible recreation facilities and programs.

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Appendix A

Program and Policy Scans

Table 1
An Overview of Federal Programs for Children with Disabilities and their Parents in Canada, 2001

National Children's Agenda

- The National Children's Agenda, in keeping with the spirit of the Social Union Framework Agreement, is an ongoing commitment among participating governments to improve cooperation among governments in order to make social programs more efficient and effective. In December 1997, Canada's First Ministers asked the Federal-Provincial-Territorial Council of Ministers of Social Policy Renewal to engage the public in developing a shared vision for enhancing the well-being of Canada's children. The Government of Quebec agrees with the objectives of the National Children's Agenda, but has decided not to participate in its development.
- In collaboration with Canada's five national Aboriginal organizations, the Council published a document entitled *A National Children's Agenda – Developing A Shared Vision*. This document invited people to discuss common values and goals for children, and to consider a vision that reflects Canadians beliefs about children and a commitment to their well-being. In addition, the document included an Aboriginal perspective on children's issues. The document did not, however, include a vision for children with disabilities.
- A supplementary document, *A National Children's Agenda – Measuring Child Well-being and Monitoring Progress*, promoted discussion about how governments and Canadians measure children's progress and share information about how to improve children's well-being.
- In May 1999, governments launched a dialogue with citizens across the country to gather comments and ideas about the draft vision, as set out in the two dialogue documents. The *Public Report on the Public Dialogue on the National Children's Agenda – Developing a Shared Vision* (2000) provide an overview of the comments and ideas provided by organizations and citizens, including children and youth, from across Canada. As a response, in part, to the actions of national disability organizations calls for the inclusion of children with disabilities in the National Children's Agenda, the document also includes an amended vision statement.
- Announced by the federal government and participating provinces and territories on September 11, 2000, the *Agreement on Early Childhood Development Initiatives* (ECDI) is a \$2.2 billion investment over five years starting in 2001-02. It reflects a recognition that all levels of government need to work together to support families and local communities in ensuring positive child outcomes. Participating provincial and territorial governments have agreed to use the increases funding to undertake a coordinated effort to: (1) promote healthy pregnancy, birth and infancy; (2) improve parenting and family supports; (3) strengthen early childhood development, learning and care; and (4) strengthen community supports.

Table 1, continued

Child Benefits

- The National Child Benefit (NCB), launched in 1998, provides the framework for child benefits. It is composed of: (1) the basic Canada Child Tax Benefit; (2) a National Child Benefit Supplement; and (3) provincial reinvestment commitments.
- The federal government provides the basic Canada Child Tax Benefit (CCTB) of \$1,104 per child under 18, plus \$219 per child under 7 if the Child Care Expense Deduction is not claimed (see Tax Deductions below).¹ It also pays the National Child Benefit Supplement to low-income families at \$977 for one child and \$1,748 for two children.
- The basic benefit begins to be reduced at a family income of \$30,004 and disappears at \$74,000 for families with one or two children. The low-income supplement begins to be reduced at \$21,214 and disappears at \$30,004. Alberta and Quebec have their own payment schedule for the CCTB.
- Revenue Canada administers the following provincial and territorial child benefit and credit programs: BC Family Bonus, Alberta Family Employment Tax Credit, Saskatchewan Child Benefit, New Brunswick Child Tax Benefit, Nova Scotia Child Benefit, Newfoundland and Labrador Child Benefit, Yukon Child Benefit, Northwest Territories Child Benefit, and Nunavut Child Benefit.
- A goods and services tax/harmonized sales tax (GST/HST) credit is available for parents with children under 19 and/or for married people with annual incomes less than \$35,980 for a one child family, \$38,080 for two children and \$40,180 for three children. Recipients have to apply for the credit each year.

Tax Deductions to Cover Some of the Costs of Disability-Related Expenses

- Since 1972, the federal government has provided a Child Care Expense Deduction (CCED) to employed parents. Costs for child care for which receipts are provided can be deducted up to maximum of \$7,000 for a child under 7, and up to \$4,000 for children aged 7 to 16. In two-parent families, the deduction must be claimed by the parent with the lower income. The CCED can be used for both formal regulated child care or unregulated care, as long as receipts are issued.
- The Medical Expense Tax Credit (METC) is available to all taxpayers with above-average medical costs and provides combined federal and provincial tax relief for about 25 percent of eligible medical costs. In 1997, the federal government broadened the allowable expenses in the METC to more accurately reflect the costs associated with a disability.
- The Disability Tax Credit (DTC) benefits individuals with physical or mental impairments by providing a “flat-rate” credit against federal income tax, payable to those who qualify. It does not cover costs incurred within the home setting. On January 1, 2001, changes to the DTC came into effect. The amount used for calculating the DTC rose to \$6,000 from \$4,293. In addition, the amount used for calculating the supplement to the DTC for children with severe disabilities was increased to \$3,500.

Paid Maternity and Parental Leaves

- Paid maternity and parental leaves are available for parents covered by Employment Insurance. To be eligible, parents have to have worked a minimum of 700 hours in the last 52 weeks.² Birth mothers are entitled to 15 weeks of paid leave, and either parent may take an additional 10 weeks. Parents can also get 15 weeks of sickness benefits in addition to maternity or parental benefits. Benefits are 55 percent of insurable earnings. Recipients earning more than \$48,750 must pay back a portion of the Employment Insurance benefit. The maximum supplement is \$413 per week. The first two weeks of leave are not covered by these benefits.
- Employment Insurance now covers part-time workers. Therefore, they may also be eligible for maternity and parental benefits if they have worked enough hours to qualify for them.
- Employment Insurance provides a Family Supplement for low-income families to raise the replacement level of lost income. Families with net incomes below \$20,921 receive the full Family Supplement and families with net incomes between \$20,921 and \$25,921 receive a partial Family Supplement. The maximum is \$413 per week.

- 1 The Canada Child Tax Benefit will be increased by \$2.5 billion a year by 2004, bringing to more than \$9 billion its annual support for low- and middle-income families with children. This will mean a maximum benefit of \$2,400 for a family's first child and \$2,200 for a second child.
- 2 This requirement will be reduced to 600 hours of insurable employment for parents of a child born or placed in their care for adoption on or after December 31, 2000.

Table 1, continued

<p><i>Programs for Child Well-Being and Healthy Development</i></p> <ul style="list-style-type: none">• The Aboriginal Head Start Initiative improves the pre-school experience of Aboriginal children, and works with their parents in urban settings, northern communities, and on reserves. The program includes attention to culture and language, education, health promotion, nutrition, social supports, parental involvement, and preschool projects. There are more than 100 Aboriginal Head Start project sites across the country. In the 2001 <i>Speech from the Throne</i>, the federal government committed to expand the Aboriginal Head Start program to better prepare more Aboriginal children for school, and help those children with special needs.• The Community Action Program for Children (CAPC) provides long-term funding to community groups to establish and deliver services that respond to the developmental needs of children from birth to six years of age who are at-risk (children living in low-income families; teen-parent families; those at risk of experiencing developmental delays, or social, emotional or behavioural problems; and those who are abused or neglected). CAPC funds prevention and early intervention programs and delivers services through parent or family resource centres, child development centres, providing parenting education and infant stimulation in selected communities.• The Canada Prenatal Nutrition Program is a comprehensive community-based program that supports pregnant women who face conditions of risk that threaten their health and the development of their babies. The program provides resources for community-based groups to offer support such as nutrition, knowledge and education, social support, and assistance to access to services. The program is delivered through Health Canada regional offices, and managed jointly by the Federal government and Provincial or Territorial governments.
<p><i>Targeted Federal Initiatives Affecting Children with Disabilities and their Parents</i></p> <ul style="list-style-type: none">• The federal government plays a central role in funding research and knowledge generation and dissemination in the area of disability policy. This includes investments such as the 2001 Participation Activity Limitation Survey (formally known as the Health Activity Limitation Survey), the National Longitudinal Survey of Children and Youth, and a variety of project-based research initiatives.• The federal government has also made investments towards the establishment of a number of Centres of Excellence. One is the Centre of Excellence for Children and Adolescents with Special Needs, which operates under the administrative leadership of Lakehead University in partnership with the Government of Nunavut, the University of Northern British Columbia, Memorial University, and Mount Saint Vincent University. Their work focuses on rural and remote communities and, in particular, on children and youth with special needs living in Canada's North.• The Federal-Provincial-Territorial Working Group on the Mental Health and Well-Being of Children and Youth was established in 1986. It has a mandate to promote mental health and wellness, improve mental health outcomes, monitor the mental health status of children and youth, monitor services for this population, and identify critical issues in service provision and integrated service delivery. The Working Group's 13 members meet on a yearly basis and submit recommendations on a regular basis to Health Canada.
<p><i>Federal Transfers to Provinces and Territories</i></p> <ul style="list-style-type: none">• In 1996, the Canada Health and Social Transfer (CHST) was introduced to replace Established Programs Financing (EPF) and the Canada Assistance Plan (CAP). The CHST provides cash and tax transfers that can be used for health, post-secondary education, social assistance, and social services.• Provincial cash and tax transfers were reduced by \$3 billion in 1996-97 and by \$4 billion in 1997-98. In 1999, the federal government announced increased CHST funding of \$11.5 billion over 5 years (\$2.5 billion for 2000). In 2000, \$30.8 billion was transferred to the provinces and territories.• The 1999 Budget introduced measures to eliminate disparities among provinces in per capita CHST entitlement (cash transfers plus tax transfers). By 2001-2002, all provinces and territories will receive the same amount on a per capita basis.
<p><u>Source:</u> Relevant federal Web sites.</p>

Table 2
Provincial Governments' Coordinating Bodies for Children's Policy and Disability Policy

Description	British Columbia	Alberta	Saskatchewan	Manitoba	Ontario
<ul style="list-style-type: none"> • Government-wide Coordinating Body for Children's Policy or Programs 	<i>Ministry for Children and Families</i> ¹	<i>Ministry of Children's Services</i>	<i>Saskatchewan Action Plan for Children</i> (including, the <i>Saskatchewan Council on Children</i>)	<i>Healthy Child Manitoba</i>	<i>Ontario Children's Secretariat</i> and the <i>Office of Integrated Services for Children</i>
<ul style="list-style-type: none"> • Includes Children with Disabilities 	Yes	Yes – except Education and Mental Health Services	Yes – Action Plan promotes an inclusive inter-departmental approach	Yes	Limited – priority given to preschool children
<ul style="list-style-type: none"> • Government-wide Coordinating Body for Disability Policy or Programs 	<i>Office for Disability Issues</i>	<i>Premier's Council on the Status of Persons with Disabilities</i>	<i>Office of Disability Issues</i>	<i>No, but has Minister Responsible for Disability Issues</i>	<i>No</i>
<ul style="list-style-type: none"> • Includes Children with Disabilities 	No	Limited	No	Yes	

1 In establishing Cabinet priorities following the election of the BC Liberal party on May 16, 2001, Premier Gordon Campbell created a Ministry of State for Early Childhood Development, and has indicated that the Ministry for Children and Families will now be known as the Ministry of Children and Family Development. The four key areas of responsibility for the renamed ministry, which have not yet been fully articulated, are adoption, child protection, community living for adults, and major boards and commissions.

Table 2, continued

Description	Quebec	New Brunswick	Nova Scotia	Prince Edward Island	Newfoundland
<ul style="list-style-type: none"> • Government-wide Coordinating Body for Children's Policy or Programs 	<i>Ministry of Child and Family Welfare</i> (Ministère de la Famille et de l'Enfance)	No	<i>Child and Youth Action Committee</i>	<i>Ministry of Child, Family and Community Services</i>	<i>Model for the Co-ordination of Services for Children and Youth</i>
<ul style="list-style-type: none"> • Includes Children with Disabilities 	Yes	No	No	No	Limited
<ul style="list-style-type: none"> • Government-wide Coordinating Body for Disability Policy or Programs 	<i>Office des personnes handicapées</i>	<i>Premier's Council on the Status of Disabled Persons</i>	<i>Disabled Persons Commission</i>	No	No
<ul style="list-style-type: none"> • Includes Children with Disabilities 	Yes	No	No		

Table 3
Early Childhood Development Programs for Children with Disabilities or at Risk of Developing a Disabling Condition

Program Description	British Columbia		Alberta	Saskatchewan
• Program Name	<i>Early Intervention Services</i>	<i>Infant Development Program</i>	<i>Early Intervention Funding</i>	<i>Early Children Intervention Services</i>
• Department responsible for policy	Children and Families	Children and Families	Children's Services	Social Services
• Administrative responsibility	Contractual arrangements with community service providers	Local Infant Development Advisory Committees	Child and Family Service Authorities	Non-profit agencies and Parent Community Boards
• Eligibility	Children from birth to school entrance age, who are at risk of developing a disabling condition.	Children from birth to 3 years, who have been identified as either developmentally delayed in one or more skills areas, or at significant risk of delay. Family must agree to participate and must live within specified geographic boundaries. Referrals from a parent, public health nurse, physician, hospital, or ministry worker.	Unknown	Children from birth to 5 years, with either a developmental disability, or who are at risk of a developmental disability. The program targets preschool children with violent behaviour.
• Supports	Provides coordination for community and tertiary pediatric rehabilitation and supports including professional guidance and support, speech and language pathology, occupational therapy, physiotherapy, and family support workers.	Provides home-based services such as consultation, counselling, group activities, and referrals.	Funding to community groups.	Provides a range of home-based supports and training for parents and families.

Table 3, continued

Program Description	Manitoba		Ontario	
	<ul style="list-style-type: none"> • Program Name 	<i>Children's Special Services</i>	<i>Provincial Outreach Therapy for Children</i>	<i>Infant Development Program</i>
<ul style="list-style-type: none"> • Department responsible for policy 	Family Services and Housing	Family Services and Housing, Children's Special Services	Community and Social Services	Health and Long-Term Care
<ul style="list-style-type: none"> • Administrative responsibility 	Family Services and Housing	Funded community agencies	Community Care Access Centres	Regional Health Authorities
<ul style="list-style-type: none"> • Eligibility 	Children from birth to five years or school entrance with a developmental disability, risk of developmental disorder, autism spectrum disorder, physical disability, or lifelong complex medical needs resulting in a dependency on medical technology.	Children from birth to five years or school entrance with a developmental disability, risk of developmental disorder, autism spectrum disorder, physical disability, or lifelong complex medical needs resulting in a dependency on medical technology.	Children with physical and developmental disabilities, or at risk of developmental delay from birth to 4 years.	Children with identified hearing loss.
<ul style="list-style-type: none"> • Supports 	<p>Early Childhood Intervention provides child development workers to assist parents and caregivers in identifying child's needs and goals in the family home or in child care settings.</p> <p>Children's Special Services also provides service coordination, respite, behavioural assessment and therapy, transportation, supplies and equipment and home modifications.</p>	Provides funding to community agencies to provide occupational therapy, physiotherapy, and speech therapy services in the family home or in child care settings.	Provides early identification services and a range of home-based supports, which may include physiotherapy, occupational therapy, speech therapy, and audiology services.	Provides screening and confirmation of hearing loss and communication development.

Table 3, continued

Program Description	Quebec	New Brunswick	Nova Scotia	Prince Edward Island	Newfoundland
• Program Name	<i>Early Stimulation Programs</i> (Programme de stimulation précoce)	<i>Early Childhood Initiatives</i>	<i>Early Intervention Services</i>	<i>Public Health Nursing</i>	<i>Healthy Beginnings</i>
• Department responsible for policy	Santé et Services sociaux	Health and Wellness	Community Services	Health and Social Services	Health and Community Services
• Administrative responsibility	Rehabilitation centres	Public Health, Family and Community Social Services, and Mental Health Services	Early Childhood Development Services	Regional Health Authorities	Regional Health and Community Services, Integrated Boards
• Eligibility	Families with a child who has significant and persistent disability.	Children from birth to 5 years, with either a developmental disability or who are at risk of developmental delay.	Children from birth to 5, with developmental disabilities, or at risk of developmental delay.	All children from birth to 4 years. Children at risk of development delay are screened more frequently.	Children from birth to school age, who are at risk of developmental delay.
• Supports	Provides physiotherapy, counselling, stimulation, and social integration services through rehabilitation centres.	Provides parents and families with a variety of coordinated prevention programs including parent education, parent support in decision-making and budgeting, and increased nutrition.	Provides grants to community groups to provide parents with community-based prevention programs, which may include parent education and parent support programs.	Provides home-based visits by a public health nurse for screening, assessment to identify children at risk of a disabling condition.	Public health nurses conduct assessments to determine if children are at low, medium or high risk of development delay, and provide referral services.

Table 4
Extra Income Support for Families with Children with Disabilities

Program Description	British Columbia	Alberta	Saskatchewan	Manitoba	Ontario
• Program Name	<i>At Home Program</i>	<i>No program</i>	<i>Outreach Program</i>	<i>Children's Special Services</i>	<i>Assistance for Children with Severe Disabilities (formally the Handicapped Children's Benefit)</i>
• Department responsible for policy	Children and Families		Social Services	Family Services and Housing	Community and Social Services
• Administrative responsibility	Support Services for Children and Youth with Special Needs and their Families		Community Living Division	Children's Special Services Branch	Regional Ministry offices
• Eligibility	<p>The child must be eligible for BC Medical Services Plan, living at home more than 50 percent of the time, and not living on a Reserve.</p> <p>The child must be dependent on the caregiver for all four activities of daily living (bathing, toileting, dressing and feeding).</p> <p>Regional Committees determine eligibility.</p>		Families with a child under 18 years living at home, and who cannot access respite services through provincial resource homes located in Regina and Saskatoon.	Varies depending on type of support required.	Families with a child under 18 years, with a severe disability that results in a functional loss, and extraordinary costs must be present, which are incurred as a direct result of the disability.
• Tests	Need		Income	Need	Income – maximum household Income of \$60,000 per year.
• Supports	Provides financial support to families for medical and/or respite needs.		Provides funding to help offset costs incurred by a family in accommodating their child at home, especially respite care.	Provides funding assistance to families for some of the out of ordinary costs of raising a child with disabilities, especially respite care, equipment and supplies, home modifications, and transportation.	Provides \$25-375 per month per family to assist in the extraordinary costs associated with keeping a child at home.

Table 4, continued

Program Description	Quebec	New Brunswick	Nova Scotia	Prince Edward Island	Newfoundland
• Program Name	<i>Allowance for Children with Disabilities</i> (Allocation pour enfant handicapé)	<i>No program</i>	<i>No program</i>	<i>No program</i>	<i>Special Child Welfare Allowance Program</i>
• Department responsible for policy	Children and Families				Health and Community Services
• Administrative responsibility	Régie des rentes du Québec (RRQ)				Regional Health and Community Services, Integrated Boards
• Eligibility	Families with a child who is under 18 years, and assessed as having a physical, mental or developmental disability for a minimum foreseeable period of one year.				Families with a child who is under 18 years, and assessed as having a physical or developmental disability.
• Tests	Need				Household financial assessment based on family size, household income, and complexity of supports required.

Table 5
Financial Support for Families Toward the Purchase of Assistive Devices for Children with Disabilities

Program Description	British Columbia	Alberta	Saskatchewan
• Program Name	<i>At Home Program</i>	<i>Alberta Aids to Daily Living Program (AADL)</i>	<i>Saskatchewan Aids to Independent Living (SAIL)</i>
• Department responsible for policy	Children and Families	Health and Wellness	Health
• Administrative responsibility	Support Services for Children and Youth with Special Needs and their Families	Authorized AADL Dealers	Authorized Agencies
• Eligibility	<p>The child must be eligible for BC Medical Services Plan, living at home more than 50 percent of the time, and not living on a Reserve.</p> <p>The child must be dependent on the caregiver for all four activities of daily living (bathing, toileting, dressing and feeding).</p> <p>Regional Committees determine eligibility.</p>	All ages (over 6 months), who have a long-term disability, are Alberta residents and have a valid health card.	<p>All ages, who have been assessed as having a permanent physical disability, are Saskatchewan residents and have a valid health card.</p> <p>Also provides grants to families with children who have complex medical conditions for rehabilitation equipment, and home and vehicle modifications.</p>
• Tests	Need	Need Income	
• Supports	Provides financial support to families towards the purchase of medical equipment, prostheses, orthotic devices.	Provides 75 percent of funding towards the purchase of the device up to \$500 per family per year.	Provides financial support towards the purchase of devices.

Table 5, continued

Program Description	Manitoba		
• Program Name	<i>Handicapped Children's Services</i>	<i>Manitoba Health Services Insurance Plan</i>	<i>Children's Special Services</i>
• Department responsible for policy	Children's Services	Health	Family Services and Housing
• Administrative responsibility	Child and Family Service Authorities	Insured Benefits Branch	Children's Special Services
• Eligibility	Families with a child who is under 18 years, and is assessed as having a physical or mental disability.	All ages, who have been assessed as having a long-term physical disability (at least six months/year).	Children from birth to five years or school entrance with a developmental disability, risk of developmental disorder, autism spectrum disorder, physical disability, or lifelong complex medical needs resulting in a dependency on medical technology.
• Tests	Need	Need Income	Need
• Supports	Provides a range of community-based supports including assistive devices.	Provides financial support towards the purchase of prosthetic and orthotic devices. Also provides support towards the purchase of hearing aids for children under 18.	A range of supplies and equipment, transportation, and home modifications.

Table 5, continued

Program Description	Ontario			Quebec	
<ul style="list-style-type: none"> • Program Name 	<i>Assistive Devices Program</i>	<i>Home Oxygen Program</i>	<i>Special Services at Home</i>	<i>Technical Help and Medical Technologies Program</i> (Les programmes d'aides techniques et de technologie médicale)	<i>Technical Help Programs</i> (Les programmes d'aides techniques)
<ul style="list-style-type: none"> • Department responsible for policy 	Health and Long-Term Care	Health and Long-Term Care	Community and Social Services	Santé et Services sociaux	Santé et Services sociaux
<ul style="list-style-type: none"> • Administrative responsibility 	Operation Support Branch	Operation Support Branch	Special Needs Unit	Régie de l'assurance maladie du Québec (RAMQ) and Santé et Services sociaux.	Santé et Services sociaux, Regional health authorities and other institutions.
<ul style="list-style-type: none"> • Eligibility 	<p>All ages, who have been assessed as having a physical disability of at least 6 months, are Ontario residents and have a valid health card.</p> <p>There are specific criteria for each device.</p> <p>Persons whose primary disability is assessed as a learning or mental disability are not eligible.</p>	<p>All ages, who have been assessed as having a physical disability of at least 6 months, are Ontario residents and have a valid health card.</p>	<p>Families with a child under 18 years, with physical or developmental disability.</p>	<p>All ages, who have been assessed as having significant and persistent incapacity.</p> <p>There are specific criteria for each device.</p>	<p>All ages, who have been assessed as having a permanent disability.</p> <p>The purchase should not be covered by another governmental program.</p>
<ul style="list-style-type: none"> • Tests 	Need	Need	Need	Need	Need
<ul style="list-style-type: none"> • Supports 	<p>For most devices, provides 75 percent of funding towards the purchase of the device. For some devices, there is a fixed amount.</p>	<p>Provides funding for oxygen and products (i.e., concentrators, cylinders, liquid systems), as well as related supplies (i.e., masks, tubing).</p>	<p>Provides families with extra funding to purchase a range of supports, including respite care, which are otherwise not available in the community.</p>	<p>Includes many programs that provide full cost recovery for the purchase, adjustment and replacement of medical equipment, prostheses, orthotics, and other technical help devices.</p>	<p>Includes many programs that provide full cost recovery for the purchase, adjustment and replacement of medical equipment such as oxygen, orthopedic shoes, and technical help for communication, as well as financial help for home and vehicle modifications.</p>

Table 5, continued

Program Description	New Brunswick	Nova Scotia	Prince Edward Island	Newfoundland
• Program Name	<i>Health Services Program</i>	<i>Services for Physically and Developmentally Challenged Children</i>	<i>Disability Support Program</i>	<i>Special Assistance Program</i>
• Department responsible for policy	Family and Community Services	Community Services	Health and Social Services	Health and Community Services
• Administrative responsibility	Family and Community Social Services Division	Family and Children's Services Division	Regional Health Authorities	Regional Health and Community Services, Integrated Boards
• Eligibility	Children who qualify for the Community Based Services for Children with Special Needs program.	Children from birth to 18 years, who have been referred by a health professional.	Children from birth to 18 years, assessed with a long-term physical or developmental disability.	All ages, who are referred by a health professional (i.e., physician, occupational therapist).
• Tests	Need	Need and income	Need	Need
• Supports	Provides full coverage of equipment for families without private health insurance, through a health card. May also assist families with private health coverage for items not covered by their plan.	Provides families with financial assistance towards purchase of devices from authorized dealers.	Provides families with a variety of in-home supports, including assistance towards the purchase of medical equipment and assistive devices.	Provides financial supports towards the purchase of equipment from authorized dealers.

Table 6
In-Home Supports for Families with Children who have Severe or Complex Disabilities

Program Description	British Columbia			Alberta
	• Program Name	<i>Professional Support for Children with Special Needs</i>	<i>Parent Support for Families with Children with Special Needs</i>	<i>Homemaker/Home Support Worker Program</i>
• Department responsible for policy	Children and Families	Children and Families	Children and Families	Children's Services
• Administrative responsibility	Contractual arrangements with community service providers	Contractual arrangements with community service providers	Contractual arrangements with local agencies	Child and Family Services Authorities
• Eligibility	Families with a child who has been assessed by a professional (i.e., doctor, psychologist, social worker), and has a mental disability or autism, or is eligible for the At Home Program.	Families with a child who has been assessed by a professional (i.e., doctor, psychologist, social worker), and has a mental disability or autism, or is eligible for the At Home Program.	Families with a child who has been assessed or referred by a professional (i.e., doctor, psychologist, social worker), and has a mental disability or autism, or is eligible for the At Home Program.	Natural, extended and adoptive children up to 17 years with chronic, physical or mental disability or disorder of organic cause.
• Tests	Need	Need	Need	Need
• Supports	Provides professional involvement to assist families or service providers in developing an intervention plan, which may include training, counselling, public awareness, or agency liaison.	Provides a range of community-based services including parent support groups, parent skills training, counselling, life skills, and organized activities.	Provides homemaker support to families in which trained personnel assume full or partial responsibility for child care, life skills or household management.	Does not provide any clinical treatments supports. Provides families with information and referral services for regional level supports, and provides some funding for community-based supports.

Table 6, continued

Program Description	Saskatchewan		Manitoba	
• Program Name	<i>Family Support Services</i>	<i>Outreach Program</i>	<i>Children's Special Services</i>	<i>Home Care</i>
• Department responsible for policy	Social Services	Social Services	Family Services and Housing	Health
• Administrative responsibility	Resource Homes located in Regina and Saskatoon	Regional Offices	Regional Offices	Regional Health Authorities
• Eligibility	Families with a child who has a developmental or physical disability, and is preschool or school-aged.	Families with a child who has a developmental or physical disability, and is preschool or school-aged, and cannot readily access the Family Support Services Program (most likely because they live in a rural area).	Families with a child who is under 18 years, and is assessed by a medical health professional as having a chronic physical or mental disability, or disorder of organic cause.	Children who have been assessed with medical needs.
• Tests	Need	Need	Need	Need
• Supports	Provides range of community-based services including parent support, parent skills training, counselling and life skills.	Provides grants to families for up to 60 days, to help offset costs associated with caring for the child.	Provides a range of community-based supports, which may include counselling, information or referral, child development, therapy services, supplies and equipment, home modification, transportation and training.	Home care provides the first 20 hours per week. If the child needs more care, the Handicapped Children's Services program will cover it.

Table 6, continued

Program Description	Ontario		Quebec		
• Program Name		<i>Behaviour Management Program</i>	<i>Development Services</i>	<i>Direct Allowance for Home Care Services</i>	<i>Direct Allowance for Family Support Services</i> (Services de soutien à la famille)
• Department responsible for policy		Community and Social Services	Community and Social Services	Santé et Services sociaux	Santé et Services sociaux
• Administrative responsibility		Local community support agencies	Developmental Services Branch	CLSCs <i>Centres locales de services communautaires</i>	CLSCs <i>Centres locales de services communautaires</i>
• Eligibility		Children from birth to 18 years, with a developmental disability.	Children from birth to 18 years, with a developmental disability.	All ages, who have been assessed as having significant and persistent incapacity. Includes an allowance for transportation and accommodation services.	Family responsible for a child or an adult with significant and persistent incapacity.
• Tests		Need	Need	Need	Need
• Supports		Provides families with home-based supports to assist in managing their child's behaviour.	Grants to individuals and non-profit agencies.	Provides supports and subsidies for in-home and home care services including personal care and domestic help.	Provides financial support and services including respite, services for unexpected emergencies, attendant services, and assistance for parenting.

Table 6, continued

Program Description	New Brunswick	Nova Scotia	Prince Edward Island	Newfoundland	
• Program Name	<i>Community Based Services for Children with Special Needs</i>	<i>Services for Physically and Developmentally Challenged Children</i>	<i>Disability Support Program</i>	<i>Direct Home Service Program</i>	<i>Community Behavioural Services</i>
• Department responsible for policy	Family and Community Services	Community Services	Health and Social Services	Health and Community Services	Health and Community Services
• Administrative responsibility	Family and Community Social Services Division	Family and Children's Services Division	Regional Health Authorities	Regional Health and Community Services, Integrated Boards	Regional Health and Community Services, Integrated Boards
• Eligibility	Families with a child who is 19 years and under, and is assessed as having a physical, mental, intellectual or emotional-behavioural disability that significantly interferes with the normal development process.	Children from birth to 18 years, assessed with a physical or developmental disability.	Children from birth to 18 years, assessed with a long-term physical or developmental disability.	Families with a child who is under 18 years, and is assessed as having a physical or mental disability.	Children of school age and older, diagnosed with a developmental, intellectual or behavioural disability, which has been professionally assessed as at risk for community integration.
• Tests	Need, but families are expected to make some financial contribution based on net income, family size, and ability to pay.	Need, but some aspects of the program are income-tested, using a sliding scale.	Need	Need	Need
• Supports	Provides a variety of supports to assist children living in the community, which may include family support, various policies for birth and adopting parents have varied considerably across the	ry. With the extension of paid of in-home supports, including respite care. Provides funding to enhance support programs.	Provides families with a variety of in-home supports, including respite care, medical transportation subsidies (for out of province care), and homemaking support.	A Child Management Specialist provides intervention services on a weekly or biweekly basis.	Provides a Behavioural Management Specialist who visits the home setting. Program varies by region. Some regions provide additional supports to physically disabled children, depending on regional needs and resources.

Table 7
In-Home and Out-of-Home Respite Care Available to Families and Children with Disabilities

Program Description	British Columbia			Alberta
	<i>Respite Services</i>	<i>At Home Program</i>	<i>Nursing Support Services</i>	<i>Handicapped Children's Services</i>
• Program Name	<i>Respite Services</i>	<i>At Home Program</i>	<i>Nursing Support Services</i>	<i>Handicapped Children's Services</i>
• Department responsible for policy	Children and Families	Children and Families	Children and Families	Children's Services
• Administrative responsibility	Contractual arrangements with community service providers or approved child care resource home	Regional Community Living Services Managers	Regional Health Authorities	Child and Family Services Authorities
• Eligibility	<p>Families with a child who has been assessed by a professional (doctor, psychologist, social worker), and has a mental disability or autism, or is eligible for the At Home Program.</p> <p>Referral from family or community services professional.</p> <p>Families receiving other respite services through Nursing Support Services or the At Home Program are not eligible.</p>	<p>Children from birth to 18 years.</p> <p>The child must be dependent on the caregiver for all four activities of daily living (bathing, toileting, dressing and feeding).</p> <p>The child must be eligible for BC Medical Services Plan, living at home more than 50 percent of the time, and not living on a Reserve.</p> <p>Regional Committees determine eligibility.</p>	<p>Children and youth under 19 years, who are residents of British Columbia, and require direct nursing care while attending selected community settings.</p> <p>The child must be deemed "stable" by a physician and have a parent or guardian responsible for care requirements.</p>	<p>Natural, extended and adoptive children up to 17 years, with a chronic, physical or mental disability or disorder of organic cause.</p>
• Tests	Need	Need	Need	Need
• Supports	Provides intermittent rest or relief for families.	Provides financial support to families towards the purchase of respite care.	Program's Nursing Respite Division provides support to children with special health care needs and their parents in selected community settings through comprehensive nursing assessment, planning, intervention, and evaluation of care.	<p>Does not provide any clinical treatments or supports.</p> <p>Provides families with information and referral services for regional level supports, and provides some funding for community-based supports, including respite services.</p>

Table 7, continued

Program Description	Saskatchewan		Manitoba	Ontario	
• Program Name	<i>Family Support Services</i>	<i>Outreach Program</i>	<i>Children's Special Services</i>	<i>Respite Services</i>	<i>Out-of-Home Respite Initiative</i>
• Department responsible for policy	Social Services	Social Services	Family Services and Housing	Community and Social Services	Community and Social Services
• Administrative responsibility	Resource Homes located in Regina and Saskatoon	Regional Offices	Regional Offices	Ministry Area Offices	Local Community Planning Groups
• Eligibility	Families with a child who has a developmental or physical disability, and is preschool or school-aged.	Families with a child who has a developmental or physical disability, and is preschool or school-aged and cannot readily access the Family Support Services Program (most likely because they live in a rural area).	Natural, extended and adoptive children up to 17 years, with one of the following conditions: mental disability, developmental delay, risk of developmental delay, autism spectrum disorder, physical disability, or lifelong extreme complex medical needs.	Children from birth to 18 years, who have been assessed with a developmental disability.	Families with a child living at home who is under 18 years, and has physical and/or developmental disabilities, and who requires 24 hours per day care, 365 days per year.
• Tests	Need	Need	Need	Need	Need
• Supports	Provides a range of community-based services, but respite care is an essential component of the program. Provides supports for families to have short-term relief.	Provides grants to families for up to 60 days, to help offset costs associated with caring for the child (i.e., for respite).	Provides families with a qualified respite care worker to provide short-term relief. Provides financing for family to hire a private worker.	Provides families with temporary relief from caring for their child in both in- and out-of-home settings.	Special initiative to provide out-of-home respite relief for families with children living in community settings.

Table 7, continued

Program Description	Quebec		New Brunswick	Nova Scotia
• Program Name	<i>Direct Allowance for Family Support Services</i> (Services de soutien à la famille)	<i>Direct Allowance for Home Care Services</i>	<i>Community Based Services for Children with Special Needs</i>	<i>Services for Physically and Developmentally Challenged Children</i>
• Department responsible for policy	Santé et Services sociaux	Santé et Services sociaux	Family and Community Services	Community Services
• Administrative responsibility	CLSCs <i>Centres locales de services communautaires</i>	CLSCs <i>Centres locales de services communautaires</i>	Family and Community Social Services Division	Family and Children's Services Division
• Eligibility	Family responsible for a child or an adult with significant and persistent incapacity.	All ages, who have been assessed as having significant and persistent incapacity. Includes an allowance for transportation and accommodation services.	Families with a child who is 19 years and under, and is assessed as having a physical, mental, intellectual or emotional-behavioural disability, which significantly interferes with the normal development process.	Children from birth to 18 years, assessed with a physical or developmental disability.
• Tests	Need	Need	Need, but families are expected to make some financial contribution based on net income, family size, and ability to pay.	Need and income tested on a sliding scale.
• Supports	Provides financial support and services including respite, services for unexpected emergencies, attendant services, and assistance to parenting services.	Provides supports and subsidies for in-home and home care services including personal care and domestic help.	Provides families with respite care services and long-term out-of-home placement options in foster homes.	Provides families with financial grants to purchase respite care services.

Table 7, continued

Program Description	Prince Edward Island	Newfoundland
• Program Name	<i>Disability Support Program</i>	<i>No program</i>
• Department responsible for policy	Health and Social Services	
• Administrative responsibility	Regional Health Authorities	
• Eligibility	Children from birth to 18 years, assessed with a long-term physical or developmental disability.	
• Tests	Need	
• Supports	Provides families with a variety of in-home supports, including respite care.	

Table 8
Mental Health Supports and Services for Children

Program Description	British Columbia	Alberta	Saskatchewan	Manitoba	Ontario
• Program Name	<i>Child and Youth Mental Health Services¹</i>	<i>Children's Mental Health Services</i>	<i>Mental Health Services – Child and Youth Services</i>	<i>Child and Adolescent Mental Health Program</i>	<i>Children's Mental Health Services</i>
• Department responsible for policy	Children and Families	Health and Wellness	Health and Social Services	Health	Community and Social Services
• Administrative responsibility	Local Ministry offices	Alberta Mental Health Board, in cooperation with Regional Health Authorities	Local District Health Boards	Regional Health Authorities	Children's Mental Health Centres and Ministry facilities
• Eligibility	Children under 18 with serious social, emotional or behavioural difficulties. Referral to program by professional via the intake and referral process of client services.	Children and youth under 18 who are assessed and referred by a physician.	Children and youth with serious and persistent mental health disorders, with less severe mental health and behavioural challenges, and those who are at risk of developing mental health and behavioural problems.	Children under 18 who are assessed and referred by a medical professional, or Community Mental Health worker for Children	Children under 18, referred by a health care professional.
• Tests	Need	Need	Need	Need	Need
• Supports	Information, assessment, counselling, and treatment provided by integrated teams at the regional level. Funding is also provided for contracted services.	Children's assessment and treatment services include information, counselling, crisis services, acute care, resource and drop-in centres, and psychiatric services.	Supports provided at local level based on community need, but can include assessment, treatment, parenting education, and family therapy. Various community-based organizations also receive support from health districts to provide services for children.	Supports include assessment, treatment, consultation, and professional and public education. Can also refer children to Winnipeg-based psychiatric hospital resources.	Supports vary by region, but can include assessment, group, individual and family counselling or therapy, residential services, day treatment, prevention programs, parenting skills, anger management, speech and language problems, parent education and training, and drug therapy.

Table 8, continued

Program Description	Quebec	New Brunswick	Nova Scotia	Prince Edward Island	Newfoundland
• Program Name	Mental Health Services (<i>Services de santé mentale</i>)	<i>Child and Adolescent Community Mental Health Services</i>	<i>Mental Health Clinics</i>	<i>Children's Mental Health</i>	<i>No Program</i> <i>Services accessed through hospitals.</i>
• Department responsible for policy	Santé et Services sociaux	Health and Wellness	Health	Health and Social Services	
• Administrative responsibility	Regional Health Authorities	Community Mental Health Centres	District Health Authorities	Regional Community Mental Health Sites	
• Eligibility	Children and adolescents. Eligibility depends of the nature of the service.	Children from birth to 18. Referral and screening process is done before eligibility for services is determined.	Children from birth to 19. Eligibility depends on the nature of the service.	Children and adolescents, self-referred or referred by a family physician.	
• Tests	Need	Need	Need	Need	
• Supports	Support includes pediatric psychiatry and other psychiatric services offered in hospitals, as well as information, assessment, counselling, therapy, prevention and toxicology services offered through CLSCs, schools, local organizations and rehabilitation centres.	Individualized assessment, treatment and evaluation for the child. Family can receive consultation and education supports.	Assessment and intervention are provided at the regional level, and vary from region to region.	Assessment and therapeutic interventions are provided in each site. Access to psychiatrists, however, is limited across the province. Invested \$250,000 to establish a multisectoral, provincial PEI Children's Mental Health Coalition and hire regional mental health clinicians to initiate a comprehensive approach to address children's mental health issues.	

Table 9
Grants or Supports for Child Care Providers to Provide Integrated Child Care for Children with Disabilities

Program Description	British Columbia		Alberta	Saskatchewan	
• Program Name	<i>Supported Child Care</i>	<i>Nursing Support Services</i>	<i>Inclusive Child Care Program</i>	<i>Child Development Program</i>	<i>Community Solutions</i>
• Department responsible for policy	Children and Families	Children and Families	Children's Services	Social Services	Social Services
• Administrative responsibility	Contractual arrangements with community service providers	Regional Health Authorities	Child and Family Services Authorities	Special Needs Program	Special Needs Program
• Eligibility	Children 12 years and under, who according to Supported Child Care policy guidelines are deemed to have a physical, intellectual, emotional, communication or behavioural impairment, and require additional support services because of that impairment.	Children and youth under 19 years, who are residents of British Columbia, and require direct nursing care while attending selected community settings. The child must be deemed "stable" by a physician and have a parent or guardian responsible for care requirements.	Children and youth with special needs, and whose parents are either working and/or in school.	Children with physical and/or developmental disabilities.	Children with special needs. Program focuses on children with multiple disabilities.
• Tests	Need	Need	Need	Need	Need
• Supports	Provides a grant to a maximum of \$107 per month to day care provider, to assist in financing extra supports for integration.	The program's Child Care Nursing Support Services Division provides support to children with special health care needs and their parents in selected community setting by providing comprehensive nursing assessment, planning, intervention, and evaluation of care.	Provides a grant to day care provider to assist in financing extra supports for integration.	Provides a grant to day care provider to assist in financing extra supports for integration.	Provides funding to community agencies that develop initiatives to promote and support the inclusion of children with special needs, and that meet the needs of rural areas.

Table 9, continued

Program Description	Manitoba	Ontario	Quebec	
<ul style="list-style-type: none"> • Program Name 	<i>Children with Disabilities Program</i>	<i>Special Needs Supports to Child Care</i>	<i>Subsidy for the Integration of a Disabled Child</i> (Subvention pour l'intégration d'un enfant handicapé)	<i>Subsidy for the Integration of a Disabled Child in After-School Child Care</i> (Subvention pour l'intégration d'un enfant handicapé en milieu de garde scolaire)
<ul style="list-style-type: none"> • Department responsible for policy 	Family Service and Housing	Community and Social Services	Children and Families	Children and Families
<ul style="list-style-type: none"> • Administrative responsibility 	Child Day Care Branch	Local ministry offices	Children and Families	Education, and School Boards
<ul style="list-style-type: none"> • Eligibility 	Children with a diagnosis of physical and/or developmental disability. Also provides support for children with behavioural disabilities.	Children with physical and/or developmental disabilities.	Children with significant and persistent disability, who face obstacles in participating in child care.	Children with significant and persistent disability, who face obstacles in participating in child care.
<ul style="list-style-type: none"> • Tests 	Need	Need	Need	Need
<ul style="list-style-type: none"> • Supports 	Provides a grant to day care provider to assist in financing extra costs associated with integration. There is also funding available for children under 12 years in before- and after-school programs.	Provides a grant to day care provider to assist in financing extra costs associated with integration.	Provides a maximum grant of \$5,131 per year for day care providers to assist with extra costs associated with the integration of a child with disabilities. A maximal grant of \$1,629 can also be provided for the costs of structural integration.	School receives a \$1,000 subsidy per year for each child with disabilities in full-time child care.

Table 9, continued

Program Description	New Brunswick	Nova Scotia	Prince Edward Island	Newfoundland
• Program Name	<i>Integrated Day Care Services</i>	<i>Preschoolers with Special Needs</i>	<i>Special Needs Grant</i>	<i>Child Care Services Subsidy Program</i>
• Department responsible for policy	Health and Wellness, and Family and Community Services	Community Services	Health and Social Services	Health and Community Services
• Administrative responsibility	Family and Community Services Regional Offices	Family and Children's Services, Early Childhood Development Services Branch	Child and Family Community Services Division	Regional Health and Community Services, Integrated Boards
• Eligibility	Children from birth to 4 years, who are at risk of developmental delay.	Children from birth to 4 years, who are at risk of developmental delay.	Child care provider applies to program for support. Regional Early Childhood supervisor determines eligibility.	Children with or at risk of developmental delay.
• Tests	Need	Need	Need	Income
• Supports	Provides a grant to day care provider.	Program specialist provides supports to day care provider.	Provides grant to day care provider, to a maximum of \$10 per hour, to hire extra staff.	Provides funding to family to help offset the costs of child care.

Table 10
Education Supports Provided to Schools to Accommodate Children with Disabilities

Program Description	British Columbia			
<ul style="list-style-type: none"> • Program Name 	<i>School-Aged Therapy Services</i>	<i>Provincial Resource Centre for the Visually Impaired</i>	<i>Nursing Support Services</i>	<i>Audiology Services</i>
<ul style="list-style-type: none"> • Department responsible for policy 	Children and Families	Education	Children and Families	Children and Families – but Ministry of Health provides 20 percent of funding for program.
<ul style="list-style-type: none"> • Administrative responsibility 	Delivered through agencies who receive funding from the Ministry and school districts	Special Education Services	Regional Health Authorities	Regional Public Health Clinics
<ul style="list-style-type: none"> • Eligibility 	<p>Children with special needs, from school entry to school exit.</p> <p>Children at risk of developmental delay.</p>	All school districts in need.	<p>Children and youth under 19 years, who are residents of British Columbia, and require direct nursing care while attending selected community settings.</p> <p>The child must be deemed “stable” by a physician, and have a parent or guardian responsible for care requirements.</p>	<p>Children must be referred by a service provider.</p> <p>All children who are referred are eligible.</p>
<ul style="list-style-type: none"> • Supports 	Provides occupational therapy and physiotherapy services.	<p>Provides essential specialized and adapted learning resources for students who are visually impaired or blind.</p> <p>Items may be borrowed from the Resource Centre for as long as the student is enrolled in the school, at no cost to the school districts.</p>	The In-School Support Services Division provides support to children with special health care needs and their parents by providing comprehensive nursing assessment, planning, intervention, and evaluation of care.	Provides universal identification of hearing loss, assessment of hearing loss, intervention, follow-up, and public education.

Table 10, continued

Program Description	Alberta	Saskatchewan		
	<ul style="list-style-type: none"> • Program Name 	<i>Alberta Learning Early Childhood Services and the Student Health Initiative</i>	<i>Designated Disabled Program</i>	<i>Supplemental Designated Disabled Program</i>
<ul style="list-style-type: none"> • Department responsible for policy 	Learning	Education	Education	Education
<ul style="list-style-type: none"> • Administrative responsibility 	School Boards	Regional School Districts	Regional School Districts	Regional School Districts
<ul style="list-style-type: none"> • Eligibility 	Children assessed with special needs, from school entry to school exit.	<p>Two levels of supports, depending on levels of need and function.</p> <p>Students with severe, low incidence disabilities (intellectual disabilities, chronic illness, orthopedic disabilities, visual disabilities, multiple disabilities, deaf and hard of hearing).</p>	School divisions with students who have severe, low incidence disabilities.	School divisions with students (identified by staff) who have severe social, emotional and behaviour disorders.
<ul style="list-style-type: none"> • Supports 	Enhanced provision of integrated health support services including occupational therapy, physiotherapy, speech, language, audiology, nursing, and respiratory services.	Provides grants to school districts to offer health supports such as occupational therapy, physiotherapy, and speech therapy.	Provides extra funding to school districts that require extraordinary, staff intensive programming.	Provides extra funding to school districts to assist in the delivery of programs to support students with severe social, emotional, or behavioural disorders, or for early intervention programs aimed at the prevention of such disorders.

Table 10, continued

Program Description	Manitoba			Ontario	
	<ul style="list-style-type: none"> • Program Name 	<i>School Age Support</i>	<i>Vision Consultant Services</i>	<i>Services Related to Deaf and Hard of Hearing Students</i>	<i>Health Support Service in School Settings</i>
<ul style="list-style-type: none"> • Department responsible for policy 	Education, Training and Youth	Education, Training and Youth	Education, Training and Youth	Education and Training, Health, and Community and Social Services	Education and Training
<ul style="list-style-type: none"> • Administrative responsibility 	Special Education Support Unit	Program and Student Services Branch	Program and Student Services Branch	Delivery varies by type of support, but may include School Boards, Community Case Access Centres, or Ministry offices	Unknown.
<ul style="list-style-type: none"> • Eligibility 	Children with special needs as defined by the <i>Education Act</i> , from school entry to school exit.	Children with special needs as defined by the <i>Education Act</i> , from school entry to school exit.	Children with special needs as defined by the <i>Education Act</i> , from school entry to school exit.	Children with special needs, from school entry to school exit.	All provincial school boards.
<ul style="list-style-type: none"> • Supports 	Funding grants to Boards. Three levels of funding based on needs assessment.	Provides support services for blind students, and consultants assist schools with expertise that would not otherwise be available.	Provides consultants for schools in rural areas, and American Sign Language instruction.	Provides a range of supports including nursing services, occupational therapy, physiotherapy, respiratory services, and speech pathology.	Provides resource services to school boards and agencies that have hearing impaired, visually impaired and deaf-blind pupils in their jurisdictions.

Table 10, continued

Program Description	Quebec	New Brunswick	Nova Scotia
<ul style="list-style-type: none"> • Program Name 	<i>Integration into Schools</i> (Integration au réseau scolaire)	<i>Special Education</i>	Atlantic Provinces Special Education Authority (APSEA)
<ul style="list-style-type: none"> • Department responsible for policy 	Education	Education	Education
<ul style="list-style-type: none"> • Administrative responsibility 	School Boards	Student Services Unit of the Curriculum Branch, and the Atlantic Provinces Special Education Authority (APSEA)	School Boards, and the Atlantic Provinces Special Education Authority (APSEA)
<ul style="list-style-type: none"> • Eligibility 	Children with special needs (i.e., physical disabilities, behavioural problems or learning disabilities).	Children with special needs as defined by the <i>Education Act</i> , from school entry to school exit.	Children with special needs from school entry to school exit.
<ul style="list-style-type: none"> • Supports 	Provides a range of supports for schools, including funding for the integration of students with disabilities into regular classes and funding for the equipment, adaptation and additional professional services required.	Provides speech and language pathology services, educational and clinical psychology, social work, and health services (such as occupational therapy and physiotherapy services). Also provides support services for children who are blind, visually impaired, deaf or hard-of-hearing.	Provides speech and language pathology services, educational and clinical psychology, social work, and health services (such as occupational therapy and physiotherapy services). Also provides support services for children who are blind, visually impaired, deaf or hard-of-hearing.

Table 10, continued

Program Description	Prince Edward Island		Newfoundland	
• Program Name	<i>Teacher Assistants</i>	<i>Atlantic Provinces Special Education Authority</i>	<i>Special Education Pathways Framework</i>	<i>Atlantic Provinces Special Education Authority</i>
• Department responsible for policy	Education	Education	Education	Education
• Administrative responsibility	English Programs and Services Branch	School Boards	Student Support Services Branch	School Boards
• Eligibility	School Boards that demonstrate need through documentation.	Students with disabilities, from school entry to school exit.	Students with disabilities, from school entry to school exit.	Students with disabilities, from school entry to school exit.
• Supports	<p>Provides schools with a teacher assistant to support students with special needs who have a mental, physical or behavioural disability.</p> <p>The teacher assistant works under the direction of a certified teacher, generally on a one-to-one basis with the student in need.</p>	<p>Provides speech and language pathology services, educational and clinical psychology, social work, and health services (such as occupational therapy and physiotherapy services).</p> <p>Also provides support services for children who are blind, visually impaired, deaf or hard-of-hearing.</p>	<p>Provides a variety of supports in educational settings through the inter-agency Model for Coordination of Services to Children and Youth with Special Needs.</p>	<p>Provides support services for children who are blind or visually impaired, and limited services for those who are deaf or hard-of-hearing.</p>

Table 11
Speech and Language Programs for Preschool and School-Aged Children

Program Description	British Columbia	Alberta	Saskatchewan	Manitoba	
• Program Name	<i>Speech, Language Pathology Services</i>	<i>Alberta Learning Early Childhood Services, and the Student Health Initiative</i>	<i>Special Needs Program</i>	<i>Children's Special Services</i>	<i>Pediatric Speech Therapy (Rural and Northern)</i>
• Department responsible for policy	Children and Families	Learning	Education	Family Services and Housing	Health
• Administrative responsibility	Public Health	School Boards	Regional School Districts	Regional Offices	Community agencies
• Eligibility	Open referral process for preschool or school-aged children for whom there is a concern about communication delay. Open referral process by public health nurse, family doctor, preschool or child care provider, parent, or school.	Children are screened for communication delay at school entry, and those assessed with special needs are supported through school exit.	School districts apply for additional support based on local needs.	Families with a child who is under 18 years, and is assessed by a medical health professional as having a chronic physical or mental disability, or disorder of organic cause.	Preschool children with disabilities.
• Tests	Need	Need	Need	Need	Need
• Supports	Provides assessment and intervention services.	Provides integrated health support services including speech and language supports.	Provides financial grants to support programs and services for students with speech and language disabilities.	Provides a range of community-based supports, which may include speech and language therapy services.	Provides funding to community agencies to provide speech and language therapy services in the family home or in child care settings.

Table 11, continued

Program Description	Ontario			Quebec	
<ul style="list-style-type: none"> • Program Name 	<i>Preschool Speech and Language</i>	<i>Speech Pathology and Audiology</i>	<i>Children's Treatment Centres</i>	<i>Program for Communication Aids</i> (Programmes d'aides techniques à la communication)	<i>Program for People with a Major Functional Disability</i> (Programmes pour les besoins des personnes atteintes d'une déficience fonctionnelle majeure)
<ul style="list-style-type: none"> • Department responsible for policy 	Community and Social Services	Health and Long-Term Care	Health and Long Term Care	Santé et Services sociaux	Education
<ul style="list-style-type: none"> • Administrative responsibility 	Community Care Access Centres	Public Health Units	Special Needs Branch, Integrated Services for Children Division	Marie-Enfant Hospital, and Rehabilitation and Early Stimulation Centres	School Boards
<ul style="list-style-type: none"> • Eligibility 	Children from birth to 4 years, with (or at risk of developing) speech and language disorders.	All children.	Children with the following six diagnoses are served: cerebral palsy; brain injury; developmental or learning difficulties; Down's Syndrome; spina bifida; and autism or Pervasive Developmental Disorder	All ages, who have been assessed as having significant and persistent disability, and for whom technical assistance is essential to communicate.	Students of all ages, with a significant and persistent disability.
<ul style="list-style-type: none"> • Tests 	Need	Need	Need	Need	Need
<ul style="list-style-type: none"> • Supports 	Provides assessment and intervention services.	Provides audiological testing, hearing aid evaluation and prescription, and counselling for the learning impaired in hospitals, children's treatments centres, some health units, and private doctor's offices.	Centres vary in size and scope of services but each provides physiotherapy, occupational therapy, and speech and language therapy as core services. A wide variety of other services and clinics are provided, depending on local needs and the mix of other providers in the community.	Provides technical help for verbal, non-verbal, and written communication and early stimulation services.	Covers the fees for equipment, technical and communication help needed for school integration of handicapped student.

Table 11, continued

Program Description	New Brunswick		Nova Scotia	Prince Edward Island	
	<ul style="list-style-type: none"> • Program Name 	<i>Atlantic Provinces Special Education Authority</i>	<i>Provincial Outreach Therapy for Children</i>	<i>Atlantic Provinces Special Education Authority</i>	<i>Speech and Audiology</i>
<ul style="list-style-type: none"> • Department responsible for policy 	Education	Health and Wellness	Education	Health and Social Services	Education
<ul style="list-style-type: none"> • Administrative responsibility 	School Boards	Hospital Corporations Extra Mural Program	School Boards	Regional Health Authorities	School Boards
<ul style="list-style-type: none"> • Eligibility 	<p>Children from birth to 21 years with a diagnosis of a low-incidence sensory impairment. This includes children and youth who are deaf, deaf and blind, hard of hearing, blind, or visually impaired.</p> <p>Children must be identified by the school district/unit for referral in consultation with the parent or guardian.</p>	<p>Children under 5 are provided with services by the Hospital Corporation.</p> <p>Children aged 5 and over are provided services through the Extra Mural Program.</p>	<p>Children from birth to 21 years with a diagnosis of a low-incidence sensory impairment. This includes children and youth who are deaf, deaf and blind, hard of hearing, blind, or visually impaired.</p> <p>Children must be identified by the school district/unit for referral in consultation with the parent or guardian.</p>	<p>Program serves all ages, but focuses on children from birth to 6 years.</p>	<p>Children from birth to 21 years with a diagnosis of a low-incidence sensory impairment. This includes children and youth who are deaf, deaf and blind, hard of hearing, blind, or visually impaired.</p> <p>Children must be identified by the school district/unit for referral in consultation with the parent or guardian.</p>
<ul style="list-style-type: none"> • Tests 	Need	Need	Need	Need	Need
<ul style="list-style-type: none"> • Supports 	When school boards require assistance in providing for children with low-incidence sensory impairments, the APSEA supports a service delivery system that assists in meeting the educational needs of these children.	Provides assessment and intervention services.	When school boards require assistance in providing for children with low-incidence sensory impairments, the APSEA supports a service delivery system that assists in meeting the educational needs of these children.	Provides assessment and intervention services including articulation, language training, voice assistance, and fluency training.	When school boards require assistance in providing for children with low-incidence sensory impairments, the APSEA supports a service delivery system that assists in meeting the educational needs of these children.

Table 11, continued

Program Description	Newfoundland	
• Program Name	<i>Speech and Language Services</i>	<i>Atlantic Provinces Special Education Authority</i>
• Department responsible for policy	Education	Education
• Administrative responsibility	Student Support Services Division	School Boards
• Eligibility	Program serves all school aged children	<p>Children from birth to 21 years with a diagnosis of a low-incidence sensory impairment. This includes children and youth who are deaf, deaf and blind, hard of hearing, blind, or visually impaired.</p> <p>Children must be identified by the school district/unit for referral in consultation with the parent or guardian.</p>
• Tests	Need	Need
• Supports	Provides screening, assessment and intervention services.	When school boards require assistance in providing for children with low-incidence sensory impairments, the APSEA supports a service delivery system that assists in meeting the educational needs of these children.

Table 12
Individual Health and Rehabilitation Services for Children with Disabilities

Program Description	British Columbia		Alberta	Saskatchewan
• Program Name	<i>Early Intervention Services</i>	<i>School-Aged Therapy Services</i>	<i>Community Rehabilitation Program</i>	<i>Home Care</i>
• Department responsible for policy	Children and Families	Children and Families	Health and Wellness	Health
• Administrative responsibility	Contractual arrangements with community service providers	Delivered through agencies that receive funding from the Ministry and school districts.	Regional Health Authorities	District Health Boards
• Eligibility	Children from birth to school entrance age, who are at risk of developing a disabling condition.	Children with special needs, from school entry to school exit. Children at risk of developmental delay.	All Alberta residents with a valid health card, who have been referred by a health care professional.	All Saskatchewan residents with a health card, who have been referred by a health care professional. Only about 4 percent of program serves children with disabilities.
• Tests	Need	Need	Need	Need Income
• Supports	Provides coordination for community and tertiary pediatric rehabilitation and supports including professional guidance/support, speech and language pathology, occupational therapy, physiotherapy, and family support workers.	Provides occupational therapy and physiotherapy services.	Provides a variety of supports, which may include audiology, occupational therapy, physiotherapy, and respiratory therapy.	Provides a variety of services, which may include occupational therapy, physiotherapy, meals, and homemaking.

Table 12, continued

Program Description	Manitoba	Ontario			Quebec
• Program Name	<i>Provincial Outreach Therapy for Children</i>	<i>Infant Development Program</i>	<i>School Health Support Services</i>	<i>Children's Treatment Centres</i>	<i>Rehabilitation Services (Services de réadaptation)</i>
• Department responsible for policy	Family Services and Housing	Community and Social Services	Community and Social Services	Health and Long Term Care	Santé et Services sociaux
• Administrative responsibility	Funded community agencies	Community Care Access Centres	Community Care Access Centres	Special Needs Branch, Integrated Services for Children Division	Regional Health Authorities
• Eligibility	Children from birth to five years or school entrance with a developmental disability, risk of a developmental disorder, autism spectrum disorder, physical disability, or lifelong complex medical needs resulting in a dependency on medical technology.	Children from birth to 4 years, with physical or developmental disability.	Children who have been assessed with medical needs.	Children with the following six diagnoses are served: cerebral palsy; brain injury; developmental or learning difficulties; Down's Syndrome; spina bifida; and autism or Pervasive Developmental Disorder	All ages, who have a significant and persistent disability.
• Tests	Need	Need	Need	Need	Need
• Supports	Provides funding to community agencies to provide occupational therapy, physiotherapy, and speech therapy services delivered in the home, child care setting, or school.	Provides a range of supports including physiotherapy, occupational therapy, speech therapy, and audiology services.	Provides a variety of services, which may include occupational therapy, physiotherapy, and respiratory therapy.	Centres vary in size and scope of services but each provides physiotherapy, occupational therapy, and speech and language therapy as core services. A wide variety of other services and clinics are provided, depending on local needs and the mix of other providers in the community.	Provides rehabilitation, adaptation, and community integration services.

Table 12, continued

Program Description	New Brunswick	Nova Scotia	Prince Edward Island	Newfoundland
• Program Name	<i>Rehabilitation Services</i>	<i>Rehabilitation Services</i>	<i>Community Supports</i>	<i>No program.</i> <i>Services provided by hospitals.</i>
• Department responsible for policy	Health and Wellness	Health and Welfare	Health and Social Services	
• Administrative responsibility	Hospital Corporations Extra Mural Program	District Health Authorities	Regional Health Authorities	
• Eligibility	All ages, as assessed by health care professionals.	All ages, assessed by a health care professional.	All ages, assessed by a health care professional. Eligibility varies by region.	
• Tests	Need, but families are expected to make some financial contribution based on net income, family size, and ability to pay.	Need	Need	
• Supports	Provides institutional and community-based supports including audiology, occupational therapy, physiotherapy, and speech therapy.	Provides institutional and community-based supports including audiology, occupational therapy, physiotherapy, and speech therapy.	Provides a variety of services, which may include occupational therapy, physiotherapy, and speech therapy.	

Box 1

Provincial Early Childhood Development Policies and Programs Promoting Child Well-Being and Healthy Development

British Columbia: The Ministry of Children and Families is responsible for the policy direction for early childhood promotion, prevention and early support activities. The province offers a range of programs targeted at preschool children. The *Family Support Services* program offers prenatal outreach, parenting support and home support services. *Public Health Services* provide speech and language services, nutrition, and dental care in partnership with regional health authorities. The *Public Health Nursing Program* provides prenatal, preschool and early school age screening, assessment, education, service coordination and referral services mainly related to growth, development and communicable disease. *Public Health Speech and Language Programs* serve preschool children at risk of or who have identified communication disabilities. The *Public Health Audiology Program* gives priority to infants and children needing services such as hearing loss identification, assessment, case management, education and rehabilitation. *Public Health Nutrition Services* include training, support and consultation through activities such as pregnancy outreach programs, kindergarten nutrition screening, and school meal programs. *Public Health Dental Services* include education and screening provided by dental hygienists and dental assistants.

Alberta: In Alberta, early childhood development programs come out of the *Alberta Children's Initiative* and are delivered through a decentralized structure. The Alberta Child and Family Service Authorities (CFSAs) work in partnership with the Ministry of Children's Services (and other agencies) to manage responsibility and delivery of services and resources. In 2000, the government created the Family and Community Support Services Advisory Team to develop a prevention and early support measurement framework to meet the needs of individual family, community support programs, and municipalities. The *Fetal Alcohol Syndrome Project* is a provincial program which aims to raise awareness, education, and piloting of strategies to reduce risk in high-risk populations and support regional resource development.

Saskatchewan: The Saskatchewan Action Plan for Children is an intersectoral strategy aimed at the development of policy options to implement more effective, integrated and comprehensive supports for young children and their families. The proposed policy framework was released in April 1999 and provides a vision, goals and principles to guide the development of community-based strategies. It outlines a comprehensive approach to meeting family needs and includes programs for prenatal supports, early screening for risk factors, services and supports to all families based on their needs, and follow-up and evaluation. In addition, the province is in the process of developing a long-term *Early Childhood Initiative* (as a part of the Action Plan) which will co-ordinate government programming for children in collaboration with community groups. In March 2001, the government announced \$75 million for early childhood initiatives.

Manitoba: Manitoba's *Healthy Child Initiative* is a cross-departmental strategy to develop programs for children from birth to six years. The Initiative includes a variety of programs under the responsibility of several ministries. The *Fetal Alcohol Syndrome program* provides a variety of activities to prevent FAS and to assist those already affected by alcohol. The *Baby First program* provides home monitoring services for overburdened mothers of newborns and is delivered by Regional Health Authorities. The *Prenatal and Early Childhood Nutrition Strategy* aims to increase prenatal and early childhood nutrition support through primarily through interdepartmental and intersectoral coordination and integration.

Ontario: Early Childhood Development programs in Ontario are coordinated through the Children's Secretariat. The *Healthy Babies, Healthy Children Program* is part of a province-wide network of prevention and early intervention services for families. The program puts into place community-based services to help mothers to learn to care for their babies and are delivered through Public Health Units. The *Best Start: Community Action for Healthy Babies program* is designed to promote the health of women before and after pregnancy by offering program resources, training and consultation to mothers. The *Better Beginnings, Better Futures program* operates in eight "high-risk neighbourhoods" and is designed to prevent emotional, behavioural, social, physical and cognitive problems, and to promote healthy child development. Services include home visits, and in-class and in-school assistance for primary schools. As well, the program operates community activities such as drop-in centres, recreation programs, breakfast/lunch programs, parents training and single-parent support groups. *Preschool Speech and Language programs* are provided through a system of services for children from birth to age 4 with speech and language disorders. Services provide early identification, access and support for parents and caregivers.

Box 1, continued

Quebec: Quebec delivers many health services, including pre- and post-natal services and early intervention through its network of CLSCs (*Centres locaux de services communautaires*). The Ministry of Child and Family Well-Being is directly responsible for developing and maintaining a provide-wide network of child care services. The province has developed a range of specialized programs, but most of its investment has been put into the educational component of the *Early Childhood Centres* and kindergarten. Developed in 1997, the policy includes kindergarten for five-year-olds, and junior kindergarten for four-year-olds living in disadvantaged neighbourhoods. As well, child care is a universal service, available at a fixed price of \$5 per day, and includes a developmental curriculum for all age levels from infants to four-year-olds. Quebec's approach is universal, rather than a targeted strategy for meeting the developmental needs of children.

New Brunswick: *Early Childhood Initiatives* program combines Public Health, Family and Community Social Services, and Mental Health Services to help ensure that children have the best opportunity to thrive and to successfully meet learning challenges prior to school-entry. ECI services may be provided before a child is born if a Public Health Nurse deems an expectant mothers at risk for health problems which the health of their unborn child. ECI services are provided by Public Health nurses and include pre-natal education, home visits, nutritional information and supplements. As well, the program mandates that Public Health nurses and hospital maternity nursing staff assess all new mothers and their infants. Based on these assessment results, mothers and infants identified as moderate-to-high risk for developmental delay are offered additional ECI supports including postnatal intervention services such as home visits, parent education, counselling and nutrition supplements. ECI Social Services are designed to support "at-risk" parents and contribute to the child's overall development in preparation for school-entry. These services may include: home-based early intervention services; day care services; early childhood social workers and home economists supports. Finally, the ECI program provide health clinics to conduct assessments on all 3.5 year olds for vision, hearing, dental, speech/language developmental, mental health/behaviour, safety, physical growth/development and nutrition. If problems are detected then referrals are made to the appropriate service (in consultation with parents/guardian).

Nova Scotia: The *Healthy Child Development Initiative* offers a range of community-based programs through existing partnerships with public and private agencies which aim to support the family unit and foster healthy child development. *Child Development Centres* provide grants enabling preschool children from disadvantaged families, and children-at-risk to participate in a 'head start' or enrichment program. *Early Intervention Services* includes eleven programs across the province. The goal of the programs is to help children from birth to five years of age with developmental disabilities reach their potential by working directly with children and families in their homes. Grants are provided to support parent education programs, community-based prevention programs, and parent support programs. In addition, the government announced funding increases to expand centre-based child care and increase quality child care options for low-income families living in rural areas of the province.

Prince Edward Island: The Strategy for *Healthy Child Development* was announced in the 1999 Speech From the Throne. It is a provide-wide, five-year strategy supporting children from the prenatal period through early school years. The focus is on developing programs aimed at prevention, early intervention, and community involvement. In its Summary Report (October 2000), the Healthy Child Development Advisory Committee, identifies 13 areas for action including: pregnancy, birth and infancy; early childhood care and education; children with exceptional needs; childhood injury; children's mental health; family literacy; parent support; screening and assessment; protecting children; environment; technology; public education and building a children's continuum.

Newfoundland: The *Healthy Beginning Program* provides early assessment and prevention supports through home visits by a Community Health Nurse to all expectant mothers. The nurses provide education, support, and referral services and play a key role in the early detection of children who may develop a low/medium/high disabling condition. Individuals are referred to appropriate services/supports on a need basis.

Box 2

Tax Measures Affecting Parents of Children with Disabilities (1996-2000)

1996

- Expanded the zero-rating of orthopedic and orthotic devices under the GST.
- Enriched the tax credit for infirm dependants.

1997

- Broadened the Medical Expense Tax Credit.
- Introduced a refundable medical expense credit for earners.

1998

- Introduced a tax credit for caregivers who care for related seniors and persons with disabilities.
- Included a training expenses for caregivers in the Medical Expense Tax Credit.
- Permitted occupational therapists and psychologists to certify individuals for the Disability Tax Credit.
- Exempted respite care services from GST/HST.

2000 Budget

- Extended the eligibility for the Disability Tax Credit to individuals requiring extensive therapy.
- Expanded the list of relatives to whom the Disability Tax Credit can be transferred.
- Increased the credit for families caring for children eligible for the Disability Tax Credit to up to \$500.
- Increased the maximum child care expense deduction available with respect to persons eligible for the Disability Tax Credit from \$7,000 to \$10,000.
- Extended the available tax assistance for expenses relating to the costs of adapting a new home to the needs of a disabled person.
- Expanded the attendant care deduction to include the cost of an attendant required for a person to attend school.
- Increased the deductible amount for the Disability Tax Credit from \$4,293 to \$6,000 for 2001. As a result, the income threshold at which the refundable medical expense supplement for earners begins to be phased out is expected to increase from \$17,663 to about \$19,705, taking into account indexation.
- Increased the credit for families eligible for the caregiver tax credit to up to \$3,500.
- Increased the credit for families eligible for the infirm dependant tax credit to up to \$3,500.
- Increased the eligible amount for the supplement to the Disability Tax Credit for children with severe disabilities to \$3,500.

Source: Finance Canada, "Measures to Enhance Tax Fairness and Achieve Economic and Social Objectives (1994-2000)," *Economic Statement and Budget Update 2000, Annex 2-3*. See <http://www.fin.gc.ca/ec2000/eca2ce.htm>.

Box 3

Extra Support Targeted for Rural Areas to Address the Needs of Children with Disabilities

Saskatchewan: The *Community Solutions* Program is the responsibility of the Ministry of Social Services, and is administered by the Special Needs Program Branch. The program provides funding to community agencies that develop initiatives to promote and support the inclusion of children with special needs, and that meet the needs of rural and northern communities. Priority is given to initiatives that seek partnerships and collaboration with other community groups and agencies, and/or include shared service delivery. The program's central focus is on meeting the early childhood needs of children and their families by providing funding to initiatives that have an attachment to child care services.

Manitoba: The *Pediatric Speech Therapy (Rural and Northern) Program* is the responsibility of, and administered by, the Ministry of Health. It provides special funding for speech and hearing services for children of all ages in rural areas. In addition, the program allocates some funds to the Ministry of Family Services and Housing through the Children's Special Services program to offer enhanced speech therapy for preschool children with lifelong disabilities, who are living in rural areas.

Ontario: The *Integrated Services for Northern Children Program* is the joint responsibility of the Ministries of Health, Community and Social Services, and Education. Local offices of the Ministry of Community and Social Services administer the program. The program targets all children with physical, developmental, and mental disabilities, who are living in northern communities. It provides an integrated network of physical, mental health, and special education services to children and families in the rural north. Programs focus on physical, psychosocial, behavioural, and educational problems.

Quebec: The *Service de déplacement des personnes handicapées* (moving service for handicapped people) is offered to people who cannot receive the health services they need in their region. CLSCs (*Centres locaux de services communautaires*) cover all the travelling and accommodation expenses for the handicapped person and their companion in order to acquire appropriate health services.

Box 4

Special Initiatives for Children with Autism or Autistic-like Tendencies and Their Families

Children with autism or autistic-like tendencies have become a priority in some provinces. Autism is a congenital developmental disorder present at birth, which is characterized by problems in three areas – social development, communication, and behaviour. It is often very difficult for families with an autistic child to manage their complex needs. The following provinces have responded with special initiatives directed at assisting families with an autistic child or a child with autistic-like tendencies.

British Columbia: The *Behavioural Support for Children with Autism Program* is the responsibility of the Ministry of Children and Families, and is administered by local agencies contracted by the Ministry. Children and youth who have been diagnosed with autism or autistic-like tendencies by a medical practitioner in consultation with families are eligible for the program. As well, children can enter the program through self-referral from family and/or community services professionals (medical practitioners, therapists, school counsellors, public health nurses). The program provides supports to families through the determination of behavioural change goals, developing plans, and the use of applied behavioural analysis procedures.

Manitoba: Manitoba has a three-year *Applied Behaviour Analysis (ABA)* demonstration project for 15 children in the province. ABA is a form of therapy based on the principles of behavioural psychology. The demonstration project is operated by St. Amant Centre (a development resource centre) and funded by Healthy Child Manitoba. A Steering Committee includes representatives from the Departments of Health; Education, Training and Youth; and Family Services and Housing, as well as members from Manitoba Families for Effective Autism Treatment, the Autism Society, Regional Health Authorities, and the Student Services Administrators of Manitoba. The province also has an *Autism Outreach Program* that is delivered in partnership by Child and Adolescent Psychiatry and the Child Development Clinic of the Children's Hospital, and Family Services and Housing's Children's Special Services Program. The goal of the program is to assist families and child care centres develop individualized programs to meet the needs of children with autism.

Ontario: The *Intensive Early Intervention Program for Children with Autism* is the responsibility of the Ministry of Community and Social Services, and is administered by local agencies contracted by the Ministry. Children from birth to age 5 years, diagnosed with autism, are eligible for the program. In addition, children who are not identified with autism until they are 5 or 6 years old are eligible for program support for up to 12 months. The range of supports varies based on individual assessment, but can include intensive behavioural intervention, training, and referrals. The family can choose to access supports from therapists employed by regional programs, or receive direct funding to employ private therapies.

Nova Scotia: The *Early Identification and Intervention Services Program* is in the development phase and is expected to be operational in the near future. Its development is being coordinated by an interdepartmental committee with representatives from the Ministries of Community Services, Health and Education. The program will provide identification, assessment and intervention services for children from birth to 6 years who have been diagnosed with autism. The long-range plan is to expand the program to provide coordinated services and supports to all special needs children.

Prince Edward Island: The *Autism Early Intervention Program* is coordinated by the Provincial Autism Committee, and is administered by regional health authorities, the Ministry of Health and Social Services, the Ministry of Education, School Boards, and community-based organizations. Children diagnosed with autism and referred by family or by a health care professional are eligible for program supports. The program provides regional clinics, parent information and resources, home-based early intervention, and support for children to participate in licensed early childhood programs.

Newfoundland: The *Autism Pilot Project* is a two-year early intervention project offered through the Ministry of Health and Community Services. It provides support for 35 children diagnosed with autism, referred by provincial diagnostic centres.

Appendix B Roundtable Participants

Thursday, May 3, 2001 – Enabling Citizenship

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Thursday, May 3, 2001 – continued

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Friday May 4, 2001 – Governing in an Integrated Fashion

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Appendix C

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CPRN Funding Sources

Core Funders

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Fisheries and Oceans
Health Canada
Human Resources Development Canada
Public Works and Government Services Canada
Transport Canada

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Canadian Pacific Charitable Foundation
Clarica
Hydro Québec
IPSCO Inc.
Noranda Inc.
Power Corporation of Canada
The Bank of Montreal
The Royal Bank of Canada
Scotiabank
Sun Life Assurance Company of Canada

Family Network Support

Canadian Pacific Charitable Foundation

Project Funders

Alberta Children's Services
British Columbia Ministry for Children and Families
Health Canada, Childhood and Youth Division
Hospital for Sick Children Foundation
Human Resources Development Canada, Social Policy Directorate
Ontario Ministry of Community and Social Services
Saskatchewan Social Services