



CPRN Discussion Paper

Governing in an Integrated Fashion: Lessons from the Disability Domain

By Michael J. Prince, Ph.D.

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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 second paper, on the governance regime affecting Canadian children with disabilities and their families, was written by Michael Prince of the University of Victoria. The paper identifies the governance and accountability structures that will allow an agenda of childhood development, family support, and social inclusion for children with disabilities to move forward in Canada. It includes 25 summary boxes, which detail the components and activities of the five sectors involved in this regime in Canada – the family and informal support sector, the voluntary sector, the commercial sector, the public sector, and the Aboriginal sector. He finds a circular and repetitive discourse on disability reform in Canada and a frustratingly slow pace of actual reform, and he draws seven key lessons from this analysis of the governance regime. Significant and lasting reforms must address *all* parts and levels of government, *all* processes of governing, and *all* sectors of society if we are to ensure the inclusion of *all* of Canada's children and families in Canadian society,

I wish to thank Michael Prince for effectively disentangling and analyzing the complex governance regime affecting children with disabilities and their families. 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.

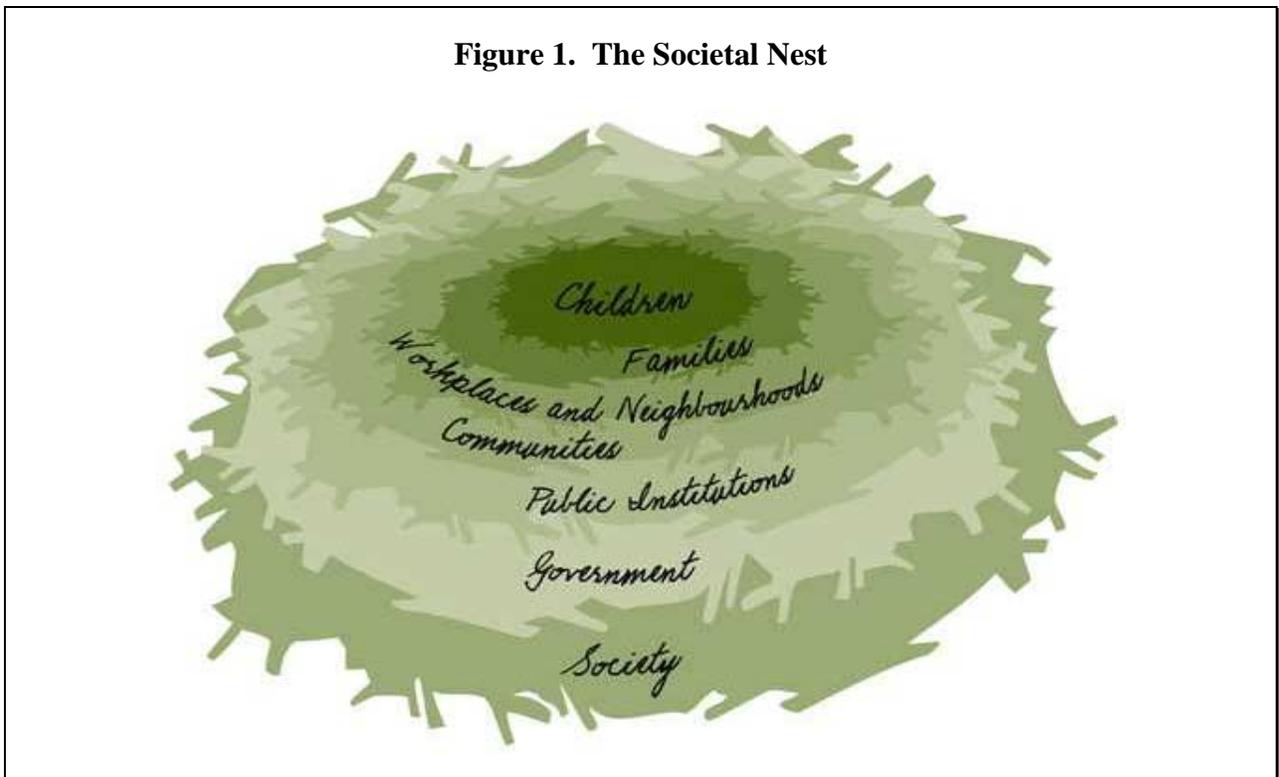
In order to have a best policy mix for children, we need:

- 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 second 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. It derives from the *Best Mix* examination of governance and accountability issues in children's policy to describe and analyze the governance regime affecting Canadian children with disabilities and their families. It identifies the governance and accountability structures that will allow an agenda of childhood development, family support, and social inclusion for children with disabilities to move forward in Canada. The ultimate intent is to encourage changes on multiple fronts that will improve governing practices such that when we say "all children" we truly mean all children.

The governance regime for children with disabilities is broadly defined. It includes not only the governmental machinery of the public sector but also governing structures and practices in families and informal support networks, and in the voluntary, commercial, and Aboriginal sectors. Each of these sectors is examined in relation to a standard set of questions: Who are the major actors in policies for children with disabilities and their families? What governance roles does the sector perform? What are the defining trends that characterize the sector in the present age? What public values and policy issues are at stake?

A Regime with Five Sectors

Families remain the most important source of long-term care and assistance for people with disabilities, whether a child, a youth or an adult. Evidence indicates that families are bearing more than their fair share of the costs of caring for their children, however. As a society, it seems we still believe that public services and social programs are, for the most part, residual to family responsibility. How else can we explain the heavy burdens and expectations imposed on families to care for their own members – with parents giving up their paid jobs, drawing down their savings, refinancing their homes, and perhaps seeking assistance from relatives, when and where available, or going on income assistance.

A true vision of full citizenship in regards to disability policy must directly consider these realities of parents who have children with disabilities. The right of these parents to a full life includes their status as parents with other children, as partners in a marriage or common-law union, as adults in or out of the paid labour market, as volunteers in community affairs, and as citizens wishing to participate in policy making and other political processes. At present, the governance regime tends to treat parents and families as *clients* and as sources of personal resources to address the needs of their children, rather than as *governors* with the right of self-determination and the capacity to manage resources themselves.

The *voluntary sector* faces both opportunities and risks in becoming greatly involved in the delivery of public programs and in meeting community needs through multilateral partnerships with government agencies. However, expanding the use of volunteers in the provision of health and social services poses some dilemmas for social policy and for the essence of citizenship in Canada. Since charity is voluntary action, the nature and scope of assistance remains unspecified and uncertain. Those in need do not have any right to assistance from private sources.

The *commercial sector* is the iceberg of the child and disability governance regime. It does not have a high profile in most debates on policy and service delivery. Not much is known about it within this policy domain, although we have a strong sense that, like an iceberg, there is a great deal that exists below the surface. As well, some groups are quite cool toward the commercial sector, seeing it as a threat to progressive reform in advancing citizenship and human rights for children with disabilities and their families.

As part of the commercial sector, professions often play a critical role in developing and shaping the identity and status of clients through their tools of assessment and diagnosis. Through processes of training, socialization and codes of practice, professionals are purveyors of a given paradigm toward children and families, toward disabilities, and toward health and wellness. The mass media is another component of the commercial sector that is clearly crucial to constructing the identity of children and adults with disabilities for the public and for policy makers. Their influence is wielded through the use of outmoded or inclusive language, and images that emphasize differences, sympathy and charity or dignity, self-determination and citizenship.

A concern with the *public sector* governance regime for children with disabilities and their families is the absence of clear, consistent and central accountability mechanisms. In the critical areas of health care and public education, regionalization has resulted in fewer and larger locally elected community forms of governance. The downloading of responsibilities to municipalities for assorted social programs, without commensurate transfers in sustainable budgetary resources, has squeezed the capacity of city governments to effectively address issues of community health.

For *Aboriginal peoples* in Canada, a widely shared and deeply felt belief is that children are a gift from the Creator and that each child is part of what makes a community whole. The birth rate of Aboriginal peoples is twice the Canadian average and has been for a number of years, resulting in the Aboriginal population being much younger as a whole. Behind these eloquent beliefs and significant demographic trends, however, are some extremely distressing indicators about the life situation of Aboriginal children and youth.

The governance regime in Canada's public sector adds a further heavy burden and set of barriers for Aboriginal children and youth with disabilities. In the area of special education, there is a critical lack of funding in First Nation communities and federal schools. A further problem is that the existing formal and standardized assessment tools for special education were developed from and for the mainstream non-Aboriginal population. This raises the understandable concern of the cultural biases and technical inadequacies of such tools for Aboriginal children and youth with special needs.

Over the past few decades, the voice of Aboriginal people with disabilities has grown stronger, with the emergence of a substantial number of organizations dedicated to Aboriginal disability issues and to Aboriginal youth. The Assembly of First Nations has taken a leadership role in formulating a position on disability issues. Aboriginal leaders stress the fiduciary and moral obligation of the government of Canada to provide for the health care and special education needs of Aboriginal peoples.

For the foreseeable future, all five sectors will continue to operate in this policy field. Restraint and retrenchment of the public sector's role in education, health, income support and social services during the last few decades in Canada has put additional expectations, demands and stresses on families, voluntary sector agencies, and Aboriginal communities. Public sector restraint may also have created certain consumer demands and business opportunities for the commercial sector.

Seven Lessons from the Disability Domain

There is a déjà vu discourse on disability reform in Canada – a strong sense that we have been here before. We find a circular repetition of words and ideas, the declaration of plans and promises, followed by external reviews of the record, and then governmental responses with a reiteration of previously stated plans and promises. This frustrating pace of reform is due to public attitudes and lack of information; the relative powerlessness of families of children with disabilities; the constraints of the economic context and public finances; federalism in the form of inter-jurisdictional bargaining, buck-passing and suspicion; and bureaucratic factors and weak accountability mechanisms.

Seven key lessons can be drawn from this analysis of the governance regime for children with disabilities and their families:

1. Canadian social programs and services for families with children generally, and for families who have children with disabilities more specifically, embody assumptions about the responsibilities and capacities of families, informal helping networks, voluntary groups, communities, and other social arrangements. These assumptions must be surfaced and critically examined as to their effects and appropriateness.
2. Reforms to the governance regime are desirable from both an individual and societal perspective, in order to address power imbalances and to promote fuller citizenship for children with disabilities and their families. Given disparities in economic and social status, reforms are wanted and expected by families, parent groups, youth, disability organizations, other voluntary sector groups, service providers, and Aboriginal communities.
3. The public sector has primacy in shaping the governance regime in terms of setting policy and establishing a legal and fiscal context within which other sectors operate. At the same time, it is inaccurate to think that the traditional approach to disability issues involved only government responsibility (that is, the public sector) and that the new vision is to move towards shared responsibility by all sectors. In fact, the approach always was, and still is, multi-sectoral.
4. Minor tinkering with programs and structures will simply perpetuate the frustrating pattern seen over the past generation, with disability issues seemingly trapped in a circle. Fundamental reforms in several arenas are essential for advancing the vision of full citizenship and inclusion for *all* children, including those with disabilities, and their families.

5. An overarching policy discourse, while useful, is far from enough to ensure horizontal coordination. What are also needed are agreed-upon outcomes, indicators, and information systems to track, assess and report on performance results.
6. There is no universally “best” governance regime for Canada’s children with disabilities and their families. Debates over the mix of roles among the sectors will never be settled, as there will always be disagreement about the proper balance to be reached. However, there are many practices deemed highly unsatisfactory, others regarded to be effective, and still others viewed as promising directions for future development.
7. Many reforms to disability programs and services have not withstood the winds of change, probably because the reforms were neither legislated nor designed as entitlements, but rather were created as discretionary benefits. Any effective strategy for reform must recognize where power is located in governments, and on how power is mobilized and then exercised.

To ensure the inclusion of *all* of Canada’s children and families, significant and lasting reforms must address *all* parts and levels of government, *all* processes of governing, and *all* sectors of Canadian society. In policy terms, the integration of people with disabilities has an important dualism. First, it means building disability considerations into all mainstream programs and policies. At the same time, it means supplementing mainstream programs where necessary with complementary services and supports for addressing the additional disadvantages faced by children and adults with disabilities.

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Governing in an Integrated Fashion: Lessons from the Disability Domain

By Michael J. Prince¹

1.0 Introduction

The purpose of this paper is to describe and analyze the governance and accountability structures that will allow an agenda of childhood development, family support, and social inclusion for children with disabilities to move forward in Canada. The governance regime for children with disabilities is broadly defined. It includes not only the governmental machinery of the public sector but also governing structures and practices in families and informal support networks, and in the voluntary, commercial, and Aboriginal sectors. We examine the institutions that define the state and civil society in the conduct of disability policy, with reference to children and their families in Canada at the dawn of the 21st century. This means a focus on *governance*, rather than simply on government and the public sector.

Parliamentarians, public interest groups, and parents regularly mention matters of governance as a significant cause for the sluggish pace of reform. The paper therefore examines the reasons why there has been relatively slow movement on the disability agenda in Canada in recent years, especially when compared to the National Children's Agenda. Moreover, we offer suggestions on how to promote more inclusive, accountable, and integrated decision-making and service delivery in public policy, as it relates to children with disabilities and their families. The intended result is a set of recommendations that will help advance the policy agenda and improve governing practices so that when we say "all children" we truly mean all children.

The paper is organized in four sections. The rest of Section 1 presents the conceptual framework that guides the subsequent analysis. The ideas of government, state, and governance are outlined, as are the concepts of the governance regime, disability policy, and accountability. Section 2 describes the roles of the personal and informal support sector, the voluntary sector, the commercial sector, Canada's public sector, and the Aboriginal sector in relation to policies that have a bearing on children with disabilities and their families. Important trends and issues in the governance of Canadian disability policy are also identified. The scope of the analysis is a broad scan of structures and roles, not a detailed inventory of programs.²

¹ An earlier version of this paper was presented at a CPRN Roundtable held in Ottawa on May 3 and 4, 2001. I am grateful to Jane Jenson and Sharon Stroick for their invitation and support, and to the Roundtable participants for their constructive and challenging comments. I thank, in particular, Gwen Burrows, Diane Richler, Dawn Walker, and Bill Young for their specific comments and detailed suggestions.

² For an overview of Canadian policies and programs for children with disabilities and their families, see the companion report to this paper, *Enabling Citizenship: Full Inclusion of Children with Disabilities and their Parents*, written by Fraser Valentine (2001).

Section 3 examines the question of why, despite considerable attention to disability issues of late, there has been so little action by governments in particular to make the regime more inclusive of children. Section 4 draws several lessons from the analysis and articulates a set of preferred values and goals with respect to a substantially reformed governance regime. Appendix A outlines a comprehensive set of recommendations for reforming the governance regime of disability policy making, within the public sector and extended to the other sectors and their inter-relationships.

1.1 Disability Policy – A Socio-Political Ecology

Thinking of how individuals, families and communities adapt, shape and respond to their surroundings is to take an ecological perspective on human and social development. Emphasizing the significance of connections between people and their environments is an approach prominent in fields such as social work practice, and child and youth care. Based on a rich body of research and professional experience, the ecological perspective convincingly argues that “family, community, and societal environments affect individuals and, in particular, the ability of parents to care for their children” (Wharf, 1992: 33). The needs of children and their parents are “nested” in multiple environments including the family, informal support networks, workplaces and neighbourhoods, which are, in turn, situated in geographic and political communities, and in wider institutions.³ Each part of this social ecology provides resources and policies – as well as opportunities and constraints – that influence the capacity of families and children to function well.

Similarly, we can suggest that disability policies and programs are nested in multiple environments – an assortment of policy fields, institutional sectors, and government jurisdictions and organizations – which interact in diverse and changing ways. The multi-level, multi-sector focus of the ecological approach is compatible with our system of federalism and our increasingly pluralistic society and system of welfare provision (Rice and Prince, 2000: 222). The ecological approach recognizes, perhaps even expects, that policies and practices operate at the local, provincial-territorial and national levels of government, as well as across the public and private sectors, in Aboriginal nations and communities, and in family systems.

Adding a political dimension to this ecological perspective helps us to better understand how policy changes happen or are stalled. A political perspective of the social ecology recognizes that there is an unequal distribution of power and influence in policy processes and governance regimes. Further, it acknowledges that certain individuals and groups are economically and socially disadvantaged and marginalized, and that the politics of policy domains include both organized mobilization for and resistance to social change. This view fits well with the socio-political model of disability, which holds that attitudinal, economic market, legal and policy barriers, rather than physical and developmental limitations, are the main difficulties preventing people with disabilities from participating fully in society (Jongbloed and Crichton, 1990). The reform focus thus centres on altering environmental barriers, changing laws and programs, and advancing human rights.

³ This is the approach also used in Jenson and Stroick (2000).

Fox and Willis (1989: 1) describe the commonly employed phrase *disability policy* as “a convenient and recognizable, though still inadequate way, to characterize interventions that seek to enable people with impairments to live in ways that are personally satisfying and socially useful.” From this *conventional perspective*, as they call it, disability policy is about methods and processes, and about what interventions are available or desirable. Disability is, therefore identified as a category of social need, which is a risk or hazard to personal and family security.

Disability policy-making is about formulating and providing benefits and services for people in need who have disabilities or who are at risk of developing a disabling condition. It is about the things that governments expressly do – to, with, and for people with disabilities and their families. In turn, disability policy analysis involves describing and explaining the goals, instruments, and processes of these interventions.

By way of contrast, Fox and Willis then define disability policy from the perspective of people with disabilities. Here, disability policy is about addressing results and focusing on “what people aspire, or could aspire, to do.” Disability policymaking is, or should be, about “enabling people to function in and contribute to society” and about addressing “what individuals should be enabled to do for themselves and for others” (1989: 3). Thus, policy analysis from this perspective involves examining and assessing the impact of all programs on the aspirations and capacities of people with disabilities, their families, and related networks. This can be described as a *disability perspective*, and is the one adopted in this report.

Aspects of both the *conventional* and *disability* perspectives are evident in Canadian policies, programs and popular discourse. Disability policy and governance in Canada, as we will show, has traditionally been viewed as, and frequently remains today, a dimension or segment of the health, education, social services, and income security fields. In the past decade, however, disability policy has also begun to be defined and treated as a distinct domain or overarching policy file. At the level of intergovernmental relations, as well as for certain governments, within the disability community of national organizations, and within the Aboriginal domain, there is evidence of general strategies that seek to link together various programs and activities with a set of guiding principles and shared objectives, or a common vision.

With a multi-sector approach to governance, disability policy encompasses the goals, decisions and actions of authoritative actors in governments, Aboriginal governments, agencies, communities, families and their informal networks of support and care, and in the great variety of organizations within the voluntary and commercial sectors. To give one example – children with disabilities both need and deserve to play and participate with other children, and recreational programs offered by all sectors can give them an opportunity to do so. Box 1 portrays something of the broad contemporary content of disability policy.

Box 1
Major Program Components of Disability Policy in Canada

Income Security	Veterans Affairs
Health Care and Wellness	Workers' Compensation
Education and Learning	Mutual Aid, Self-Help and Voluntary Action
Child Care and other Social Services	Criminal Justice
Housing	Human and <i>Charter</i> Rights
Transportation	Community Supports and Services
Employment and Training	Communications and Broadcasting
Recreation, Sports and Leisure	Social Planning and Research
Aboriginal Affairs	Labour Codes and Workplace Standards
Individual Funding	Cultural Heritage
Access to Buildings and Facilities	Social Marketing and Public Awareness
Taxation and other Fiscal Arrangements	Corporate Social Responsibility Activities

From an enabling viewpoint, *any* policy is a disability policy if it supports and includes people with disabilities. Along with providing programs and services, redistributing income, and regulating behaviours, disability policy entails constructing a discourse through the creation of structures and practices. The official delineation of disability policy in terms of scope, goals, and priorities is a fundamental part of the governance process. Different governments and different sectors put an emphasis on varied mixes of these policy fields and program elements, informed by their distinctive histories, resource capacities, and overall agendas and priorities.

1.2 Citizenship and Human Rights for Children, Parents, and Families

As living concepts, citizenship and human rights are classic, cozy, complex, contested, and critical ideas. Both are classical ideas in the history of political thought and action; both are cozy or welcoming in that they are highly appealing as public virtues; and both are complex with many sides and parts to them. Consequently, they are contested concepts since they mean different things to different people and groups, and are used as critiques of the costs of downsizing and restraint within health and social programs in recent times.

Interestingly, while most contemporary discourse on Canadian disability policy stresses citizenship as the master value, the children's movement and the child and family policy field tends to emphasize the notion of rights. Rather than a tension, this offers an opportunity for building public support and advancing the governance regime for children with disabilities, since both ideas have distinctive strengths and complementary focal points.

As Bryan Turner states, “by contrast with the discourse of citizenship, ‘human rights’ appears to be more universal (because they are articulated through the United Nations charters), more contemporary (because they are not tied to the nation-state), and more progressive (because they are not related to the management of people by a state).” Turner maintains that “aboriginal rights questions cannot be easily approached within the framework of (nation-state) citizenship concepts.” He adds, “the point about the concept of *human* rights is that they are extra governmental and have been traditionally used to counteract the repressive capacity of states. By contrast, citizenship has been more frequently associated with state-building and state legitimacy” (Turner, 1993: 178-179).

This last point is of particular relevance to the role of the federal government. The 1996 Federal Task Force on Disability and the 1999 *Social Union Framework Agreement*, among other recent policy developments, have consciously employed the concept of citizenship – with its related ideas of mobility and full participation – as a means to justify a continued and renewed role by Ottawa in health care, social services and income support. Together, citizenship and human rights offer a wide coverage of the socio-political ecology, that is, of the state and civil society.

In terms of the legal aspects of citizenship and human rights, there are four levels of laws and authoritative statements of preferred conduct and relationships. Within Canada are three levels: constitutional law and statutory human rights laws; statutory laws of general application; and laws of specific application to a given policy domain, client group, or type of behaviour. In the international arena is a collection of statements of ideals and guiding principles intended to influence policy commitments and developments within nations.

An overview of Canadian sources of citizenship rights and human rights is provided in Box 2. The listing is a sampling of actual and generic examples. The courts and related tribunals and commissions play a crucial role as well in interpreting and applying these sources and specific rights through case law.

The enactment of rights for people with disabilities within human rights legislation and the entrenchment of constitutional equality rights for people with disabilities within the *Canadian Charter of Rights and Freedoms* have had important consequences in Canada. These are now legally entrenched on an equal basis with the rights accorded to women, and to people of minority races, cultures and religions. The prohibition against discrimination under provincial human rights statutes has extended, in the past 15 years, from issues of employment for those with physical handicaps to include services, facilities and accommodation for people with both mental and physical handicaps. Increasingly, these statutes have become expansive instruments of rights protections.

Canada is also a signatory to a number of international agreements that guarantee political, social and economic rights for children and for people with disabilities. See Box 3 for major examples over the past 50 years.

Box 2
Canadian Sources of Citizenship and Human Rights

Constitutional and Statutory Rights

Constitution Act, 1867 and 1982
Canadian Charter of Rights and Freedoms
Historic and Modern Treaties between Aboriginal Nations and the Crown
Human Rights Codes and Laws: federal, provincial and territorial

General Framework Legislation

Broadcasting Act
Building/Housing Codes
Canada Elections Act (and equivalent provincial/territorial laws)
Criminal Code
Employment Equity Act, 1996
Income Tax Act (federal and provincial/territorial equivalents)
Labour Codes/Employment Standards Laws
National Transportation Act (and provincial/territorial equivalents)

Social Legislation

Canada Health Act
Canada Pension Plan
Child and Family Services
Education and School Acts
Employment Insurance
Income Assistance Programs

Freedom of choice, self-determination, equality of opportunity and human dignity are recurring principles in these declarations, adopted in various ways by numerous United Nations (UN) organizations and programs. They have provided philosophical inspiration, moral guidelines and pragmatic direction for Canadian organizations of and for persons with disabilities in lobbying the federal, provincial, territorial and local governments, as well as businesses and groups in other sectors (Kallen, 1989; Prince, 1992).

The impact of the legal entrenchment of this framework has been both direct and indirect. Successful legal challenges have been important, but so too have been the indirect ways in which the legal entrenchment of rights has influenced policy and attitudes. There has been a shift from the traditional way of viewing people with disabilities to the introduction of a systemic analysis of the discrimination faced by people with disabilities. The notion that disability is a result of individual pathology has given way to at least a nominal recognition that the roots of inequality are in the state and market organization of social relationships.

Box 3
**International Agreements on Human Rights, Rights of the Child, and
Rights for Persons with Disabilities**

United Nations (UN) Universal Declaration of Human Rights (1948)

UN Declaration on the Rights of the Mentally Retarded (1971)

UN Declaration on the Rights of Disabled Persons (1975)

UN International Year of Disabled Persons (1981)

UN World Program of Action Concerning Disabled Persons (1983)

UN Decade of Disabled Persons (1983-1992)

UN Convention on the Rights of the Child (1989)

*UN Resolution 46-110, Principles for the Protection of Persons with Mental Illness and
for the Improvement of Mental Health (1992)*

UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993)

UN Human Rights Commission Resolution 2000/51 (2000)

The 1989 *United Nations Convention on the Rights of the Child*, to which Canada became a signatory in 1991, is the key document that community groups, youth organizations and rights advocates use to advocate for reforms and policy responses by governments at all levels (Mitchell, 1996 and 2000). The *Convention* incorporates all children and deals with a broad range of fundamental personal and community needs. As well, the *Convention* has contributed to the shift in thinking and practice from the medical model to a rights-based model and the concepts of inclusion and participation by young people in policy-making processes.

The formulation of children's rights portrays children and youth as legal personalities, and accepts that they are capable of making choices based on reason and responsibility. Public services and programs for children can thus be seen "as a social provision for citizenship claims irrespective of age, character of dependency or position within the kinship group" (Turner, 1986: 97). As Laura Middleton puts it, "children have rights as children and not just as proto-adults" (Middleton, 1999: 120; Centre for Educational Research and Innovation, 1988).⁴ As the idea of children's rights is adopted and extended across policy domains, it will have the effect of changing the distribution of rights and duties within families, and between families and the public sector. In addition, the role of age as a fundamental determinant of who is a citizen will be further altered.

⁴ An alternative view is to see children and youth as the next generation of citizens. From this perspective, children and youth are citizens-in-waiting. Their status of full membership and participation in society awaits them at some point in the future. Examples of this view are found in programs guided by a social investment model of public policy, such as education, training, and some early childhood initiatives.

In a comment made of the United Kingdom, which also applies to Canada, a disability policy specialist said not long ago, “there has yet to be any real debate in this country about the needs of non-disabled parents raising children with impairments” (Middleton, 1999: 128). True, some Canadian governments have recently been consulting with parents and family service agencies to explore this topic, but the basic point is valid – there is little general discussion or appreciation of the needs or rights of parents who have children with disabilities. This is a setting of multiple roles, claims and relationships: parental or guardian rights; the child’s rights; the rights of other children in the family; the rights of grandparents; and so on. There also is a question about what kind of rights. For example, procedural rights to be heard and informed; civil liberties such as freedom from punishment; access to entitlements such as inclusive education and recreation services; accessible transportation; or the right to have supportive services in the home.

Research on children with disabilities has been inclined to emphasize, at least until very recently, a passive and dependent view of children. Researchers tended to individualize and pathologize childhood disabilities, focusing on impairments, service needs and usage. Consequently, research has concealed the role of children with a disability as “social actors negotiating complex identities within a disabling environment” (Priestly, 1998). This comment points to the perspective on citizenship favoured here. Citizenship is not a destination or a status that one eventually achieves, acquires or attains. Rather, *citizenship is a journey, or set of pathways over the life span. It is an ongoing process of making claims on others, accepting claims on one’s self, and negotiating within various organizations and sectors. Citizenship is a way of living in a society and of being in the world.* This perspective applies to the rights of children with disabilities, their siblings, and their parents in addition to grandparents, great-grandparents and other kin.

1.3 Governance – Rethinking the Relations of State and Civil Society

Our interest in this study is with *governance*, which is a much wider concept than government or the state. The concept of governance lifts our gaze beyond government and the state to consider other arenas and activities of Canadian life. Vincent Lemieux (2000) offers a discussion of governing and governance that is compatible with this analysis and, therefore, may easily be adopted. His definitions of these terms are as follows:

- *Governing* refers to all those activities of social and political and administrative actors that can be seen as purposeful efforts to guide, steer, control or manage (sectors or facets of) societies.
- *Governance* refers to processes of governing by public policy networks that include both public and private sector [that is, non-governmental] actors. Government is one of the actors, but does not necessarily play a central role. The processes of governing comprise three distinct activities: policy initiation, policy development, and policy implementation.

The importance of Lemieux’s view is threefold: (1) his emphasis on the multiplicity of processes and actors; (2) that the practices of governance involve inter-relations or networks among several sectors; and (3) that government’s role in governance is not the same as in traditional forms of governing, where governments occupied a more dominant position.

While notions of government and state are, by definition, public sector oriented, governance takes society into account, spanning its public and private divisions, governmental and civil organizations, and mainstream and marginal groups and activities. The concept of *government* or *the state* as used here refers to federal, provincial and territorial governments, plus school boards, local governments, and related municipal agencies such as parks and library boards.

A Multi-Sector Approach – The Pluralism of Governance

The notion of governance is institutionally wide, adding to the analysis the diverse realm of families and kinship networks; the vast sector of non-profits, mutual aid and voluntary organizations; and the domain of Aboriginal nations, communities and agencies. In some important ways, all these sectors are relatively distinct from and autonomous from the state, despite the existence of policy connections and issues of resource dependencies.⁵

There are several good reasons for adopting a sectoral approach to examine the institutions and agencies involved with policies for children with disabilities and their families. First, the reality is that there are five sectors presently involved, in varying ways, as policy shapers, program governors and service providers: governments and other the public sector bodies; voluntary organizations; commercial firms and professionals; Aboriginal communities and organizations; and families and informal helping networks.

Second, to realize the vision of full citizenship articulated in numerous disability policy papers over the last decade implies the commitment and participation of all segments of Canadian society. Indeed, an objective of *In Unison*, the joint federal-provincial-territorial approach to disability issues, is “to mobilize all sectors to enhance the full and equal participation of people with disabilities.”

Third, it ties in with several important socio-political trends of our times. Interest in multi-sectors approaches to social policy has grown in relation to feminist critiques of the welfare state, and attention to the personal as political; the rise of Aboriginal nationalism, and the drive for self-determination; and a reappraisal of the public sector during the 1980s and 1990s in the face of growing deficits and debt loads, and the attendant need to downsize and restructure government activities.

Fourth, each sector, as a societal-level institution, is a form of collective action for allocating resources, addressing human needs and providing social services and benefits (Johnson, 1987). If we are to understand how the present governance regime operates and how it might become more integrative, then it is essential to consider the multiple sectors and their inter-relationships.

⁵ A reality of all the sectors is their fuzzy boundaries. Foster homes illustrate the overlap between sectors in social policy, in this instance between the public sector and families. A foster home is “an ordinary home in which people have agreed to take children who have been committed to the care of [child] protection authorities.” Aptly, they have been called the backbone of the child welfare system in Canada as “more children are in this type of facility than group homes and large institutions” (Cruickshank, 1991: 79). Other boundary overlaps occur between families and either agencies in the voluntary sector or municipal government services in the public sector.

The point is that governance, as a way of thinking about social policy and citizenship, suggests that *all* sectors of society, and not simply governments, are responsible for improving outcomes for children with disabilities and their families. In our pluralist and globalizing age, the claim for governance by many individuals and groups argues that governments are no longer the supreme authority of the political community and do not effectively represent the breadth of diversities within the population (Rice and Prince, 2000).

The *traditional and still prevalent* governance regimes in family and child welfare policy (Callahan, 1985; Armitage, 1993) and in disability policy (Federal-Provincial-Territorial Ministers Responsible for Social Services, 1998; Prince, 2000), as well as in the public sector more generally (Maxwell, 2001), share many features. These features can be combined, as shown in Box 4.

These processes represent the organizational expression of long-established governance practices in these policy domains, elaborating on the three processes noted by Vincent Lemieux in his discussion of governing. This is the regime currently in place – but under pressure to change. State and civil society actors are promoting new ideas and practices, which affect three major groupings of these practices and processes.

The first three processes in Box 4 involve planning, democracy and managing complexities due to interdependency. In particular, there are mounting public concerns that involvement should go beyond simply sharing information with Canadians about programs and decisions. The growing expectation is that there should be meaningful citizen participation, public engagement and advocacy in the development, design and evaluation of policies, structures and program delivery practices. The publics here include parents, children with disabilities, other family members, voluntary organizations, commercial firms, professional associations, and Aboriginal peoples and their political and service organizations.

Setting policy goals and priorities relates to strategic planning and thinking, often including the formulation of a vision and mission statement, as well as policy development and decision-making. Over the last 25 years, the idea of disability policy as a domain of governmental activity has gained widespread acceptance by federal, provincial and territorial authorities. Many governments now have explicit disability action plans to inform their programs, which are specifically or largely designed for people with disabilities. As mentioned earlier, the concept of “full citizenship” has become the preferred way of presenting policy goals and promoting the status of persons with disabilities (Prince, 2001a).

Creating structures and mandates is a core activity of governance for establishing authority roles and relationships, with direct implications for practice in terms of setting the scope for eligibility and determining the overall size of a client population. Processes four through eight in Box 4 relate to this activity. Allocating resources includes the assignment of staff, finances, other supports, information and research, time and political will. This relates closely to the design and delivery of services and programs, which can be accomplished by grants, by in-house staff or by contracting out, among other options.

Box 4
**Prevailing Governance Practices in the Family,
Child Welfare, and Disability Policy Domains**

1. Community involvement and public participation in policy development is limited if not discouraged. Clients are treated as recipients, rather than as participants. Adults with disabilities are commonly labeled as unemployable.
2. Policy-making and decision-making are highly centralized at the political executive and senior management levels of bureaucracies. A minor role, if any, is played by legislatures.
3. Narrow mandates are focused on protection, investigation and rehabilitation of a small population group. The service system has multiple-access points and eligibility requirements. Organizations operate as silos that are separate from one another. Jurisdictional gaps and problems exist between school boards, municipalities and health and social services.
4. Front-line human service workers have limited professional autonomy, though established professions have greater authority. There are insufficient supports and services, as well as disincentives, which do not enable clients to become self-sufficient.
5. Program-oriented rather than person-centred approaches dominate service provision. Service delivery is often decentralized in regional and local ministry offices or, through contracting out, in voluntary and private sector agencies.
6. Family members (parents, siblings and extended kin networks), caregivers, and the role of neighbours and friends, are undervalued by policy and service systems.
7. Some cooperative intergovernmental relations exist, yet much of the history of child welfare and disability policy is classical federalism, based on the independent actions of individual governments. Thus, there is inadequate portability of benefits and services. Children and families experience problems of “getting lost in the maze of programs” and “falling between the cracks.”
8. Only slight recognition of the distinct needs, historic disadvantages, and cultures of Aboriginal peoples in policy or programming.
9. Expertise, hierarchy, the principle of ministerial responsibility, and budgets are the primary considerations in policy advice and decision-making. Accountability is hierarchical, that is, reporting upward.
10. There is little formal evaluation or publication of program results. Adjustments to policy perhaps occur in response to crisis.

Managing interdependencies and transitions relate to intra-governmental and inter-governmental relations, as well as to inter-sectoral relationships and life changes and stages. It concerns seeking to achieve a degree of integration and cooperation among actors and agencies within a government, between a government and its legislature, amongst governments, and across sectors, in a bilateral or multilateral manner.

The final two processes in Box 4 relate particularly to matters of accountability. Performance measurement and evaluation require the setting of benchmarks and desired outcomes, as well as monitoring progress and assessing results. From that stems an opportunity for organizational learning and improvement, linking back lessons and conclusions to inform the development and modification of the first six processes described.

Because of its importance in the new discourse and practices of governance, accountability deserves some further attention. A time-honoured perspective on accountability defines it as the obligation to answer for a responsibility conferred. However, newer perspectives are emerging. For instance, the Auditor General of Canada (1999) now defines accountability as “a relationship based on the obligation to demonstrate and take responsibility for performance in light of agreed expectations.” While still covering the traditional concerns of prudence and probity, this wider notion allows for accountability among partners in the formulation of policy frameworks and the delivery of services. It is more consensual and less hierarchical than classical concepts of accountability. It stresses the importance of transparency (access to and the disclosure of significant information), and is keenly interested in learning from experience. Effective accountability mechanisms include clear roles and responsibilities, performance expectations balanced against capabilities, well-defined management structures, specific evaluation provisions, partner dispute resolution mechanisms, and appropriate monitoring systems.

The federal Auditor General also argues that, in collaborative arrangements where government shares policy formation and management with other parties who are delivering programs, there should be *more*, not less, accountability – among partners, between each partner and their governing body, and to the public and affected communities (Auditor General of Canada, 1999).

The Federal Task Force on Disability Issues is one of many groups that have stressed the importance of clear lines of accountability in meeting disability policy goals.⁶ “Accountability,” the Task Force said, “begins at the ministerial level and extends to questions of process – how government works and how citizens access government programs and services. It also includes measuring the effectiveness of government programs” (Canada, 1996: 25). The Task Force advanced two reasons for a strong accountability mechanism. First, “to ensure reconciliation between the needs of Canadians with disabilities with changing programs, policies and laws, and to ensure that the change process continues apace.” Second, a strong accountability mechanism will provide organizations representing Canadians with disabilities with the “information they need to determine if the services they require are available” (Canada, 1996: 34, 36).

⁶ Another example is the review of special education programs and services by the Prince Edward Island Department of Education (2001), which speaks of *interactive accountability*. It states, “accountability is not a simple matter of one level of a system holding another level accountable. Effective accountability systems are highly interactive, based on clearly established requirements for practice, and continually setting for goals for growth to close identified gaps. The Department of Education has an opportunity to work with the school system in articulating an appropriate accountability framework for special education, a framework which is interactive and focused highly on goals for growth rather than administrative dominance.”

The personal and informal, voluntary, commercial, and Aboriginal sectors, together with the state, form the governance regime of disability policy. This regime is an interacting set of different kinds of knowledge and ideas, mandates and laws, organizations and sectors, and policies and programs. Drawing from the wide literature on public management and policy, as well as on past and present practices, and adapting it to the purpose of this study, eight governance processes can be identified for the disability policy domain, which are set out in Box 5.

Box 5
Governance Processes for the Disability Policy Domain

- | | |
|--|--|
| 1. Involve multiple publics. | 5. Deliver services. |
| 2. Set policy visions, goals and priorities. | 6. Create structures and mandates. |
| 3. Manage interdependencies and transitions. | 7. Measure performance and evaluate results. |
| 4. Allocate resources. | 8. Learn, research and adapt. |

Individually and collectively, these governance processes are of profound importance for the well-being of children with disabilities and their families. The disability governance regime matters for child development by influencing the multiple environments in which children, their families, and their relevant mix of siblings, friends, neighbours and communities are nested. More specifically, the governance regime is fundamental in determining the nature and extent of access to various supports and programs, and whether or not services are known to families and are available in a form that is appropriate and timely for their needs. All of these dynamics of the governance regime are critical for determining the everyday lived experience of citizenship and human rights for children with disabilities and their families.

This particular governance regime, like other social institutions, contains contradictory practices and effects. For example, the regime involves the allocation of substantial resources by several sectors. However, depending on their distribution, resources and benefits are experienced as residues and burdens. Beyond resources and agency delivery systems, the regime rests upon a vision, however disjointed it seems, of such core ideas as child development, disablement and citizenship. Yet it also perpetuates outmoded notions of exclusion, charity and stigma (Rioux and Prince, 2001).

A central finding of this study is that a paradigm shift is occurring away from the medical model toward a rights-based model, though the shift is slow and the regime contains many examples of continuity in traditional perspectives on children and disability. To better understand and assess the overall regime and these dynamics, we turn now to a mapping of the sectors involved.

2.0 The Current Disability Governance Regime – Mapping the Sectors

In Canada, the disability governance regime, as mentioned earlier, includes families and their personal and informal support networks, the structures and practices of the voluntary sector, the commercial sector and professional associations, the governmental and related state machinery of the public sector, and the Aboriginal sector. Each of these sectors is examined here in relation to a standard set of questions. *Who are the major actors in policies for children with disabilities and their families? What governance roles does the sector perform? What are the defining trends that characterize the sector in the present age? What public values and policy issues are at stake?* To answer these questions, each sector is examined in turn, within which this analysis looks at three clusters of governance functions:

- Policy planning, involving the multiple publics, and managing interdependencies
- Creating structures and mandates, allocating resources, and the delivery of programs, and
- Accountability processes.

In keeping with a social-ecological approach (Bronfenbrenner, 1979), our mapping begins with children and their families at the center of the analysis. Family caregiving and child development both take place within a larger setting of numerous groups and different institutions. The sector of families is nested in and shaped by other sectors, and shapes other sectors as well. This seems doubly appropriate in this study, with our goal of advancing an inclusive agenda for all children and their families. Further, in the case of children and adults with disabilities, with well over 90 percent living in non-institutional settings, the informal sector is arguably more important than the public and voluntary sectors in providing personal, social and health care (Johnson, 1987: 64).

2.1 The Personal and Informal Support Sector

Routinely, we depict families as the most integral, intimate system of care for all members in society, and especially for children and youth. “We recognize that the family unit (including the extended family) is the most sensitive, aware and caring support group for people with disabilities” (House of Commons, 1999: 3). “Persons with disabilities are our parents, our brothers, our sisters ... and ourselves” (Canada, 1999a: 1).

What we call the personal and informal support sector lacks the centralized institutions and officially structured interventions of the other sectors surveyed here (see Box 6). Informal care, “though often just as highly ordered and organised, is rooted not in commitment to tasks but in attachment to persons; it is a property of relationships not of jobs” (Abrams, *et al.*, 1989: 6). To call the care provided by families “informal caring” is misleading in the sense that this caring work, when conducted over time, is rooted in considerable experience and emerges from a multi-service perspective that most officials in the formal systems lack. As the mother of a child with a developmental disability remarked at a recent provincial consultation process, “I am the expert of my children. I realize today that I am not only an expert about being my children’s mother but on what life is all about living with disabled children” (Alberta, 2000: 24). Parents and other family members develop “expertise” through their daily experiences, their own educational and professional backgrounds, and in relation to working with novice service providers.

Box 6

Personal and Informal Support Networks for Families

Immediate Family

Extended Family

Neighbours and Friends

Parenting Self-Help Groups and Parenting Support Groups

Parent-to-Parent Support

Everyday Helping Activities and Networks

The informal sector has been called “care *in* the community” by relatives, friends and neighbours. This is in contrast to the notion of “care *by* the community,” meaning through formal organizations in the public, voluntary or other sectors. The informal sector comprises, then, the everyday unofficial helping actions and networks in Canadian social policy. In this section, we can say some things about the social and formal organizations evident in this domain and about the roles served by parents, guardians, siblings and significant others in the care of children with disabilities. Further, we can identify some significant policy issues concerning children with various disabilities and their families.

Informal care is provided by kin such as parents, sisters, brothers, aunts, uncles, grandparents or great-grandparents, but also by foster homes, neighbours, close friends, and other parents and families in similar circumstances. The care provided includes practical support for the activities of daily living, such as transportation and food shopping, as well as emotional support.

Along with experiencing profound love and personal enrichment, parents raising children with disabilities experience many challenges and demands (see Box 7). The type and severity of disability is certainly a factor influencing the coping and caring capacity of families who have children with disabilities. Other factors include the family’s financial resources, advocacy skills, family history, cultural perspectives, interpersonal dynamics, the quality of publicly supported services, and the nature of informal social supports that are available to the family (MacAuley, 1995). Siblings, for instance, are an important component of family and childhood. Depending on the presence of these and other elements in their socio-political ecology, a family may be well supported, stressed, isolated or seriously overextended (D. Valentine, 1993).

Box 7

What is Involved in Parenting Children with Special Needs?

All parents or guardians with children and youth have needs for a range of services, benefits, and supports. This is the spirit behind and intent of the *United Nations Convention on the Rights of the Child*. Parenting children with disabilities compounds this requirement for a set of basic supports and resources.

Most parents or guardians who have children with disabilities face additional challenges to those faced by parents raising children without special needs. These additional challenges include:

- **Day-to-Day Care:** Children with disabilities may require more physical care and for a longer period. Parents must take on the multiple roles of therapist, teacher, playmate, and advocate. They may also struggle with behavior problems, greater susceptibility to illness, sleep disorders, and medical emergencies.
- **Services:** Most parents spend many hours on the telephone and taking their child to appointments. With current cutbacks in services, they may face long waiting lists or, depending on where they live, may have to travel substantial distances. Some needed services are simply not available.
- **Information Needs:** Parents often have to work hard to find, gain access to, and sustain services for their children. Parents often struggle to learn how to locate services, including entitlements to disability-related benefits for their children. Information on what is available, where and from whom is rarely easy to determine.
- **Dealing with Professionals:** Parents must deal with a range of specialists and professionals, perhaps on a daily basis. For some parents, this can be a daily battle. Challenges involved here include managing access to specialists; avoiding the medicalization of the child (through labelling as assessed and diagnosed), the loss of family intimacy; and educating specialists about the life history of the whole child.
- **Child Care:** Accessible, affordable child care is an issue for many families with young children. It is usually an even larger issue for parents of children with special needs. Although some child care centres will do everything they can to accommodate children with disabilities, others will refuse to admit them. While the issue of child care (including before- and after-school care) disappears for most children as they get older, it remains a key issue for children with disabilities over the age of 12 who still need care.
- **Education:** Parents of children with disabilities cannot take for granted that their child will be educated at their local school, and many will have to fight for this if it is what they want. Despite the fact that there is a greater acceptance of the idea of inclusion, there are not always supports in place, nor teacher willingness and ability, to make it work. Current cuts to special education funding pose a threat to the education of many children with special needs.
- **Emotional Support:** Children with disabilities may require more emotional support, as may their parent(s) and other children in the family. For instance, whom does the child play with? Both children and parents may experience being devalued and stigmatized, and feel they always have to fight for resources and to be included. Parents can feel isolated, and many desire the ability to network with other parents so as to share information, problem solve, obtain empathy, and possibly organize to advocate for service improvements.
- **Financial Costs and Adequate Income:** Families who have a child with a disability require more time off work, are more likely to work reduced hours and to decline overtime, live in single income families, have non-reimbursed out-of-pocket expenses for disability-related supports and, not surprisingly, are therefore more likely to live in poverty (Canadian Association of Community Living, 2000a).

The result can be physical and emotional exhaustion for the parent(s). It can also strain relationships with spouses and other family members. The additional cost of raising a child with a disability can cause financial strain. The needs of the child may force one parent to quit his or her job, or to seek part-time or less demanding work. Lone parents face even greater challenges in finding, keeping and paying for appropriate childcare.

Source: Adapted and significantly expanded from Voices4Children [sic], 2000.

The Self-Help and Family Support Movements – Approaches to Governance

Since the 1970s, there has been a growth in the self-help and family support movements in Canada, the United States, and other countries. Organizations in these movements operate within the voluntary sector as formal structures linked to other public and private agencies, as well as in the network of informal and mutual support groups. A study done in the mid-1990s estimated that “nearly 30,000 families and perhaps more individuals are involved in self-help [or] support groups” (MacAuley, 1995: 7). In the voluntary sector, parent groups may be “closely affiliated with organizations or associations, such as health associations, hospitals, schools or advocacy organizations. They may use the organization’s name and publications, share its philosophy and actively participate in fundraising campaigns” (Canadian Association of Family Resource Programs, 1999). In the natural network, these groups are typically stand-alone and operate at local levels.

Parenting support groups for families who have children with disabilities can vary in many ways, as one would expect, given their locale and contextual nature. There are, however, some common features. Groups focus on the needs of the parents, are frequently (though not always) organized and led by parents, meet on a regular basis, share information and experiences, and offer emotional support. Support groups can be like another family, with relations of support extending outside the group and sustained over many years.

In terms of the leadership and structure of parent support and self-help groups, there are three types of governance models:

- ***Parent-led Groups:*** Parents meet on their own to share information, give and receive emotional support, and create a sense of belonging. Guidance of the group is peer leadership, coming from one or more of the parent members. The structure is often informal.
- ***Professionally-led Groups:*** Professionals serve as leaders in facilitating the group. “Their main goal is to give accurate and appropriate information about specific conditions or disorders. They may also offer emotional support. Professionally facilitated support groups are sometimes quite structured, with limited informal sharing among members” (Canadian Association of Family Resource Programs, 1999).
- ***Partnership Groups:*** This model is a hybrid of the self-help orientation of parent-led groups and the support orientation of professionally-led groups. “Some groups fall somewhere in between professionally facilitated support groups and self-help groups. A professional may help the group run, but stays in the background as much as possible, encouraging parents to set the agenda [and] lead the discussion” (Canadian Association of Family Resource Programs, 1999).

Beyond leadership and structure, groups can vary by having a cross-disability or specific disability focus, and by whether membership includes children with disabilities and other members of the immediate or extended family. In fact, in addition to parent groups, there are groups for siblings, grandparents, and friends. The formation of these groups relates, in part, to frustrations in dealing with medical and other professionals, and with public and private sector bureaucrats when seeking to obtain information, advice, services and support.

Rising interest in self-help groups by parents and governments also relates to their cost-effectiveness as a health promotion strategy and their flexibility in responding to a wide range of issues and problems. For parents and other family members, self-help groups have the capacity to offer empathy and understanding in a way that other sectors and agencies may be unable to do.

Research suggests that many parents of children with disabilities do not join support groups because they are unaware of their existence in their community, unsure how to contact them, or simply lack the time to participate. Some parents do not join such groups because they feel it would not be effective for them, while others worry that the group would generate more anxieties than assurances. Others may believe they are not a “group person” and would feel uncomfortable sharing private feelings and experiences with strangers (Philp and Duckworth, 1982; Canadian Association of Family Resource Programs, 1999). An alternative to support groups is a one-to-one connection that may occur through word of mouth or, perhaps increasingly, via the Internet through national and even international Web support boards for parents and for youth.

Issues – Costs, Capacities, and Citizenship

Despite the value of group support, the family remains the most important source of long-term care and assistance for people with disabilities, whether a child, a youth, or an adult. As Box 7 details, families provide for the care *of* their children with disabilities, as well as caring *for* them. From the literature on social support and social policy (Johnson, 1987; Rice and Prince, 2000), three findings about the informal sector stand out:

1. The informal sector provides more care to family members in need, especially children and older persons, than do the other sectors.
2. Families greatly predominate in the informal sector as providers of care, compared to friends, neighbours and informal groups.
3. Within families, women are overwhelmingly the chief caregivers. This raises issues about the balance of responsibilities among sectors and between genders in Canadian society, and about the impacts of caring upon the carers, the cared for, and significant others.

Many other issues of costs, capacities and citizenship that are directly related to disability and to child and family policy confront this sector. These include the following:

- There is a risk of governments expecting too much from these informal support systems of families, including grandparents (McCallion and Janicki, 2000), and of not appreciating the additional burdens placed on families because of the past and present restraints of public programs.
- There are tensions and trade-off between paid work in the labour market and the unpaid and often unrecognized work in the family. Competing demands of paid work and work in the home can lead to psychological stress, particularly among parents with preschool children, most commonly women (Lero and Johnson, 1994).

- Out-of-pocket expenses and foregone earnings are substantial burdens for many low- and modest-income families of children with special needs, representing 10 or 15 percent or more of non-discretionary expenses on the monthly household budget (Lukemeyer, Meyers and Smeeding, 2000). Tax credits and other public programs are far from adequate in compensating for these costs.
- Aged parents who are still caring for their adult children with developmental disabilities face particular challenges. They worry about what is happening to their own health and what the long-term future will be for their children. Respite care for this group of parents is a pressing need.
- The social networks of many children with disabilities are limited due to their exclusion from school, recreation and leisure programs, and other mainstream services. They risk loneliness, isolation, low self-esteem and increased stress (Lord and Hutchison, 1997).
- Difficulties emerge due to the lack of extended or even immediate family members living nearby, who might be sources of help and support.
- Problematic, at times, are the ambivalent or suspicious relations between professionals and parents in self-help and support groups and, more generally, in encounters between families and formal systems of care and treatment.
- Within our increasingly multi-racial and diverse society, there is a need for culturally sensitive services to support caring for children with disabilities (Rounds, Weil and Bishop, 1994). Of course, this issue pertains to the Aboriginal, public and voluntary sectors as well.

Like other sectors, the domain of families serves various functions. These include identifying needs, modeling core social values, providing a multitude of services and supports, and collaborating with other organizations. Families also engage in advocacy activities. They evaluate public and voluntary programs by offering responses to policy makers and officials based on their experiences in trying to navigate the complex of agencies, rules and services at multiple levels of government.

For parents caring for their children with disabilities, and seeking, securing and sustaining services for their child and the family (usually from the public sector), the pressures are intense and the obstacles high. The costs can be even higher, and devastatingly so, resulting in family breakups, personal bankruptcies, or giving children up to the state to ensure their care, due to lack of services and personal supports.

The evidence indicates that families are bearing more than their fair share of the costs of caring for their children. As a society, it seems we still believe that public services and social programs are, for the most part, residual to family responsibility. How else can we explain the heavy burdens and expectations imposed on families to care for their own members – with parents giving up their paid jobs, drawing down their savings, refinancing their homes, and perhaps seeking assistance from relatives, when and where available, or going on income assistance.

Unquestionably, many if not most parents who have children with disabilities face a number of barriers in accessing and exercising their citizenship (see again Box 7). Justifiably, they feel they carry a disproportionate amount of responsibilities and enjoy too few rights. They often struggle mightily to access even basic public services and programs for meeting the most fundamental of human needs for their children and themselves. Given these burdens and obstacles, their sense of belonging to the wider civil society and market economy may seem tenuous and strained.

A true vision of full citizenship in regards to disability policy must directly consider these realities of parents who have children with disabilities. As Marilyn Callahan observes, parents are “deserving of opportunities, not just in relation to improving their ability to “parent” but as people with the right to full lives.” (1993: 194). The right of these parents to a full life includes their status as parents with other children, as partners in a marriage or common-law union, as adults in or out of the paid labour market, as volunteers in community affairs, and as citizens wishing to participate in policy making and other political processes. At present, the governance regime tends to treat parents and families as *clients* and as sources of personal resources to address the needs of their children, rather than as *governors* with the right of self-determination and the capacity to manage resources themselves.

2.2 The Voluntary Sector in Canada

The voluntary sector in Canada – also called the non-profit, charitable, or third sector – includes over 200,000 organizations. Voluntary sector organizations are formally structured, non-governmental, non-profit distributing, self-governing, and involve a degree of voluntary participation in the administration and conduct of activities (Canadian Centre for Philanthropy and Canadian Policy Research Networks, 1998: 6). Within this population of organizations, there is, of course, incredible diversity in history, philosophy, scope of interests and operations, fields of activities, size and formality. Other significant differences are whether or not they are registered charities (about 63 percent are not), their sources and amounts of revenue, and their financial stability.

Voluntarism, Social Supports and Citizenship

Voluntary organizations are of great significance to children and families and to disability policy, for a number of reasons. For example, they have a longstanding role in the provision of health care, social services and public advocacy for children and families and for people with disabilities (Rice and Prince, 2000). Voluntary sector organizations such as the Red Cross, YMCA-YWCA, and Women’s Institutes have historically been leaders in social reform and social provision.

Children’s Aid Societies are a good example of this historical role that carries on today. They were established through the late 19th century and into the mid-20th century across a number of provinces. They remain most prominent in Ontario, where there are 52 Children’s Aid Societies together with a provincial association. As a kind of semi-public organization with community governance, they have legal mandates with delegated powers from a province to deliver provincial child welfare services.

As well, with a locally elected board of directors, a Children's Aid Society typically provides some locally defined services. Funding is often secured through a combination of provincial grants and support from the local community (Wharf, 1993).

Our present age presents both opportunities and risks to the voluntary sector in becoming greatly involved in the delivery of public programs, and in meeting community needs through multilateral partnerships with government agencies. Public opinion research indicates that Canadians view the voluntary sector as highly credible and as a valuable institution for serving the public interest (Ekos Research Associates, 1998). The voluntary sector is also looked upon as having considerable potential capacity to engage in social reform and to influence the social policies of municipal, territorial, provincial and federal governments.

There has, of late, been a revived interest in the voluntary sector by governments. The federal government seemingly "rediscovered" the voluntary sector in 1997 (Phillips, 2001). The National Children's Agenda, *In Unison* (the intergovernmental vision on disability policy), the *Social Union Framework Agreement*, and *Future Directions* (the federal government's recent statement on disability policy) all call for greater participation by voluntary sector organizations in disability and family policy.

Increasing the use of volunteers in providing health and social services poses some dilemmas for social policy and the essence of citizenship in Canada, however. Since charity is voluntary action, the nature and scope of assistance remains unspecified and uncertain. Those in need do not have any right to assistance from private sources. Moreover, some Canadians worry that voluntary sector agencies are attempting to make up for gaps and shortfalls in public programs and services that, in our new age of budget surpluses, should receive enhanced funding.

An idealized notion of voluntary organizations emphasizes the independence of the sector from government and the private sector, as well the inclusion of clients and caregivers in governance matters. It also entails identifying needs on the strength of community requirements, and developing programs to meet those needs. A common reality, however, is that considerable inter-connections exist between voluntary and public sector organizations, including elements of control and constraint. These inter-connections are apparent across all the processes of governance.

Government departments and agencies directly affect the mandates and shape the very mission of voluntary organizations. This can occur through the expression of new policy directions and priorities, cuts in core funding, or by the allocation of funds to voluntary service organizations or think tanks to do particular kinds of research, to create certain positions, or to manage specific program services. Government funding practices may also promote voluntary agencies to chase contract dollars, submit proposals in new areas, and hastily form new partnerships with other community groups in order to be eligible for consideration of public funds. Voluntary sector service agencies can also become so closely aligned with certain sets of providers and population groups that they are seen as the advocates for that particular group.

Governments tend to respond, with funding, to groups with the loudest voices politically, demonstrating the so-called “squeaky wheel” phenomenon. This situation results in a fragmentation of interests, which works against developing a pan-disability perspective in public policy. A similar dynamic can occur with family and parent support groups.

Voluntary Organizations and Governance Processes

For the purposes of this study, four functional segments of the voluntary sector are worth highlighting. These segments focus primarily on: (1) children and families, (2) disability issues, (3) children with disabilities and their families, and (4) other community health and social services. Within each category are foundations, professional groups, and organizations variously devoted to advocacy, policy development, research, and service provision.

Although data specific to this governance regime are not available, no doubt there are great provincial-territorial variations in the prevalence of these types of organizations’ activities and the levels of active volunteering by Canadians (Canadian Centre for Philanthropy and Canadian Policy Research Networks, 1998; Reed and Selbee, 2000). Specific organizations frequently have multiple levels, reflecting the size and federal system of the country. The Learning Disabilities Association is a case in point, with a national association, provincial-territorial associations, and numerous local associations based in particular cities.

Box 8 presents a sample of the voluntary organizations in Canada that deal with children and families in general, with disability issues, and with children with disabilities and their families. This classification is meant to be indicative and plausible, rather than exhaustive and definitive. It shows that numerous organizations deal largely with *either* child and family *or* disability issues, but also that there are quite a few voluntary sector organizations that span *both* fields. Many of the spanning organizations, though, are engaged primarily in research, advocacy, or public education, rather than in the direct provision of integrated health and social services to families and their children.

In large part, the lack of service integration may reflect the separate historical development of these policy domains. In part, too, the emphasis on education, research and advocacy may reflect the fact that “voluntary organizations do not possess power to affect change, and hence must rely on persuasion and other avenues in attempting to convince policy-makers of the need for change” (Wharf, 1992: 23).

Box 8
Voluntary Sector Organizations that are Specialists or Spanners
Concerned with Child and Family or Disability Issues

Child and Family Organizations

Boys and Girls Club of Canada
Canadian Association for Young Children
Canadian Youth Foundation
Child Poverty Action Group
Child Welfare League of Canada
Family Service Canada
Vanier Institute for the Family
YMCA/YWCA

Disability Organizations

Canadian AIDS Society
Canadian Association of Independent Living Centres
Canadian Association of the Deaf
Canadian Council on Rehabilitation and Work
Canadian Hard of Hearing Association

Organizations that Span Both Fields

Autism Society of Canada
Caledon Institute of Social Policy
Canadian Association for Community Living
Canadian Association of Family Resource Programs
Canadian Child Care Federation
Canadian Coalition on the Rights of Children
Canadian Council on Social Development
Canadian Institute of Child Health
Council of Canadians with Disabilities
Learning Disabilities Associations
National Children's Alliance
National Youth in Care Network
Roehrer Institute

Boxes 9, 10, and 11 in this section present selected information on organizations in the voluntary sector engaged in disability and/or child and family matters in relation to governance processes.

Box 9
**The Voluntary Sector – Policy Planning,
Consultation, and Coordination Structures**

National Strategy for Persons with Disabilities: The Community Definition (1999), developed by the Council of Canadians with Disabilities and several other organizations

Canadian Association for Community Living

Coalition of National Voluntary Organizations

Joint Table Process (established in 1999)

National Children's Alliance (est. 1996)

National Children's Agenda: Public Dialogue Process (1999-2000)

Panel on Accountability and Governance in the Voluntary Sector (1997-99)

Regional Intersectoral Committees (Saskatchewan)

Self-Help Clearinghouses

Social Planning Councils

United Way Organizations

Voluntary Sector Roundtable (created in 1995)

Volunteer Bureaus

Voluntary sector organizations commonly engage in identifying issues, offering solutions and priorities, and advocating for reforms. Many organizations generate and disseminate information to raise public and political awareness, and to educate the larger community on disability issues and on child and family issues. Larger voluntary organizations, in particular, engage in policy development. Social planning councils, located in several cities across the country, are another source of planning and consultation. In recent years, government departments and agencies are consulting voluntary organizations and coalitions more regularly. One interesting arrangement is the series of regional intersectoral committees in Saskatchewan formed as part of that province's Action Plan for Children. Participants include representatives from voluntary organizations who work with representatives from First Nations and Métis communities, school boards, the police, municipalities, and the provincial government.

The Coalition of National Voluntary Organizations is an umbrella organization that represents 130 national voluntary charities in a range of policy fields. The Coalition's mandate includes lobbying, advocacy, communication, and forming partnerships with member organizations, the research and academic community, as well as the media.

A priority of the Coalition of National Voluntary Organizations in recent years has been to achieve a more coherent public policy for children and youth, including contributing to the formation in 1996 of the National Children's Alliance. The National Children's Alliance is a cluster of more than three-dozen national organizations (many of whom are listed in Box 7) dedicated to the well being of all children and youth in Canadian society. The National Children's Alliance worked to promote the adoption of the National Children's Agenda by the federal, provincial and territorial governments, which occurred in May 1999, as well as the adoption of the *Agreement on Early Childhood Development Initiatives* by these governments in September 2000. The National Children's Alliance is now advocating for further investments through these agreements and other programs for children and youth. Among its strategic directions are commitments to "ensuring participation in federal/provincial/territorial decision-making processes, especially with respect to (1) emphasizing accountability and transparency, (2) developing indicators to measure progress, and (3) encouraging citizens' engagement" (National Children's Alliance, 2001: 2-3).

Another recent development in the sector that is exceptional, if not unprecedented, is *A National Strategy for Persons with Disabilities: A Community Definition*, produced in November 1999 by a coalition of 13 national disability organizations. The first element of the community definition states that any strategy must include the issues of children and seniors with disabilities. This document (Council of Canadians with Disabilities, 1999: 5) observes, "'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. In most cases, very limited supports are available to parents who care for their children at home. Children with disabilities are still excluded from the mainstream of education, access to health care and social services."

As Box 10 illustrates, a variety of disability organizations and child and family service agencies have frequently emerged from the efforts of citizens, clients or caregivers. These often establish an innovative service or fill a perceived gap between needs and available public supports. "Many of these agencies are supported at least in part by government funds, but they cherish and value their independence" (Wharf, 1993: 102). This valued autonomy, however, needs to be balanced with expectations and requirements for accountability to public funders and private donors alike.

Box 10
**The Voluntary Sector – Creating Program Structures,
Allocating Resources, and Delivering Services**

Community-based Service Agencies

Contract-based Service Agencies

Foundations

Self-Help Groups

Service Clubs (e.g., Canadian Legion, Elks, Kiwanis, Rotary, Shriners, and so on)

United Way Organizations

The range of services and benefits provided by voluntary child and family and disability-oriented agencies is quite broad, encompassing public education and information, referrals, resource libraries, respite care, day care, after-school care, camps and other recreational and sports programs, health support, counselling, mentoring, peer support, and mutual-aid, among others. Organizations helping children (and perhaps others) with disabilities include, for example, the British Columbia Coalition of People with Disabilities, the Easter Seal Society of Ontario, the Moncton Volunteer Centre, and the Prince Edward Island Association for Community Living, to name but a few.

Foundations and United Way organizations are important sources for fundraising and resource allocation amongst voluntary agencies within many cities and communities. So, too, are provincial lotteries and gaming commissions. Numerous service clubs at the local or provincial level also provide direct financial assistance to service agencies or to families who have children with disabilities. In addition to those service clubs listed in Box 10, the Jaycees, Knights of Columbus, and Lions Clubs are other such examples.

The Accountability-Autonomy Balance for Voluntary Agencies – Trends and Issues

In an earlier period, voluntary organizations identified new and basic community needs and started programs, with governments then assuming responsibility for them. Over the past 20 years, in a reversal of that trend, governments have been cutting programs and off-loading or contracting out services to the voluntary sector. A major concern within the voluntary sector generally is that governments have unrealistic expectations of the existing capacity of the sector and their local communities to assume these activities. The pattern is one of voluntary organizations playing a greater role in meeting human and social needs, but with declining and conditional resources. Projects are funded, but core funding for infrastructure such as a volunteer coordinator, for example, often is not.

Many in the sector characterize the fundraising environment as “cut-throat,” and the overall atmosphere reflects considerable donor fatigue. A related risk is that greater reliance on the voluntary sector by governments might weaken access by families to service and programs, particularly if voluntary sector organizations have devoted time to one specific clientele and not to the needs of other children with disabilities.

“Pressures to strengthen accountability have arisen partly from outside observers and stakeholders who have been alarmed by a number of scandals in Canada and the United States, and concerned by the more aggressive fundraising that has become evident in recent years. At the same time, representatives of the sector have recognized that improved accountability is important to preserve public confidence and trust on which nonprofit organizations depend” (Canadian Centre for Philanthropy and Canadian Policy Research Networks, 1998: 24-25).

The report on accountability and governance in Canada’s voluntary sector (Broadbent, 1999: 6), in response to such concerns, defined accountability as “the requirement to explain and accept responsibility for carrying out an assigned mandate in light of agreed upon expectations. It is particularly important in situations that involve public trust.” In considering how to enhance accountability in the voluntary sector, the Panel acknowledged that extensive accountability already existed, and that accountability in the sector is multi-layered and concerns different audiences, various activities and assorted means. This is evident from the range of mechanisms reported in Box 11.

Box 11 The Voluntary Sector – Accountability Structures and Processes
Annual General Meetings, Monthly Meetings and Annual Reports
Audits by Internal or External Auditors
Boards of Directors
Charitable Gifts/Fundraising Laws (Alberta and Ontario)
Codes of Ethics for Fundraising and Practice
Conditions in Grants and Service Contracts
<i>Corporations Acts</i> (federal and provincial)
Employment Standards laws (federal and provincial)
<i>Income Tax Act</i> (federal)
Professional Codes of Ethics
Program Reviews and Evaluations
<i>Societies Acts</i> (provincial)

Budget details and board dynamics are crucial factors that shape the accountability-autonomy balance of voluntary organizations. “Where governments provide a major part of the funding for nonprofit organizations, those organizations may find themselves more accountable to government than to non-governmental communities. In many nonprofits, this tendency is mitigated by the composition of the board of directors, which tends to be drawn from members of the local community rather than from government” (Canadian Centre for Philanthropy and Canadian Policy Research Networks, 1998: 4). A related issue is the need to update provincial corporations and societies legislation to clarify the liability of directors on voluntary boards. A longstanding issue at the national level is the need to reform federal income tax rules dealing with charities and to remove the excessive and outmoded restrictions placed on democratic activities of advocacy. This is a critical issue of governance for the entire voluntary sector and for other organizations in civil society as well.

Canada’s voluntary sector contains many long established organizations for children and families and for children and youth with disabilities. It is, nonetheless, a dynamic sector, exhibiting continued growth, adaptation and leadership. As Boxes 8 and 9 show, many new organizations, associations and coalitions have formed in recent years, tackling the issues of child poverty, child and youth development, and the rights of children. Some new structures deal with enhancing coordination within the voluntary sector, while others deal specifically with better managing relations between the sector and the federal government.

In addition, some existing organizations that have worked in the social policy field for some time have initiated research and policy advocacy activities that explicitly bridge the child and family and disability realms. The Caledon Institute of Social Policy is an example (Torjman, 2000), which joins company with the leading organizations that span these realms such as the Canadian Association for Community Living and the Roeher Institute.

Another trend of the last 25 to 30 years is that people with disabilities, mainly adults but at times youth, are organizing on their own. They are taking control of organizations that had been set up *for* them, and establishing new organizations governed by principles of self-determination and consumer control. Such developments are concrete examples of political citizenship in action (Prince, 1992; Prince, 2001a).

The rich history and the dynamic quality of the voluntary sector means that both paradigms of disability are in effect. Across this sector, one can find the conventional medical perspective along with the enabling rights-oriented perspective in the mission statements and *modus operandi* of different organizations. On one hand, this duality of paradigms covers both the personal and the political sides of experiencing disability. On the other hand, it poses challenges for building coalitions within the voluntary sector and for promoting the integration of children with disabilities and their families in all policy agendas and activities. In the world of public affairs and policy, changing frameworks takes a considerable period of time to play out (Rioux and Prince, 2001).

2.3 The Commercial Sector and Professional Associations

The commercial sector in Canada –also called the private, for-profit, proprietary, business and market sector – consists of formal organizations in the economy, under private ownership and control, which seek to be profit making. These corporate entities, formally constituted and separate in their internal governance from governments, produce and or trade in goods and services for profit (Crane, 1980). Our interest here, of course, is with the entrepreneurial auspices of health, educational, recreational, and social services for children and families.

Commercial firms rely primarily on resources derived from fees, charges or payments made by clients, customers or user of their goods or services. They may also receive grants, loans, tax benefits and contracts from governments. Profits generated are distributed to the firm’s owners, investors, shareholders, executives, and perhaps employees. The range of organizations in the commercial sector, are outlined in Box 12.

Box 12
Types of Organizations in the Commercial Sector
Individual entrepreneurs, proprietors or professional practitioners
Family Businesses
Partnerships
Incorporated Companies
Professional Associations and Firms
Business and Industry Councils
Labour Councils and Federations
Private Sector Unions

Similar to the other sectors, there is considerable diversity within the commercial sector as to size, activities, occupations, professional groups, and the history of organizations. Likewise, with similarities and overlaps with other sectors, the commercial sector has fuzzy boundaries. Like all sectors apart from the public sector, the commercial domain is non-governmental and thus distinct from the state. The commercial sector overlaps with the voluntary and Aboriginal sectors, for example, through corporate giving, business people sitting on voluntary agency boards, and firms working with Aboriginal governments and communities on economic development projects. The commercial sector also overlaps with the informal sector through businesses that are owned and operated by families. Moreover, at least according to one family therapist, there are other similarities between families and businesses in terms of their underlying structural patterns and system theory concepts of boundaries, hierarchy, power and coalitions (Deacon, 1996).

Professions as a collectivity are found in all the sectors, though for the most part professionals and their associations are concentrated in the public and commercial sectors. Even professionals located primarily within the public sector (e.g., nurses, planners, social workers, and teachers) have self-governing bodies that have some arms-length autonomy from government. Professional associations, then, are themselves a form of governance, with a delegation of authority from the public sector for the entry, education, certification, ethics, and discipline of members of the profession.

Corporate and Professional Governance

“Corporate governance is the processes, structures, and relationships through which the stakeholders, as represented by a board of directors, oversee the activities of the business enterprise” (Sexty, 1993: 58). This definition of governance is similar to that of Lemieux, which was presented earlier in the report. Governance is a decision-making system, whether formally created or not, which all corporations have in some form. The stakeholders in corporate and professional governance are multiple (Sexty, 1993), as outlined in Box 13.

Box 13
Stakeholders in Corporate and Professional Governance

Governments – federal, provincial, territorial, municipal, First Nations, foreign

Shareholders and owners

Boards of Directors

Board Chairs

Chief Executive Officers and Presidents

Management – senior or executive, middle, and supervisory

Employees

Unions

Professional Associations – international, national, provincial, and local

Lenders and creditors

Suppliers

Consumers, customers, clients, or patients

Public interest groups

Mass media

Society at large

Professions often play a critical role in developing and shaping the level and nature of health care and social services. They also participate in the management structures of service agencies, regulatory bodies, and policy committees. More than that, professionals construct the identity and status of clients through their tools of assessment and diagnosis. Through processes of training, socialization and codes of practice, professionals are purveyors of a given paradigm toward children and families, toward disabilities, and toward health and wellness.

Professions have been called “private governments,” meaning interest groups that can exercise significant powers in their own right. In addition, professions seek to influence and participate in policy development, implementation and evaluation. They can do so by virtue of their expertise and by granting or withholding their support for particular policies and proposals, thereby helping to determine the legitimacy of a status quo and the political feasibility of reform ideas.

The mass media – television, radio, movies, videos, newspapers, magazines, and now the Internet – is another component of the commercial sector that is clearly crucial to constructing the identity of children and adults with disabilities for the public and for policy makers. Their influence is wielded through the use of outmoded or inclusive language, and images that emphasize differences, sympathy and charity or dignity, self-determination and citizenship. The media is also a tool that can be harnessed by advocates in the informal, voluntary and Aboriginal sectors – and by others in the commercial sector – for advocating general reforms and advancing individual and group claims by influencing public opinion.

We have been speaking of professions as a general category, but of course there are tremendous differences among the occupational groups that are or claim to be professions. The differences can be presented in terms of three broad classes:

- ***Established Professions:*** law, teaching, nursing, and various branches of medicine and science, including psychology and psychiatry
- ***Aspiring Professions:*** social work, early childhood education, school-based child and youth care, and
- ***Marginalized Occupations (non-professions):*** visiting homemakers, foster parents, and attendants to persons with disabilities.

This hierarchy of status corresponds to different levels of social prestige and recognition, self-regulation, autonomy in making decisions about people, training and expertise required, and compensation and working conditions. Further, across different fields of Canadian social policy, the level of professionalization varies. The extent of professional development is generally low in certain personal social services such as home support workers and private home day care providers, higher in education, and still higher in family law. For other fields with little or no professionalization, which are characterized by low pay and the beliefs that the work is neither high-skill nor has a career ladder, there usually are severe recruitment and retention problems. For many of these occupations, there is a significant gender dimension in that most paid providers are women and most people looking for these home support services for themselves or a family member are women. For home and community care, there are additional challenges in finding staff with child-specific experience.

The Iceberg of Child and Disability Policy

The commercial sector is the iceberg of the child and disability governance regime. It does not have a high profile in most debates on policy and service delivery. Not much is known about it within this policy domain, although we have a strong sense that, like an iceberg, there is a great deal that exists below the surface. As well, some groups are quite cool toward the commercial sector, seeing it as a threat to progressive reform in advancing citizenship and human rights for children with disabilities and their families.

The commercial sector has recognized the case of children with special needs as a viable market, and some private agencies focus on children. However, there is little readily available literature on the role of the commercial sector in providing services and programs to children and families, especially with respect to children with disabilities and their families.⁷ We lack systematic and comprehensive information on the current role of businesses or professions in the provision of, for example, personal disability supports. Similarly, we lack evidence on the cost effectiveness of the commercial provision of attendant supports, home making assistance, respite for family caregivers, or technical aids and devices. There is much heat but little light on the question of whether private firms are offering disability supports to children and youth that are available, portable and affordable.

In government policy papers, parliamentary reports and submissions to committees, there is a general absence of references to the commercial sector. Unlike the other sectors, it is infrequently considered in as explicit a manner. Even the most recent provincial government strategy papers on disability issues (Alberta, 2001; Manitoba, 2001) pay only brief attention to this sector, although both papers do point out the need for greater involvement of the corporate world in the development and implementation of policies and programs. Perhaps this relative neglect of the commercial sector is understandable when we are discussing children with disabilities versus working age adults. The neglect may be due to a longstanding focus in Canadian disability policy on introducing and expanding a “safety net” of public programs in support of families (Rice and Prince, 2000), a focus that has been more recently reinforced by the *Canadian Charter of Rights and Freedoms*, the human rights perspective in child policy, and the goal of citizenship in disability policy.

Box 14 presents an illustrative profile of how the commercial sector relates to families with children and youth.

⁷ An exception has been the debate in the child day care literature in Canada over the past 20 years on the relative merits and limitations of public and cooperative child care versus for-profit child care.

Box 14
Commercial Sector Activities that Relate to
Children with Disabilities and their Families

1. Employment for parents and guardians providing an income for their families, and the status and network of contacts for the family.
2. Family-friendly work policies and benefits, such as flexible hours and unpaid leave. The provision of social services for employees and other family members through employee assistance programs.
3. Professionals engaged in private practice who provide fee-for-service activities. Privately contracted individuals, clinics, firms, and specialized institutional facilities that are involved in learning and tutoring, home help, rehabilitation, respite care, psychiatric and psychological diagnostic testing and assessments, counselling, and many other areas of the human services. Private schools for children with special needs, such as those with autism.
4. Purchase-of-service arrangements, whereby public or voluntary agencies or families contract with a commercial operator to deliver and perhaps manage a service.
5. The “duty to accommodate” and other workplace equity policies for adults with disabilities.
6. Sources of training, employment, and career opportunities for youth and adults.
7. Participating on voluntary agency boards or government advisory councils. An example is the Employability Council, created in 1999, which provides advice to the Alberta Minister of Human Resources and Employment on how to enhance the employment opportunities for persons with disabilities. Council members include employers, representative of disability associations, and individuals with disabilities.
8. The production and reproduction of images, words, and role models through advertising and marketing. Such message may be positive or negative.
9. Other elements of corporate social responsibility, which may involve, among other actions, donations in cash or in kind to family service programs or agencies.

Once again, the overlap among sectors emerges from this survey of commercial activities, as evident in contracting processes or corporate giving. However, in many respects, the list in Box 14 presents an idealized picture of what might or should happen in the commercial sector. Aspects of each of the types of activities are taking place in the Canadian economy, but there are tremendous gaps and a notable unevenness of effort. The commercial sector is active in lobbying governments for changes in employment equity laws, labour codes, and even the International Labour Office on conventions on family-friendly workplaces. Yet, many if not most businesses do not have a comprehensive package of family-friendly policies. Levels of corporate giving in Canada are modest in comparison to the United States and other countries. There are some early adopters of the duty to accommodate persons with disabilities in the workplace, but there are many resisters too.

As the Alberta Premier's Council on the Status of Persons with Disabilities has stated, many employers are still not attuned to their duty to accommodate the needs of individual employees with disabilities. As a result, discrimination on the grounds of physical or mental disability has become the largest category of human rights complaints in many provinces (Alberta, 2001; see also Manitoba, 2001).

The Market Place, Professions, and Citizenship – Partners or Protagonists?

What ought to be the role of the commercial sector in ensuring that Canada provides child protection measures, access to essential services such as education, and opportunities for children and youth to develop to their fullest potential? Major social policy initiatives such as the Canada Health and Social Transfer, *In Unison*, the *Social Union Framework Agreement*, the National Children's Agenda, and the *Agreement on Early Childhood Development Initiatives* are silent on this fundamental question of governance. In the words of a recent disability strategy paper, "there are many private providers who receive funding in an environment that lacks guidelines to define when a service is best provided by the private, voluntary or public sector" (Alberta, 2001: 73). Policy work has been done of late on federal-provincial-territorial, federal-Aboriginal, and government-voluntary sector relations, but there is a clear need to extend these discussions to the commercial sector.

The relation between the marketplace and citizenship is a topic in political beliefs that is subject to strongly held and divergent viewpoints. For conservatives and classical liberals, citizenship is based on markets and freedom from state intervention. Liberty and full membership in society is achieved in large part through participation in the labour market and related elements of the economy. Citizenship here means *market participation*. This perspective is reflected in the policy documents of Canadian governments that speak of the economic integration of persons with disabilities. In contrast, for welfare liberals and social democrats, citizenship depends on a reduced reliance on the market economy for determining the status of people, and instead emphasizes both an active role for the state and lively participation in civil society and political affairs as critical dimensions of citizenship. Citizenship here means *inclusion* – in publicly supported day care centers, schools, recreational facilities, and other aspects of a community's social infrastructure. Thus, there is a contested relationship between the commercial sector and social citizenship (see Box 15).

As an overarching institution in our market society, the commercial sector embodies the ideas and rhetoric of individual and family self-reliance, free trade, efficiency and productivity, private profit, risk and innovation, and a limited role for government. The concept of citizenship is about rights and duties, societal membership and political participation, all of which inform ideas about justice, equality and identity.

Box 15
The Commercial Sector, Social Policy, and
Citizenship – A Dynamic Relationship

“Citizenship is an abatement of ... economic relationships. The political achievement of full citizenship where it involves significant social rights is a direct challenge to capitalism. ... The dynamic feature of capitalism is precisely the contradiction between politics and economics as fought out in the sphere of social citizenship” (Turner, 1986: 6 and 11-12).

“The intrusion of social security organizations into the operation of the private market has, throughout the history of social security in Canada, brought into conflict opposing systems of values and beliefs. In essence, the private market, which has been the paramount institution in society for the distribution of income, goods, and services, has been challenged by the development of alternative institutional arrangements which utilize other criteria to determine the distribution of income, goods, and services, such as need, contractual rights, and the status of age, residence, and citizenship” (Guest, 1985: 2).

Efforts to promote full citizenship for children with disabilities and their families also poses threats and opportunities for professions. A rights-based approach certainly challenges and comes up against the traditional role of certain professions in terms of biomedical practices. It also favours other professions and occupations, such as law and the advocacy work of social workers, nurses and youth workers. The pursuit of greater professional status (as traditionally defined) by child and youth care workers runs the risk of reproducing the expert-based approach to professional-client relations. With a growing accent on self-determination in the informal, voluntary, and Aboriginal sectors, a critical stance is taken toward professionals who, at times, are seen to disempower or even blame individuals and families.

2.4 Canada’s Public Sector

Canada’s public sector is a vast collection of governments and countless other public agencies. To make the task at hand manageable, our prime focus here is on the federal, provincial and territorial governments, with some additional discussion of the court system, municipalities, and school boards. To sketch out which public sector organizations and governments perform what governance functions, this section outlines the main institutional actors with respect to the three clusters of governance functions, first for governments generally and then, more specifically, for the child and family policy and disability policy domains.⁸

Box 16 deals with the governance processes of including the public or particular publics in the policy process. It also maps policy development – the setting of strategic goals and overall priorities, and ways to manage interdependencies within a government and among governments.

⁸ The following analysis is extensive rather than exhaustive in coverage. Our intent is to convey the general scope and nature of governance practices in the public sector and to indicate trends.

Box 16
**The Public Sector – Policy Planning,
Consultation, and Coordination Structures**

General to Government

Mayors' and Premiers' Offices and the Prime Minister's Office

Executive and Privy Councils

Finance and Treasury Departments

Attorney General and Justice Departments

Intergovernmental Departments or Secretariats

Aboriginal or Native Affairs Departments or Secretariats

Women's Ministries, Secretariats and Advisory Councils

Seniors' Secretariats and Advisory Councils

Specific to Child and Family Issues or Disability Issues

Premiers' Councils on Disability Issues

Premiers' Councils on Children or Youth

Designated Ministers responsible for Disability Issues or Children

Offices of Disability Issues

Ministries of Child and Family Services

Children's Secretariats

Federal Task Force on Disability Issues (1996)

Federal-Provincial-Territorial Ministers responsible for Social Services, and various working groups of officials

In Unison – Federal-Provincial-Territorial process of consultation with each other and with disability groups and Aboriginal organizations (1997-1998)

National Children's Agenda public dialogue process (1999-2000)

Legislative Committees and Task Forces on Children and Families or on Disability Issues

Parent Advisory Committees

House of Commons' Committees (various types and processes, 1980-2001)

With respect to structures that are *general to government*, the first five listed are common to the federal, provincial and territorial governments. Comparable positions exist in larger municipalities and school boards across the country. These are the central agencies of government.⁹ They have responsibility that extends across a government to coordinate policy. Central agency mandates are broadly horizontal in nature and include the authority to have input into most if not all other departments and agencies. They are, for example, responsible for constructing governments' overall agendas, including Throne Speeches, budget plans, and major policy strategies.

The later three types of structures that are *general to government* are clientele agencies, that is, organizations specific to particular constituencies such as Aboriginal peoples, seniors and women. These clientele agencies have neither the history nor the authority of central agencies within governments in Canada. Moreover, not all governments have clientele agencies. Among those that do, there is variation in whether it is a unit internal to the bureaucracy or a separate department such as a public advisory council. A scan of government Web sites indicates that few of these clientele agencies have an explicit focus on disability issues.

With respect to structures that are *specific to disability issues*, there is considerable variation across governments. In the provinces of Alberta, Saskatchewan, Quebec, New Brunswick and Nova Scotia, responsibility for disability issues is located in public bodies with a statutory foundation, which are attached to the legislative assembly or the premier's office. This affords these bodies profile and stability in their role. The law establishing the Disabled Persons Commission in Nova Scotia also specifies the formation of a coordinating committee of cabinet. British Columbia had a premier's advisory council for persons with disabilities from the late 1980s to the early 1990s, although it lacked a legislative base.

Today, British Columbia, as well as Canada and Ontario, have offices of disability issues. These are administrative units staffed by a modest number of officials, located within particular departments or ministries. Of those jurisdictions with such structures, nearly all also have ministers designated as responsible for disability issues. British Columbia is an exception.¹⁰ Most of these disability agencies, however, do not explicitly include or highlight children with disabilities in their mandates and activities. Manitoba, Newfoundland, Prince Edward Island, the Northwest Territories, Nunavut, and the Yukon Territories do not have councils or offices, although Manitoba is planning to establish a disability strategy with supporting structures.

Even greater variation exists among jurisdictions with respect to government-wide structures that are *specific to child and family issues*. British Columbia, Alberta, Quebec, and Prince Edward Island have cabinet portfolios dedicated to this policy domain. In its 2000 *Throne Speech*, the Prince Edward Island government also announced plans to create a premier's council on healthy child development, supported by a secretariat within the public service.

⁹ In addition, there are the central agencies of *intergovernmental* relations in Canada, namely, First Ministers' Conferences and Annual Premiers' Conferences.

¹⁰ There has not been a minister designated with responsibility for disability issues in British Columbia since the mid-1990s.

British Columbia's newly renamed Ministry of Children and Family Development (previously known as the Ministry for Children and Families) is perhaps the most comprehensive and ambitious in spanning functions and seeking to integrate programs and practice fields of various professions. The Liberal government in British Columbia, elected in May 2001, has also created a Minister of State for Early Childhood Development, to assist the Minister of Children and Family Development. According to the Premier's Office, the role of the Minister of State is to "increase public access and responsiveness" to the large Ministry of Children and Family Development, and to "provide a new level of accountability in meeting specific commitments" (British Columbia, 2001: 1). Even in British Columbia, however, special education programs, disability income benefits, the Children's Commission, and mental health services are located in, or report to, other government ministries.

The territorial governments and three provinces – Manitoba, New Brunswick and Nova Scotia – appear to have no specific structure for government-wide coordination and planning of family and child policy. New Brunswick and Saskatchewan both have youth councils, where the focus is on teenagers and issues such as school-to-work transitions, rather than on younger children.

Over the last decade, governments in Canada have been active in holding policy consultations and planning processes in fields relevant to children with disabilities and their families. Provinces have held public consultations on child and family services, including child protection services in certain provinces, child day care, early childhood development, social assistance, and social policy more generally. A range of techniques have been used to engage citizens and stakeholders including advisory groups, task forces, policy discussion papers, roundtables, town hall meetings, and other public dialogue fora. A common pattern is that a government triggers the process by releasing a discussion paper, conducting public consultations, and revising the policy statement, which may be accompanied by new or amended legislation. The process may stretch over the entire life of a government's mandate or beyond.

Public consultations and policy planning exercises can afford families and community-based groups valuable avenues for networking amongst themselves, as well as for accessing and influencing the public policy side of this governance regime. A striking illustration is the National Children's Agenda (NCA), a federal-provincial-territorial initiative (which Quebec did not take part in) to move policies and programs forward to improve the well being of children. The document released for the public dialogue process in 1999, *A National Children's Agenda: Developing a Shared Vision*, caused concern among parents and guardians of children with disabilities. As the Canadian Association of Community Living (CACL) observed, concerns were raised that "the NCA did not include or reflect the reality of children and youth that have a disability." Families expressed concern that the proposed framework equated "healthy child development" with "normal child development," and "suggests that children are ready to learn when they reach certain milestones in their cognitive ability, communication, physical and motor skills." It also appeared that the framework equated disability with a failure to make "children ready to learn" (Canadian Association of Community Living, 2000).

As a result of the interventions by CACL and other groups and individual families, an amended vision statement and subsequent policy agreements (such as the *Agreement on Early Childhood Development Initiatives*) were developed.¹¹ These explicitly refer to the need for programs and services that are inclusive of children with different abilities and life circumstances (Federal-Provincial-Territorial Ministers Responsible for Social Services, 2000; Prince, 2001b).

When Canadians reflect on public administration, most probably think of government departments and agencies with budgets, staffs and facilities for the delivery of numerous benefits, programs and services. These are the governance processes reviewed in Box 17. They cover the establishment of policy mandates; the division of labour through the formation of different portfolios, departments and agencies; and the allocation of financial, personnel and other resources to support the provision of services. Disability policy, as Box 1 indicated, is a wide domain covering most areas of public affairs. Many of these areas – culture, recreation, employment, housing, and transportation – fall largely within the responsibility of provincial, territorial and municipal governments in Canada.

Four departmental areas are primary in the *child and family policy* and *disability policy* domains. These are education, health, human resources, and social services or child and family services. Each of these is discussed below.

The Governance of Public Education

Education is of fundamental importance to individuals, groups and societies. Article 29 of the *United Nations Convention on the Rights of the Child* states that the education of children ought to be aimed at “the preparation of the child for responsible life in a free society, in the spirit of understanding, peace, tolerance, equality of sexes, and friendship among all peoples, ethnic, national and religious groups, and persons of indigenous origin.” Canadian children and youth commonly spend more waking hours in the school system than even at home. Compulsory, publicly provided education for children and youth has been justified for several reasons, as outlined in Box 18.

As a policy domain, education in Canada is highly provincialized as a public issue, and in the structure of professional bodies and other stakeholders. Salient features of educational governance in Canada are the predominant role of the provinces and minor role assigned to the federal government; publicly funded denominational schools in certain jurisdictions; and historic and contemporary issues of education for official language minorities. Other features are the existence of locally elected school boards, and various funding mixes of provincial grants and local property taxes. The result is that Canada has 13 provincial-territorial education systems that are “extraordinarily complex and diversified” (Woolstencroft, 1990: 151).

¹¹ A further contributing factor at the federal parliamentary level was a joint meeting of the Sub-Committee on the Status of Persons with Disabilities and the Sub-Committee on Children and Youth at Risk, which discussed the exclusion of children with disabilities. This exchange of ideas among Members of Parliament helped to have children with disabilities included in the *Agreement on Early Childhood Development Initiatives* of September 2000 (House of Commons, 2001).

Box 17
**The Public Sector – Creating Program Structures,
Allocating Resources, and Delivering Services**

General to Government

Attorney General/Justice
Culture and Recreation
Employment/Labour
Finance/Revenue
Housing/Municipal Affairs
Provincial Lottery and Gaming Commissions
Public Works
Transportation

Specific to Child and Family or Disability Issues

Child and Family Services Departments or Divisions
Community and Social Services Departments
Community Mental Health Centres
Education Departments
Family Courts
Health Authorities – Regional and Local Boards
Health Departments
Human Resources Departments
Indian Affairs and Northern Development
Library Boards
Parks Boards and Recreation Boards
School Boards and Parent Advisory Councils
Veterans Affairs Canada

Box 18
Potential Roles and Purposes of Education

Over the past 150 years or so, four perspectives on the fundamental role of education to personal, economic, social and political development have been articulated at different times and in different ways (Manzer, 1985; Mahon, 2001). Today, all four perspectives are evident in Canada's educational systems in varying forms, supported by various interests. Each perspective has implications for curriculum as well as for the status of citizenship.

Public education is considered to be a social right and duty in itself. Schooling is also an instrument for fostering the fuller development of citizenship and human rights. The first two perspectives give emphasis to the interests of society and the economy, while the latter two emphasize the interests of the individual and particular groups. For children with disabilities and their families, all four roles of education are essential and attractive; yet the final one in particular is central to realizing inclusion and a sense of belonging.

Schooling as Civic and Moral Education

Training for democracy

Educating "virtuous citizens"

Teaching the moral standards of the community, and the duties as well as rights of citizenship

Schooling as Job Preparation

Serving the requirements of the labour market and wider economy

Training employable workers, that is, preparing young people for earning a living

Teaching technical, vocational, and practical life skills

Schooling as Individual Development

Nurturing each student's intellectual, artistic, social, physical development

Offering child-centred learning

Educating the whole person

Schooling as Group Identity and Social Cohesion

Maintaining the identity of particular groups in Canadian society, such as Aboriginal peoples, official language minorities, religious groups

Providing opportunities for *all children and youth* through mainstreaming and inclusive education policies and practices

A recent trend in educational governance is the consolidation of school districts in most provinces, thus reducing the number and increasing the size of school boards (Canadian School Boards Association, 2000). Ronald Manzer has commented that, “with the movement to larger units of school administration,” the opportunity for citizen participation in policy making by local school governments has substantially declined (Manzer, 1985: 127). From the time when Manzer made this observation, the number of elected school boards across the country has further declined. Other trends are the home schooling movement, and increasing parental choice and influence in local education, spurred on by the formation of parental advisory committees in all provinces, and by real or threatened program cuts and school closures.

Another trend is the drive towards standardized testing in schools and across school districts. Funding formulas can be tied to how students perform on standard tests. As a result, children with disabilities, who may test differently, may be asked *not* to take these tests. An unintended consequence of such testing and related performance measurement can be that the students with disabilities are marginalized and stigmatized. Relevant to this study, an important trend since the 1970s has been the growth of special education services and the inclusion and mainstreaming of special education students within Canadian schools. As Young and Levin (1998: 3) observe:

A delivery and support apparatus emerged alongside special education. New programs and classes were created for special need students. New categories of teachers, such as resource teachers and behavioural class teachers, were also created. ... Provinces created special education branches and targeted funding to support special education programs and staff. Today, running throughout the school system is a large apparatus dedicated to the area of special education, even though one supposed purpose of the activity is to eliminate the differences between disabled and nondisabled students.

Among the issues related to this particular policy and organizational trend is the legal question of who has what rights and duties concerning the placement of special education students. There has been a growing trend toward applying principles of natural justice to special education. This means that “students and parents must be kept informed of the school’s proposals for students, and that they be given the right to a hearing” (Young and Levin, 1998: 125-126). While these are important procedural rights, they seem very different from some groups’ vision of citizenship rights for school-aged children with disabilities.

Even where there is a legislated right to access public education, as a recent provincial report on disability in Alberta notes, “a number of barriers prevent children with disabilities from fulfilling their potential, attaining equal status, making their best personal contribution, and realizing their inherent worth. Fragmented and uncoordinated services, funding issues, and inadequate teacher preparation and support are among the reasons why school jurisdictions may not be able to meet the needs of some students with disabilities. Individual school boards have a great deal of discretion in a system where standards for special education programs have not been set and province-wide evaluation procedures have not been established. The [1988 *Alberta School*] Act also limits student and parental choice and involvement in decision-making as it grants the school board full authority to decide when a child is to be removed from the home school for a segregated learning experience (as long as the board pays for the new program)” (Alberta, 2001: 36). Educational governance, therefore, can restrict equitable access to learning opportunities for children and youth with disabilities.

Health Care Governance in the Public Sector

The complexity of the governance regime for health policy in Canada that confronts and often baffles parents of children with disabilities is due to the organization of the health system around vertical silos of provider groups and governments. The silos include the powerful, self-regulated professional associations of physicians and surgeons; provincial departments of health; regional health authorities; hospital societies and boards; community health councils; hospital-based mental health services in special facilities; and local clinics and centres for assorted services that vary in different parts of the country.

Trends over the last decade in health care governance in Canada include numerous reviews and reforms of legislation, programs and structures. At the provincial and territorial level, some jurisdictions amalgamated their health and social service departments, and sought to clarify what ought to be their core health care responsibilities. Virtually all jurisdictions embarked on a process of regionalization of health service delivery and governance, which typically entailed reducing the number of boards and authorities at the regional and community level. For children with disabilities and their families, a salient trend has been provincial efforts to shift budgetary resources and the policy focus away from acute care to community health and home care. Along with this has been an increasing reliance on mental health promotion and prevention strategies (Gourlay, 1998).

Despite these many reform efforts, Judith Maxwell argues convincingly that, “if there is a crisis in health care, it is in the governance of the system. Decision making authority is so fractured in this complex system, and competition among politicians and professionals so intense that there is little scope for joint problem solving” (Maxwell, 2001: 22).

Family and Social Services

Certain programs, as noted in Box 17, do reside in the same government portfolios. Now, almost universally across the country, home care, rehabilitation services, mental health services, and aids to daily living are in departments or ministries of health. Similarly, education supports are in education portfolios. In most provinces and territories, responsibility for developmental disabilities, early childhood development, home and family supports, respite care, and integrated child care services are in community and social services or child and family service ministries. In a few provinces, however, some of these activities are in health and wellness departments. Leisure services are situated in recreation, municipal affairs, or community services departments. Income benefit programs are variously located in social services, child and family services, or human resource departments. Wherever they are located, a common trend across Canadian jurisdictions in the last 10 years has been the removal of children’s income benefits and disability benefits from the social assistance system into separate programs, and especially the use of federal spending power to deliver these benefits directly.

Approaches to Governance and Service Delivery

Program governance and service delivery occur in a more or less centralized or decentralized manner. Indeed, five different approaches are apparent across the Canadian public sector in the regime for children with disabilities and their families. These are presented along a spectrum of how elaborate and ambitious are the policy networks, from least to most complex.

- **Centralized:** The centralized model involves program administration by headquarter branches or regional and local offices of provincial departments or ministries. This is the main pattern for providing aids to daily living, inclusive child care, income support, in-home family supports, respite care, and services for developmental disabilities.
- **Decentralized or Delegated:** A more decentralized model is where service delivery and administration occurs through delegated provincial bodies such as regional health authorities, as well as by local governments, school boards and community centres. This is the prevailing pattern for providing educational supports, home care, rehabilitation services, mental health services, and recreation programs. Examples are Children's Aid Societies in Ontario and elsewhere, Quebec's *Centres locaux de services communautaires* (CLSCs), which provide health and social services, and the federal government's Community Action Program for Children and Aboriginal Head Start Initiative.
- **Coordinated or Interdepartmental:** In this model, a government establishes a cross-departmental structure and process for the planning and delivery of services. Examples are the Nova Scotia Child and Youth Action Committee, the Saskatchewan Action Plan for Children and its ADM Forum, and Ontario's Office of Integrated Services for Children.
- **Consolidated:** This model involves the formation of a large department or ministry that pulls together several policy and program activities, which were previously located across a number of government portfolios. The Ministry of Children and Family Development (previously called the Ministry for Children and Families) in British Columbia, Quebec's *Ministère de la Famille et de l'Enfance* (Ministry of Child and Family Welfare), and the Ministry of Children's Services in Alberta are the leading examples. Even still, these giant departments do not completely envelop the children's policy and disability policy field. Matters of health, justice and income assistance remain housed in other departments.
- **Federalized:** This model refers to situations where the management of service delivery is directly shared by both orders of senior government. The Canada Prenatal Nutrition Program, for example, which provides resources to community-based groups, is delivered through Health Canada's regional offices and managed jointly by federal and provincial-territorial governments. The Canada Customs and Revenue Agency likewise administers family and child benefits and tax credit programs, not only for the federal government but also for several provincial and territorial governments. Such instances of collaborative arrangements have increased throughout the 1990s (Auditor General of Canada, 1999).

The employment of assorted delivery models suggests that one approach is not automatically superior to the other in all program fields, and also indicates that governments have been experimenting in recent years with more elaborate reforms. It is worth noting here also that any of these approaches may reflect *conventional* governance practices (see Box 4) through a program-centred rather than person-centred approach to service provision. Any of the models, too, can fragment decision-making, creating coordination challenges and bewildering the public on matters of program access and accountability (Tindal and Nobes Tindal, 2000).

Public Accountability

We now turn our attention to the various aspects of accountability. Box 19 summarizes the governance processes related to these, which relate to benchmarking, performance measurement, setting outcomes, and conducting program audits and evaluations. They also include policy reviews and analyses, advocacy for individual clients and groups, and the investigation and adjudication of disputes and complaints.

The accountability structures that are *general to government* are common across jurisdictions. That is, all senior governments in Canada have auditors general, court systems, human rights bodies, legislative committees, and operate under the *Canadian Charter of Rights and Freedoms* as well as the principles of individual and collective ministerial responsibility. Most, though not all, have medical officers of health and ombudsman offices.¹²

The *Charter* and human rights laws in all jurisdictions contain references to the prohibition of discrimination on the grounds of physical and mental disabilities. A recent trend has been the addition to federal and some provincial human rights laws of a “duty to accommodate” persons with disabilities, a provision yielding new jurisprudence on the scope and meaning of this duty. Otherwise, these structures do not contain a specific orientation on disability issues. Their focus is on legal, financial and political accountability, and tends to be interpreted from the traditional perspective of accountability, that is, answering for a responsibility conferred. Many of these structures’ processes are triggered by individual complaints, and decisions are made on a case-by-case basis. Provinces also have a variety of one- and two-step processes that include internal reviews and appeal boards for mental health systems, income assistance programs, social services, and perhaps welfare-to-work programs (Gorlick and Brethour, 1998; Gourlay, 1998).

Accountability structures that are *specific to child and family policy or disability policy* are newer additions to the governance regime and not as common across Canadian jurisdictions as those structures that are *general to governments*. Only four provinces – British Columbia, Alberta, Saskatchewan and Manitoba – have children’s advocates, all established since 1989. Certain other provinces have offices of child representatives, notably Ontario and Quebec, but these tend to relate more to the child protection and family law systems (Mahon, 2001: 85). One province, British Columbia, also has children’s commission and commissioner.

¹² Newfoundland, Prince Edward Island, the territorial governments, and the federal government do not have a general ombudsman office. In February 2001, the Premier of Newfoundland indicated his government’s intention to create such an office.

Box 19
The Public Sector – Accountability Structures and Processes

General to Government

Auditor General's Offices

Courts, the *Canadian Charter of Rights and Freedoms*, and the Court Challenges Program

Human Rights Commissions and Tribunals

Legislative Assemblies and Committees

Medical Officers of Health – Provincial, Regional and Local

Ministerial Responsibility

Ombudsman Offices

Specific to Child and Family or Disability Issues

Canadian Coalition on the Rights of Children

Child, Youth and Family Advocate Offices

Children's Commissions

Consultation and Investigation Processes

Legislative Committees and Task Forces

Reporting requirements to United Nations committees for various Conventions

Responsibility of Designated Ministers

Special Education Advisory Committees, Individual Education Plans, and Identification, Placement and Review Committees

These offices tend to combine a mixture of advocacy, analysis and accountability functions. Routine and *ad hoc* consultation or investigation exercises can also serve as accountability events and opportunities to include and possibly empower parents or guardians and their children.

Several jurisdictions have legislative standing committees that are devoted to child and family policy, and a few have committees or sub-committees that are dedicated to disability issues. As typically structured, however, these committees have inherent limitations in mandate and resources, and face governmental barriers in producing significant and sustained policy reforms and innovations by governments (House of Commons, 2001).

The mandate, composition and effectiveness of these committees differ across jurisdictions, and can change within a particular governmental system over time. As noted previously, several jurisdictions have a minister designated as responsible for children and families or disability issues. Practice both within and across jurisdictions, however, suggests that these are often different ministers in a cabinet.

Accountability and advocacy structures also exist in specific program areas that pertain to children with disabilities and their families. Special education programs and services in Ontario, is an example, as described by Bradt and Hardwick-Leclerc (2000: 4-5):

There are procedures in place for parent involvement in board wide planning and individual student and program progress. Special Education Advisory Committees, Individual Education Plans, and Identification Placement and Review Committees all serve important advocacy and accountability functions. Each collaborative process requires nurturing so that it serves students and ensures that parents are meaningfully involved.

In Ontario at least, these structures are rooted in provincial regulations from the Ministry of Education, rather than in legislation. When these procedures work, they are examples of the newer form of accountability – an interactive and less hierarchical relationship. To make them work requires stable funding for programs, support for research and development, shared knowledge about learning disorders, mutual values among the participants, and training for parents and school staff to effectively engage in such processes. Funding and staffing trends in recent years, however, pose a number of challenges to these accountability systems in special education. According to two Ontario special education teachers and administrators, “the roles of school staff and the composition and dynamics of staff interaction have undergone significant change. The legislated withdrawal of school administrators from teacher unions, decreased teaching and clerical staff, and increased deployment of educational assistants have significantly affected special education delivery” (Bradt and Hardwick-Leclerc, 2000: 4). The upshot, in their view, is a decline in team bonds and trust within schools, resulting from the creation of different group affiliations.

In summary, there has been considerable policy and structural reviews and reforms within the Canadian public sector in recent years. The pace, depth and breadth of these changes themselves have posed significant challenges to families who have children with special needs of all kinds. In the critical areas of health care and public education, regionalization has resulted in fewer and larger locally elected community forms of governance. At the same time, the downloading of responsibilities to municipalities for assorted social programs, without commensurate transfers in sustainable budgetary resources, has squeezed the capacity of city governments to effectively address issues of community health. A related concern of the public sector’s governance regime for children with disabilities and their families, indeed for the disability policy domain as a whole, is the absence of clear, consistent and central accountability mechanisms. Such mechanisms are vital in advancing the agenda for inclusive and more integrated services and programming.

2.5 The Aboriginal Sector in Canada

For Aboriginal peoples in Canada, a widely shared and deeply felt belief is that children are a gift from the Creator and that each child is part of what makes a community whole. The birth rate of Aboriginal peoples is twice the Canadian average and has been for a number of years, resulting in the Aboriginal population being much younger as a whole. Behind these eloquent beliefs and significant demographic trends, however, are some extremely distressing indicators about the life situation of Aboriginal children and youth (Indian and Northern Affairs Canada, 2001):

- Diabetes is epidemic among Aboriginal people and communities, with First Nation people three times more likely to be diabetic than other Canadians.
- A disproportionately higher incidence of special needs exists among First Nation students compared to the general Canadian population.
- Aboriginal peoples are more likely than other Canadians to have hearing, sight and speech disabilities.
- Most Aboriginal peoples live at or below the poverty line. In major cities in the western provinces, four times as many Aboriginal peoples as other citizens live below the poverty line.
- The suicide rates of registered Indian youth (ages 15 to 24) are eight times higher than the national rate for females, and five times higher for males.

Recently, an all-party parliamentary report stated, “the situation of Aboriginal children is a national embarrassment and requires urgent action” (House of Commons, 2001: 28).

In the area of special education, to take one example, there is a critical lack of funding in First Nation communities and federal schools. A further problem is that the existing formal and standardized assessment tools for special education were developed from and for the mainstream non-Aboriginal population. This raises the understandable concern of the cultural biases and technical inadequacies of such tools for Aboriginal children and youth with special needs (Canada, 1996b, Vol. 3: 437).

The governance regime in Canada’s public sector adds a further heavy burden on and set of barriers for Aboriginal children and youth with disabilities. As a Federal Task Force reported not that long ago (Canada, 1996: 20-21):

Aboriginal Canadians with disabilities have many needs that parallel those of other Canadians with disabilities, but they must seek solutions in a morass of jurisdictional forces that have led to fragmented policies and a patchwork of supports and services, where those are available at all. The net affect of this jurisdictional morass is that Aboriginal Canadians with disabilities are much more disadvantaged than their fellow Canadians. For on-reserve Aboriginal people with disabilities, the lack of supports and services in their home communities means that they may have two stark choices:

- To stay in their community and not have access to the basic types of services and supports that would allow them to exercise some control of their own destiny, or
- To leave their homes and communities to search for the basic necessities of life.

The irony is that in the end, whatever they do, they may be denied access to those necessities, because it is the overlapping [nature] and lack of collaboration among jurisdictions that dictate their eligibility. For Aboriginal Canadians with disabilities living off reserve, access to services and supports may be only marginally better, since mainstream programs do not usually deliver services that respond to their needs. And without adequate resources, they do not have the purchasing power to buy what they need.

What makes this irony a tragedy, is that the disability rate for Aboriginal peoples in Canada is at least double the national average, and many of these disabilities are likely preventable.

In 1993, a federal parliamentary committee looking into the lives of Aboriginal peoples with disabilities, remarked that “the most significant change that has taken place since 1981,” the International Year of the Disabled Person, is that “the voice of Aboriginal people with disabilities has grown much louder and much stronger” (House of Commons, 1993: 6). Almost a decade later, this is even more apparent with the emergence of a substantial number of organizations dedicated to Aboriginal disability issues and Aboriginal youth. Boxes 20, 21 and 22 map the main institutional actors within the Aboriginal sector in Canada that play a role with respect to the child and family policy and disability policy domains.

Aboriginal Perspectives on Disability Issues

The Assembly of First Nations (AFN) has taken a leadership role in formulating a position on disability issues. In July 1998, it released a discussion paper, *First Perspective: An Approach to First Nation’s Disability Issues* (Assembly of First Nations, 1998b). Later that year, at the annual Confederacy of Nations, the AFN adopted a position statement on disability. The following vision on disability was approved at that time (Assembly of First Nations, 1998a):

First Nations people with disabilities have inherent Aboriginal and Treaty rights which they have a sacred duty to protect. It is the shared responsibility of First Nations society to eliminate barriers that restrict them from fulfilling their sacred duty and the opportunities for contributing to their own greater well being and that of their Nation.

Box 20
**The Aboriginal Sector – Policy Planning,
Consultation, and Coordination Structures**

National Political Organizations:

- Assembly of First Nations
- Congress of Aboriginal Peoples
- Inuit Tapirisat of Canada
- Métis National Council
- Métis National Association of Women
- Native Women's Association
- Pauktuutit (Inuit Women's Organization)

Aboriginal Health Institute

Aboriginal Networks on Disability (national, regional, provincial)

Aboriginal Reference Group on Disability Issues

Aboriginal Round Table on Disability Issues (1997)

Aboriginal Youth Council

Assembly of First Nations Youth Advisory Working Group

Inter-Tribal Deaf Council

Joint HRDC-Aboriginal Technical Committee on Social Policy (1996-1997)

National Aboriginal Diabetes Association

National Aboriginal Social and Health Associations (e.g., nurses, physicians)

National and Provincial-Territorial Associations of Native Friendship Centres

National Secretariat on Disability Issues (AFN)

In addition, the following five principles are to guide the implementation of this vision:

1. All activities related to First Nation people with disabilities must include and meaningfully involve them.
2. These activities should build on the capacity of First Nation people with disabilities to contribute to their own community.
3. These activities should be based on genuine partnership that respects legal, financial and ethical relationships of equality.
4. These activities should serve to empower First Nation people with disabilities individually and collectively through improved skills and knowledge and through more effective associations that enable them to influence the policies, programs and services that affect their lives.
5. These activities must respect the political and cultural diversity of First Nation people with disabilities without comprising their autonomy and goal of self-determination.

The position statement further resolved that the AFN establish an Action Plan for meeting the critical needs of First Nation people with disabilities, and that the federal departments of Indian Affairs and Northern Development, Health Canada, and Human Resources Development Canada be approached for the necessary resources. To advance this agenda, the AFN is networking with other Aboriginal organizations as well as other national disability organizations, including the Council of Canadians with Disabilities, the Canadian National Institute for the Blind, and the Canadian Hard of Hearing Association.

One of the many noteworthy structures in this sector is the Aboriginal Reference Group on Disability Issues (ARGDI). Established in 1997, ARGDI is a national body with representation from Inuit peoples, Métis, First Nations and urban-based Aboriginal peoples. Its origins trace directly to the social policy renewal process begun by First Ministers in 1996. From that beginning, which eventually led to the *Social Union Framework Agreement* in 1999, a joint Human Resources Development Canada–Aboriginal Technical Committee on Social Policy was established. Its purpose is “to engage national Aboriginal organizations in technical level discussions relating to the three priority areas of Social Policy Renewal (Children, Disabilities, and Values, Principles and Objectives that underlie the Social Union)” (Aboriginal Reference Group on Disability Issues, 2001).

ARGDI produced a discussion paper called *One Voice: The Perspective of Aboriginal Peoples with Disabilities* (Aboriginal Reference Group on Disability Issues, 1998). A top aim of this group is to ensure that Aboriginal people with disabilities, their families, and support institutions have an avenue to engage and provide input into the development of employment and training programs, specifically within Human Resources Development Canada. This is not surprising given that department’s prime mandate. A secondary goal of ARGDI, which is relevant to children with disabilities and their families, is to promote understanding, awareness and knowledge of Aboriginal disability issues.

In a similar context, the National Aboriginal Clearing/Connecting House on Disability Issues, formed in 1998, arose from consultations between Aboriginal groups and the Federal Task Force on Disability Issues in 1996. These consultation talks “re-confirmed the lack of detailed and timely information regarding program initiatives designed to address the concerns of Aboriginal people with disabilities. The information gaps were noted most in remote and isolated communities, especially north of sixty” (National Aboriginal Clearing/Connecting House on Disabilities, 1998: 1-2). Thus, the Clearing/Connecting House is intended to serve as an information centre, providing Aboriginal people with access to the information they need to gain access to all available assistance that will support them in living more independent lives.

Health Canada, Aboriginal Peoples and Children with Disabilities

Health Canada is a strategic government department in relation to Aboriginal peoples, their health policy and services, and to Aboriginal children with disabilities. For First Nation people, Health Canada provides non-insured health benefits, meaning benefits that are not insured under provincial and territorial medical plans. Benefits provided by Health Canada include patient transportation (especially for those First Nation peoples who live far from where services are delivered usually), vision care, dental services, and crisis intervention for mental health services. These benefits are available to all registered First Nation peoples regardless of income or location across Canada.

In addition, Health Canada funds a series of community programs, which include initiatives dealing with diabetes, home and community care, and the First Nation component of the Canada Prenatal Nutrition Program. This last program seeks to address the specific health needs of at-risk pregnant women who are most likely to have unhealthy babies. Another example is that, since 1998, Health Canada has had a multi-year funding agreement with the British Columbia Aboriginal Network on Disability Society, to administer the First Nations Health Information Resource Centre. The membership of the Society, founded in 1991, includes the parents and guardians of children with disabilities.

The Aboriginal Head Start Initiative was first launched in 1995 as a four-year pilot project for Aboriginal families living in urban and northern communities. It has since been extended and has expanded to include First Nation families living on reserves. During the initial stages, Aboriginal groups were consulted extensively on the design principles and goals of the initiative. Projects focus on children up to 6 years of age and their families, and can include the promotion of cultures and languages, health, education, nutrition counselling, and enhanced social supports. The basic aim of the Aboriginal Head Start Initiative is to provide Aboriginal preschool children with a positive sense of themselves, a desire for learning, and opportunities to develop fully and successfully as young people.

The principles and guidelines for the Aboriginal Head Start Initiative do address the topic of children with special needs. The philosophy is that “each child is a gift to their community and is present in a community to teach that community something. The child is, therefore, to be viewed as someone to learn from rather than as a person presenting a problem to be managed” (Health Canada, 1998: 24).

Moreover, descriptors such as *learning disabilities* “shall not be used as labels for individual children. Children’s strengths and needs must be the basis for developing appropriate programs and the descriptors should be used only as necessary for administrative purposes related to funding and data collection” (Health Canada, 1998: 25).

Each Aboriginal Head Start project is to develop policies and procedures on a number of activities related to addressing the needs of Aboriginal children with special needs (including informal assessments, developmental screenings, and developing action plans). This is to be done in concert with the family and with community service providers. As well, programs are to support the family in accessing appropriate resources, including the option of engaging Elders and traditional healers. The Aboriginal Head Start Initiative guidelines also state that if the “current facility and human resources are unable to effectively provide a child with a safe environment and experiences for development and growth, the Project may request that the child attend an alternate program until such time as the child’s needs may be met by the Project. For example, an additional staff person with specialized training may need to be hired or changes to the facility may need to be made” (Health Canada, 1998: 25).

In 1999, Health Canada asked the Assembly of First Nations to provide a list of First Nation health priorities for consideration in upcoming budgets. Among the priority areas identified were disability issues. The AFN identified the need to develop a strategy to provide support for children with disabilities, their families and communities, particularly at schools. As well, there is a need to address the inadequacies and absence of support services and access to medical devices for children with disabilities, especially in northern and remote communities. Other priorities deal with disease, injury and suicide prevention strategies, and an expansion of the Aboriginal Head Start Program to make additional resources available to support children with learning disabilities, developmental delays, and physical limitations. Work continues with an updated set of health priorities for 2001-02, and a renewed call for the development of a comprehensive First Nation children’s health policy framework (Assembly of First Nations, 2001).

Box 21 identifies the mechanisms in place to create programs, allocate resources and deliver services to Aboriginal children with disabilities and their families.

Box 21
**Creating Program Structures, Allocating Resources, and
Delivering Services to Aboriginal Children and Families**

Child Care Centres on Reserves

Delegation Enabling Agreements (e.g., between provinces and First Nations for service delivery)

Education Authorities and Schools

First Nation Band Councils

First Nation Child and Family Service Agencies

First Nation Community Groups

Métis Child and Family Service Authorities

National Aboriginal Clearing/Connecting House on Disability Issues (1998)

Native Friendship Centres

Treaty and Tribal Councils

Urban-based Service Agencies (e.g., Urban Multi-Purpose Aboriginal Youth Centres)

The state of financing and service provision in the Aboriginal sector shows the following trends (Prince and Abele, 2000):

- The National Child Benefit includes a First Nation component, whereby First Nation communities administer the reinvestment part of the federal initiative on reserve by adjusting their social assistance programs. They then reinvest these funds in programs for families and children. This reinvestment could include disability-related activities.
- The network of Native Friendship Centres across the country has expanded significantly over the past few decades. There are now about 115 centres, along with a national association and seven provincial and territorial associations.
- Administrative and, in some cases, policy responsibility for health services has been transferred to many Bands, Tribal Councils, and their agencies. This process is recognized and encouraged by the Aboriginal Head Start Initiative measures.
- Responsibility for child and family services – including, in a limited number of cases, child protection mandates and the formation of native child and family service centres to serve multiple Aboriginal communities – has been transferred to many First Nations.

Accountability as Inclusive and Respectful Relationships

As with other sectors, there are multiple accountability structures and processes within Aboriginal communities and governments (see Box 22). Many resemble the mechanisms found in the public and voluntary sectors, reflecting our Western system of governance and past policies of assimilation and control. Some practices, though, reflect more of an indigenous approach to accountability.

Box 22
The Aboriginal Sector – Accountability Structures and Processes

Assembly of First Nations Resolutions

Audits of Fiscal Arrangements and Budgets

Community Feedback Mechanisms

Cultural Traditions and Practices

Delegation Agreements

Elections to Councils, Friendship Centres, and Service Agencies

General and Annual Meetings of Councils and Boards

Indian Act

Internal Constitutions (written or unwritten) and By-Laws

Policy Reviews

Program Transfer Agreements

Self-Government Agreements

Treaties (both traditional and modern land claim agreements)

With respect to the Aboriginal Head Start Initiative, for instance, an impact evaluation project will be developing and piloting methods of testing children that are relevant to Aboriginal families and that involve training community members to conduct evaluations. Pilot testing is taking place in the spring of 2001 in four to eight project sites. Then, probably in the fall, an impact evaluation will be conducted in about 12 representative sites, seeking to determine the effects of participating in Aboriginal Head Start projects on children, families and communities.

According to Taiaiake Alfred, a Mohawk scholar, “this sense of responsibility or accountability can be understood in terms of a simple (though crucial) requirement for universal inclusion, and the maintenance of strong links between those charged with the responsibility of decision-making and those who will have to live with the consequences of their decisions. Accountability in the indigenous sense needs to be understood not just as a set of processes but as a relationship” (1999: 91). As well, “the indigenous concept of accountability demands an intimate knowledge of the particular culture of the community, and consistent close contact with the people. It is not enough to balance the books: a leader must constantly work to make sure the people know that he or she is answering to them and respects the appropriate protocol and procedures within the context of that culture” (Alfred, 1999: 93).

A noteworthy aspect of accountability here, with great relevance to matters affecting children and families and to disability issues, is the constant assertion by Aboriginal organizations and leaders of the responsibility of the federal government. Whether in speeches, resolutions, negotiations, or policy documents, Aboriginal leaders stress the fiduciary and moral obligation of the government of Canada (through treaties, laws and international covenants) to provide for the health care and special education needs of Aboriginal peoples. For example, for virtually all First Nations, educational jurisdiction falls under the *Indian Act*, with administrative responsibilities delegated to band councils. First Nations are still striving to obtain full and operational control over education as part of their inherent right to self-government. As well, through the AFN, First Nations have been calling for a national strategy, in partnership with the federal government, to address the special education requirements of First Nation children.

Much of the debate on accountability in this sector centres on Aboriginal leaders asserting an obligation on the part of federal authorities to adequately address the daunting packet of problems and needs confronting Aboriginal children, their families and communities. Yet, in the face of these significant challenges, there are some encouraging trends. Michael Bach (Roehrer Institute, n.d.: 3) observes that the “reliance on traditional community approaches, repatriation of children and adults with disabilities to Aboriginal communities, self-government, and the return of authority to Aboriginal communities is yielding promising results.”

3.0 A Complex Governance Regime and Considerable Government Rhetoric, But Why the Lack of Integrated Action?

This section does four things. First, it offers a summary overview of the five sectors as they operate in the governance regime for children with disabilities, and raises some implications for citizenship and children's rights. Second, it describes a selection of observations by various stakeholders that characterize the governance regime and disability policy record over the period from 1981 to 2001. Third, it presents what we call the "déjà vu discourse" on the circular and repetitive nature of disability reform. Finally, the section identifies and briefly reviews several explanations for why we are still a long way from meeting policy commitments and from integrating the children's agenda and the disability policy agenda.

3.1 The Existing Regime – Implications for Children's Rights and Citizenship

The study began by mapping the governance regime for children with disabilities and their families in five sectors. This has been necessary to describe the major features of each sector and to outline activities, issues and trends. Taking this approach, however, is not meant to suggest that the sectors are completely separate from one another or that each is a homogeneous entity with distinct boundaries. In reality, the sectors are linked in many ways and contexts. Each is characterized by substantial internal diversities in organizational types, sizes, mandates, functions and power. Each sector also has fuzzy boundaries, with numerous organizations and governing process spanning across two or more sectors. The density and capacity of each sector varies within and across each city, region, province, territory, and First Nation of Canada.

The sectors have been examined in two ways. The first and primary way has been to treat each sector as a macro-level institution for the provision of services and care for meeting human needs. The second has been to regard each sector as embodying somewhat different bundles of ideas and values. Across the sectors, we see varying, at times contradictory, policy values and paradigms. These competing paradigms – whether human rights, medical care, Aboriginal self-determination, social welfare, or others – are embedded in different programs and agencies, supported by different professions, and housed in various government portfolios and sectors.

It is worth noting as well that the idea of a "governance regime" is a conceptual tool for analysis, not a concrete thing. Further, the regime is not fully developed in that there is no overarching set of goals, procedures and rules around which the expectations and actions of the five sectors converge in order to coordinate their activities. Indeed, no sector has a single concerted voice. In each, there is a cacophony of voices, which accompanies internal competition over limited resources and over influence and values. Nonetheless, some broad trends are discernible.

Over time, there has been an internationalization of the regime through the work of social movements that span borders and the United Nations. There has also been a judicialization of the domain through the increased use of litigation and complaints to human rights tribunals and other legal arenas. The socio-political paradigm has grown in acceptance, but the medical model remains, declining in relative profile perhaps but far from gone in policy, professional discourse and practice. The result is certainly tension, yet also there is a broadening and shifting in the vision and goals for both the children's agenda and for disability strategies.

We can conclude from this analysis that the governance regime for children with disabilities and their families has the following features:

- Multiple sectors with a galaxy of organizations
- Complexity in the number of processes, ideas and values at play
- It is a patchwork, with gaps in the types of organizations and governance processes available within jurisdictions, among the sectors, and across the country
- Evolving ideas can be found on a number of levels and in various directions, along with changing notions about disability, accountability, and self-determination
- Some working examples of integrative practices exist that may serve as models for others to examine and adapt, and
- For the foreseeable future, all five sectors will continue to operate in this policy field, and all will face continuing challenges and issues.

Where we are presently in Canada might be called a *potentially progressive situation*. There is a level of public sector willingness to take further steps, and there seems to be little if any public resistance to the idea of full citizenship for people with disabilities. However, public understanding of children's rights may be less well developed and positive at this point. Restraint and retrenchment of the public sector's role in education, health, income support and social services during the last few decades in Canada has put additional expectations, demands and stresses on families, voluntary sector agencies, and Aboriginal communities. Public sector restraint may also have created certain consumer demands and business opportunities for the commercial sector. However, any further shift in the balance of provision and support from the public sector to the other sectors – perhaps with the exception of the Aboriginal sector – would be problematic.

The analysis presented here and elsewhere shows that it is only in the past 15 years or so that governments have developed explicit disability policies. These policies have been less than comprehensive, however, tending to focus on adults and the issue of employability. Moreover, it is only in the last five years that the federal government in concert with provinces and territories has articulated a children's policy under the National Children's Agenda, although it is one that initially made no direct reference to children with disabilities. Our examination of the personal and informal support sector confirmed that the families of children with special needs bear much more than a fair share of the costs and duties of care. Clearly, an imbalance still exists between private and public responsibilities for supporting children and youth.

3.2 Characterizing Canada's Disability Policy Record from 1981 to 2001

Frustration and disappointment are two major themes running through reviews on Canadian disability policy over the past two decades. Repeatedly, reports by parliamentary committees at the federal level, national disability organizations, Aboriginal groups, academics, and children's rights groups tend to be unfavorable.

Such reviews are disapproving of:

- **Inaction** by government on many disability issues
- **Incomplete implementation** of promised reforms
- **Inattention** by government officials to the adverse effects of other policy decisions on people with disabilities, and
- **Isolation** or disconnection between children with disabilities and their families from both the broader disability agenda and the National Children's Agenda.

A Canadian study on policies for persons with disabilities done nearly a quarter century ago, entitled *A Hit and Miss Affair* (Brown, 1977), still would be a fair portrayal of this policy domain, especially with respect to how children with disabilities are treated in mainstream programs and governance arrangements. Moreover, as the Standing Committee on Human Rights and the Status of Disabled Persons (House of Commons, 1990a: 5) observed, “in critical ways, achievements of the 1980s lived up to expectations. Pre-eminent among the advances for persons with disabilities was constitutional recognition. The inclusion of disabled persons in Section 15(1) and (2) of the *Canadian Charter of Rights and Freedoms* remains an outstanding achievement of Canadian governments – both federal and provincial.”

In fact, the authors of the achievement were disability groups. The original version of the *Charter* proposed by the federal government in October 1980 did not include any reference to “mental and physical disability” as specific grounds of discrimination. The phrase was added to the final version of April 1981 after strong and persistent lobbying by disability organizations, which was supported by other social groups. The successful inclusion of this *Charter* guarantee of equality came from their struggle.

The Standing Committee also said of the 1980s, “we have seen new levels of awareness and sincere, if sometimes, patronizing goodwill. While there have been some noteworthy achievements, progress has overall been modest. ... Sadly, the range of issues remains substantially undiminished. ... What is plainly needed now is action” (House of Commons, 1990a: 1, 3). Later that same year, in a follow-up report, the Committee frankly stated in reply to a government response to their earlier report, “a convincing message that the government means business is still needed in the area of disability. ... Disabled persons are not, and have not been, a priority. Our report also sets out how successive governments have been ineffective in carrying out actions that would demonstrate priority action” (House of Commons, 1990b: 3, 4).

Five years later, the same Committee offered a blunt assessment of the 1991-96 National Strategy for the Integration of Disabled Persons that was close to winding up at that stage. They concluded, “the National Strategy was not a ‘strategy’ but a series of ‘tactics.’ Consequently, the problems of leadership, coordination, and collaboration for various players within the government remain unsolved” (House of Commons, 1995: 11). Rather than a regime of policy coordination, the Committee saw the federal strategy as a loose set of marginal programmatic activities.

At about the same time, a leading text on Canadian social policy and social work reached a similar conclusion. “Canada has no overall framework for social justice for persons with disabilities and, unlike for seniors or the unemployed, has never aspired to build one” (Armitage, 1996: 76). There are also comparable inferences about policies for children and families in the literature (Pulkingham and Ternowetsky, 1997).

These critiques and, more importantly, similar criticisms coming loudly from the disability community prompted the federal government to establish a Task Force on Disability Issues in 1996.¹³ In a submission to the Task Force, the Council of Canadians with Disabilities argued a position shared by many other groups. They stated that Ottawa had abandoned Canadians with disabilities and that disability issues were conspicuously absent from Canada’s political agenda. “Since their election in 1993, the Liberal government has dramatically decreased support and initiatives in the area of disability” (1996: 1).

In October 1998, the federal, provincial and territorial governments released *In Unison: A Canadian Approach to Disability Issues*. Articulating a new approach to disability issues, the document speaks of working toward a “holistic and multisectoral approach to reform.” In advancing this new agenda, “governments agree that their initial efforts should focus on improving the efficiency and effectiveness of programs and the coordination between programs”(Federal-Provincial-Territorial Ministers Responsible for Social Services, 1998). The old approach to disability issues, still much in evidence, reflects the conventional governance practices outlined in Box 4.

In November 1999, a coalition of disability organizations presented to Canadian governments *A National Strategy for Persons with Disabilities: The Community Definition*. “In recent years,” the coalition noted, “the community of persons with disabilities has witnessed an approach to disability issues which is piecemeal and uncoordinated, favoring ‘disability initiatives’ and ‘special projects’ which do not have sufficient scope or depth to achieve the equality promised in the *Charter of Rights and Freedoms*” (Council of Canadians with Disabilities, 1999: 1).

In Unison and related government documents are seen as responding chiefly to persons with disabilities of working age, largely ignoring the issues concerning children with disabilities and their families. Likewise, the National Children’s Agenda needs to consistently include issues affecting children with disabilities, as noted by the Canadian Association for Community Living, the National Children’s Alliance, and many other organizations.

¹³ The creation of the Task Force on Disability Issues was prompted by the federal government’s response to the House of Commons’ Standing Committee report on the 1991-96 National Strategy for the Integration of Persons with Disabilities. The government response put forward the message that there was little if any future role for the federal government in disability issues, which was echoed by the Minister of Human Resources Development of the day, Doug Young. This created considerable unrest within the disability community and among many Liberal MPs who believed that Ottawa had an ongoing, if not expanding, obligation to this disadvantaged and vulnerable group of Canadians. This led to the involvement of the Prime Minister’s Office and the idea of the Task Force. Many elements of the Task Force report were quickly adopted, perhaps aided by the fact that, in a cabinet shuffle, Pierre Pettigrew replaced Doug Young as the Minister of Human Resources Development.

In November 1999, a report from the Canadian Coalition for the Rights of Children entitled *How Does Canada Measure Up?* was sharply critical of the treatment of various groups of children, especially children with disabilities. The Coalition argued that “children with disabilities have varying opportunities to live full and decent lives, and the supports they need are not considered an entitlement but a private privilege. Many families of children with disabilities do not receive adequate assistance. Early identification and intervention services are not universally available, and the right to appropriate education in the most enabling environment is not guaranteed.”

Finally, in June 2001, a joint report from the Sub-Committee on Children and Youth at Risk and the Sub-Committee on the Status of Persons with Disabilities concluded that “while progress may be occurring, it is painfully slow and not without setbacks” (House of Commons, 2001: 14).

3.3 The Déjà vu Discourse on Disability Reform

After two decades of disability policy making, there is a strong sense that we have been here before. We find a circular repetition of words and ideas, the declaration of plans and promises, followed by external reviews of the record, and then governmental responses with a reiteration of previously stated plans and promises. To illustrate this déjà vu discourse on disability reform, two examples are briefly examined – policies for Aboriginal children with disabilities, and the idea of a disability lens for the policy process. Both illustrate a broader pattern of ideas proposed before by a number of committees and task forces.

Case 1 – Policies for Aboriginal Children with Disabilities

Aboriginal children with disabilities and their families rarely receive focused attention in the policy realm. However, many of the issues that affect this group are similar to those affecting Aboriginal peoples with disabilities as a whole. The déjà vu discourse about this larger population group serves to illustrate the issues.

In 1981, in a follow-up to their *Obstacles Report*, the House of Commons Special Committee addressed the matter of indigenous people and disabilities. The Committee concluded there was considerable evidence to show that “federal departments do not consult among themselves in a systematic fashion when implementing policies and programs which affect Native people.” The effect of this non-consultation, the Committee pointed out, was “wasted money and effort on the Government side, and confusion and mistrust on the part of those Native persons whom the efforts are intended to help” (House of Commons, 1981a: 11 and 12).

In 1993, the Standing Committee released the first report on Aboriginal people with disabilities since 1981, called *Completing the Circle*. This report echoed the problems of confusion and mistrust, observing that “arbitrary legal classifications, such as those that separate status from non-status Indians, have too often served to confuse and complicate the lives of Aboriginal people with disabilities. Such barriers to progress must be eliminated” (House of Commons, 1993: v).

The Committee noted that, “while some things have changed since 1981, there has been little measurable progress in many areas” and that “over and over again, Aboriginal people with disabilities recounted their skepticism about promises made by the federal government. Talk has been plentiful, but actions have been few and far between” (House of Commons, 1993: 5 and 6). As well, concerns about the lack of cohesive action in the federal government were again raised: “consultation and co-ordination within the federal bureaucracy remain weak links in promoting better lives for Aboriginal people with disabilities” (House of Commons, 1993: 18).

In 1999, *A National Strategy* developed by disability organizations remarked that persons with disabilities within the First Nation, Métis, and Inuit communities “are faced with a confusing web of programs and eligibility requirements. As a starting point, responsibilities and eligibility rules should be reviewed and clarified, in consultation with the community of persons served by these programs” (Council of Canadians with Disabilities, 1999: 5). Once more, we read of the problems related to arbitrary program categories, client confusion, poor coordination within government, jurisdictional challenges, and insufficient consultation with affected communities.

Starting in the fall of 2001, the federal Parliament Sub-Committees on Children and Youth at Risk and the Status of Persons with Disabilities plan to examine “the situation of Aboriginal children from birth to age 12.” This review will include “the issue of Aboriginal children with disabilities, an issue which is representative of both a classic horizontal issue, and an issue in which the most vulnerable members of society ‘fall through the cracks’ of our existing policies and programs” (House of Commons, 2001: 20-21).

Case 2 – A Disability Lens for the Policy Process

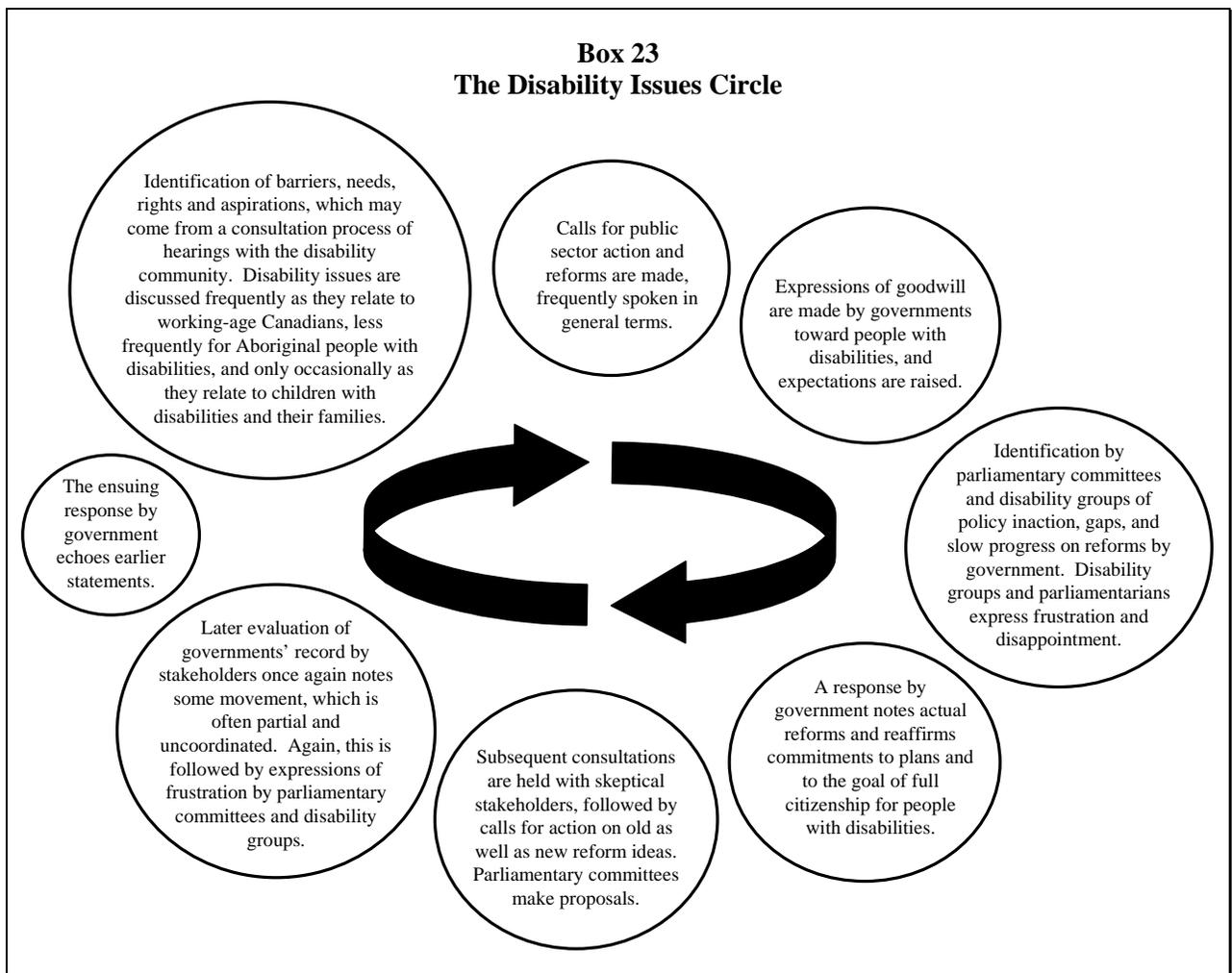
The idea of a “disability lens” for the public policy-making processes of the federal government is another case of a proposal oft repeated over the last 20 years but yet to be implemented. The 1981 *Obstacles Report* observed that most federal decisions are taken without regard to their impact upon the lives of children, youth, and adults with disabilities. Accordingly, the Committee recommended that the federal government establish a review at the cabinet level similar to that for the Status of Women, which would ensure ongoing consideration of the concerns of people with disabilities, including children and their families. The government’s response at the time was one of general interest and an expressed intention to explore the implementation of the proposal.

Three governments and 14 years later, another parliamentary committee reached a similar finding. “Federal institutions have not succeeded in bringing about the systemic changes that are required to build disability-related concerns into the basic premises that guide policy formulation and programme implementation” (House of Commons, 1995: 5). That Committee recommended that “all memoranda to cabinet and other relevant cabinet documents should immediately include a mandatory section that assesses the impact of any proposed measure on persons with disabilities” (House of Commons, 1995: 22).

Four years later, yet another parliamentary committee found that as ministers outlined their departmental activities to the committee, members “could not but notice the uneven understanding and uncoordinated activities undertaken by the various federal departments” (House of Commons, 1999: 2).

In addition, “many decisions about the nature of initiatives ... fail to take people with disabilities into account.” The committee proposed that “using a disability lens on government policies, programs and legislation could assist in breaking down the barriers between government departments and programs” (House of Commons, 1999: 2). Disability organizations have made a similar plea for an “access and inclusion lens” to be “applied to all activities of all governments, from human resources practices to the broad range of programs delivered” (Council of Canadians with Disabilities, 1999: 4).

Along with being about words, déjà vu discourse includes a series of practices by various actors consisting of action, inaction, and reaction. As a parliamentary committee recently stated, “disability issues seem trapped in a circle” (House of Commons, 1999: 2). Box 23 outlines a sequence of stages that the disability policy and governance domain has gone through on a number of occasions since the early 1980s. The focus here is largely on the federal legislative arena in relation to the governmental executive, and the external disability community. One of the cumulative effects of this pattern of circling back for the past 20 years is that many of the steps outlined in Box 23 are now taking place concurrently.



A simplified model of reality, this summary is intended to show the main features and recurring elements of disability policy analysis, advocacy and evaluation, which seem to circle back to the beginning, time and again. Groups that have participated over this period have no doubt become more cynical. They also have learned to recast issues and ideas in different ways, tailor analysis and advocacy to shifting contexts, and to come equipped with data where possible. As yet, however, we have not been able to break free from this déjà vu discourse to make significant advances in the policy agenda for children with disabilities and their families.

Are there ways to overcome this frustrating circular pattern and to truly advance the agenda? Over the 20-year period from 1981 to 2001, the Prime Minister's Office and central agencies such as the Department of Finance and Treasury Board have gained authority, while cabinet and line ministers and their departments have lost influence. However, according to Donald Savoie (1999: 338):

The strengthening of the center has not meant that the federal government is now better able to articulate a comprehensive policy agenda. Indeed, the only time it is able to do so is when a powerful outside element comes into play, which forces it to act. When this occurs, the various organizational cultures and even outside forces are held in check by a consensus that something must be done. The other necessary ingredient is for the prime minister to remain focused, firm and tenacious. These circumstances, when they are all in sync, enable the center to pursue successfully a new policy agenda.

Savoie's analysis is highly instructive for many sectors in the governance regime for children with disabilities. It provides families and advocates, as well as parliamentarians, ways of thinking about what reforms to the governance regime may be most effective.

3.4 Governmentality – How We Think about Governance

It must be asked why we are still a long way from implementing promises and meeting prior commitments to coordinate reforms and provide concrete resources for children with disabilities. Why are we trapped in a déjà vu discourse? Why is disability not a fundamental policy priority for governments? These are questions regularly posed and examined by legislators, disability advocates and clients – but rarely so by governments. At times, governments touch upon these questions in their responses to parliamentary reports and critiques by disability groups and child and family organizations.

A partial explanation may be provided by the notion of *governmentality*, which refers to how, in various groups or sectors, we collectively think about governing and exercising authority (Dean, 1999). It is a set of attitudes about the role of governments, but also of the state and the wider realm of governance within and across sectors. The archetypal position of governments contains several elements.¹⁴ Each of these elements is examined in turn.

¹⁴ We identified this list of themes from a survey of federal government documents spanning the last 20 years, typically made in response to parliamentary reports.

First, governments claim they *do* have a vision for disability issues and, more fundamentally, for people with disabilities. This vision is of an inclusive society, as articulated in various documents including *In Unison*, the *Social Union Framework Agreement*, *Future Directions*, and various Throne Speeches. Second, federal and provincial governments point out that they have assumed leadership for disability issues over the years. Significant actions taken by Ottawa, alone and in conjunction with other governments and sectors, helped build an extensive range of activities for removing barriers and offering opportunities. Consequently, the disability domain looks quite different in 2001 than it did in 1981, although deplorable conditions persist.

Third, governments admit that there is much more to do on disability issues in Canada, that the agenda remains unfinished and, in a basic sense, it always will be. Debates over the mix of roles among the sectors will never be settled, as there will always be disagreement about the proper balance to be reached. Fourth, the agenda is dynamic and somewhat beyond the control of any single government. The policy agenda changes and grows as public attitudes and perspectives on disability evolve, and it adjusts in response to program developments, pilot projects, and court cases, among other factors. Fifth, governments argue that realizing the vision of citizenship – the full participation of people with disabilities within Canadian society – is a responsibility shared among *all* sectors, and is not the sole responsibility of governments and the state.

Getting children with disabilities on the agendas of governments in the form of plans and strategies is one thing. Receiving serious attention and sustained action by policy-makers and officials is quite another. Mainstream organizations in all sectors need to take up the fight for inclusion and responsibility for mainstreaming the issues to all organizations advocating on behalf of children and youth. As the previous analysis shows, there has been more advancement in certain jurisdictions, in certain policy sectors, and in certain time-periods than in others. Some progress has been made in the areas of shelter and transportation, for example, but relatively less has been realized in the areas of income maintenance and home support services (Jongbloed and Crichton, 1990).

For the 1991-96 National Strategy for the Integration of Persons with Disabilities, a deputy ministers' committee on issues concerning persons with disabilities was established, but it met infrequently. This coordinating function was delegated to a committee of assistant deputy ministers who, in many cases, further delegated this role to more junior departmental officials. Over time, this led to a diminished profile, authority base and accountability regime for this National Strategy (House of Commons, 1993: 5). A number of other explanations for the frustrating pace of reform include the following, which will be examined in more detail below:

- Public attitudes and lack of information
- The relative powerlessness of families of children with disabilities
- The constraints of the economic context and public finances
- Federalism in the form of inter-jurisdictional bargaining, buck-passing and suspicions, and
- Bureaucratic factors and weak accountability mechanisms.

Public Attitudes and Lack of Information

Established public beliefs and lack of awareness is one factor noted to account for limited policy reform and social change. Public interest in and support for disability-related initiatives for children and adults seems favourable but diffuse, and positive but not pressing. Jenny Morris explains that “the experience of aging, of being ill, of being in pain, of physical and intellectual limitations, are all part of the experience of living. Fear of all these things, however, means that there is little cultural representation, which creates an understanding of their subjective reality” (Morris, 1992: 164). The federal government’s strategy paper on disability, *Future Directions*, has similarly observed that “attitudinal barriers ... still exist among many people who do not understand that persons with disabilities can and do make a positive and meaningful contribution to our society” (Canada, 1999a). It must be noted, though, that other beliefs – such as ‘the child is the responsibility of the parents’ and that ‘women are the primary caregivers in families’ – are other deep-rooted attitudinal barriers to adequate services for, and properly valued work by, families and caregivers (Beauvais and Jenson, 2000; Callahan, 1985; Morris, 1992).

In addition, information about the nature and extent of disability among Canadians generally, children more specifically, and especially Aboriginal children and youth is outdated, incomplete or even inaccurate, although there have been some improvements in recent years. For close to 20 years now, mental health programs and services for children and youth have been topics of policy discussions in Canada, but we still lack adequate information on the well being of children (Canadian Institute of Child Health, 2000; Mahon, 2001).

Likewise, the state of data on program expenditures for children with disabilities is appalling, whether for a specific budgetary year, over time, or across jurisdictions. We simply do not know how much or how little in public resources are devoted to fostering the full inclusion and equal opportunities of children with disabilities.

Policy is often based on the knowledge derived from data. No data, no problems to address. To date, the Health Activity Limitation Survey of 1991 has been the only national survey on disability topics. A follow-up survey planned for 1996 was cancelled due to budget cuts. After extensive lobbying and discussion, led by the Canadian Institute of Child Health, there is to be a survey in 2001 called Participation Activity Limitation Survey. The change in focus from *health* activity limitation to *participation* activity limitation, and the fact that a new round of current information will shortly be generated, is an important aspect of the evolving social policy process. Also this year an Aboriginal Peoples Survey II is to be conducted as a post-censal survey as a follow-up to one done in 1991.

Such attitudinal, cultural and informational features have important public policy implications. As a parliamentary committee noted not long ago, “the Canadian public needs to be educated or disability issues will fall off the public and political agenda” (House of Commons, 1999: 1). To promote change in the attitudes and awareness of Canadians, the disability community has a necessary part to play, although the public sector has a fundamentally central role in partnership with other sectors.

Many attitudinal barriers and cultural biases are embedded in programs, policy designs, administrative data sets, and service delivery systems. The classic paradigm in social policy of the “worthy poor” remains in effect today across many program files, with the result of excluding or segregating disability issues and people with disabilities from the public domain (Rioux and Prince, 2001). This problematic positioning is repeated with the marginal status of disability studies in most universities and think tanks in Canada.

The Relative Powerlessness of Families of Children with Disabilities

The socio-political ecology perspective introduced at the outset of this paper closely relates to this explanation by pointing out inequalities in the distribution of power, opportunities, conditions, and life chances. Groups representing children or youth with disabilities are generally far less powerful than business and industry groups, and even other social policy groups representing, for example, broader health care or education interests. “The fragmentation of disabled lobby groups [by income, place, or type of impairment] reduces support for particular policy issues and diminishes their effectiveness” (Jongbloed and Crichton, 1990: 36).

Most disability, family or parent groups lack regular and easy access to senior government decision makers and, in the aftermath of program cutbacks in the 1990s, relations of trust between governments and the disability community are weak and in a process of rebuilding. This relative powerlessness reflects the highly marginalized status of children with disabilities and their families, whether measured by income, employment, educational attainment, or the absence of supports and incentives. These multiple dimensions of subordinate status translate into marginal resources and limited capacity for influencing governments and other governance regimes.

Moreover, coalition building and networking with other social groups has not been as advanced as it might be. Writing in the early 1990s, Brian Wharf commented that “the powerful social movements – labour, women, and First Nations – have neglected child welfare. In a very real sense children are the orphans of the major social movements in Canada” (1993: 103). This study has confirmed that, nearly a decade later, this remains the case for children with disabilities.

The socio-political ecology perspective also draws attention to the critical idea that, in policy reform processes, there is often resistance to intended social or economic changes. This seems especially the case when a group actively seeks new or enhanced rights of citizenship. Bryan Turner has written that “citizenship provides a challenge to existing patterns of power and authority, and therefore any growth of citizenship will be met with political struggles by dominant groups to preserve their advantages within the status quo” (1986: 104). In disability policy, the drive to achieve greater inclusion within school systems, to introduce a comprehensive disability income insurance plan, or to strengthen human rights provisions have all been met with some resistance by various interests (Jongbloed and Crichton, 1990; Morris, 1992; Prince, 2001).

The Constraints of the Economic Context and Public Finances

For most of the last 20 years in Canada, fiscal austerity, deficit reduction, program reviews, and public service downsizing have been profound drivers of the public policy context for all issues, including disability issues. This period was also marked by two serious recessions in the Canadian economy. These events and priority concerns both reflected and reinforced broader shifts in policy thinking, evident across many nations – away from state intervention and social issues, and toward market approaches and economic issues (Rice and Prince, 2000). Consequently, “proposals for persons with disabilities have not formed a prominent part of the debate on the future of redistributive social policy. This is partly because their relationship to issues of the global economy is slight, and partly because of the way issues of equity have been sidelined by economic issues” (Armitage, 1996: 77).

Part of the reason that children with disabilities have been ignored or insufficiently linked with the wider disability and children’s agendas is that when “welfare” left Health and Welfare Canada in 1993 and became part of the then newly formed ministry of Human Resources Development, responsibility for disability went with it. The federal government’s focus on disability has since centred on employability, an emphasis that is part of the federal government’s broader theme in social policy of “investing in people.”

Certainly, expenditure implications associated with major program reforms have been and remain a significant factor in government thinking. The great unstated concern deals with the worry of what economists call the “moral hazard” of social programs, especially insurance programs for certain risks. The theory behind this notion, and hence the worry by officials, is that establishing or expanding programs will give people more of an incentive to self-identify as having a disability and, conversely, less of an incentive to avoid risks that may produce a claim for compensation. This perspective is rarely stated in documents or given emphasis in public by policy makers. This does not mean, however, that it is not a concern of government bureaucracies.

Proponents of reform, however, believe that the financial costs to the public purse have been overplayed and used as an excuse to avoid taking responsibility and demonstrating leadership on matters of equality (House of Commons, 1985: 82). As well, they argue that this tends to ignore the human costs and social benefits, and to downplay the financial costs to private household budgets in caring and advocating for children with disabilities.¹⁵

¹⁵ A recent parliamentary report endorsed by members from all federal parties notes: “We recognize that during a period of cutting costs, administrative measures need to be put in place that contain expenditures but we share the concern of independent policy analysts and disability organizations that the current disability income support programs operated by the federal government, notably the Canada Pension Plan-Disability (CPP-D), has not recognized the fundamental realities of many people who live with a disability” (House of Commons, 2001: 17).

Federalism in the Form of Inter-Jurisdictional Bargaining, Buck-Passing and Suspicious

Delays and inaction in implementing children's and disability rights, reforms, ideas and plans can be partly explained by the need for federal-provincial agreement on a number of recommendations put forward by parliamentary committees, children's groups, disability groups and government advisers. In short, inter-jurisdictional bargaining takes time.

For international statements of human rights for children and people with disabilities to have the force of law in Canada, they must be accepted by the federal, provincial and territorial governments and incorporated into various statutes. Evelyn Kallen makes the important point that "Canada's adoption of the declaration, covenants, and protocol does not automatically update the rules, policies, and laws of every company, organization, and level of government in the country. At every level of Canadian society, there are formal regulations and informal practices that are contrary to the principles of human rights. Violations of omission and commission in the innumerable laws and regulations enacted in the past require considerable time and attention in order to be properly redrafted so as to conform fully with international human-rights principles" (Kallen, 1989: 12).

For Aboriginal peoples of all ages with disabilities, the division of powers associated with federalism presents incredible complications and jurisdictional barriers. In particular, there is the ongoing buck-passing between the two orders of government over which order is responsible for funding and providing services for urban-based Aboriginal children, youth and adults living in cities rather than on reserves (Prince and Abele, 2000). Moreover, there is a residue of suspicion by provinces toward the federal government because of past federal initiatives that were followed by unilateral cuts in transfers. Thus, in the new post-deficit era, provinces may see an examination of broader reforms as a federal attempt to increase its influence in the disability, health or family policy sectors, all of which are primarily within provincial jurisdiction.

Bureaucratic Factors and Weak Accountability Mechanisms

This is probably the most frequently repeated reason cited by disability groups, child and family organizations, and parliamentarians for the lack of substantial and sustained action on disability issues by government. Federal reports from 1981, 1985, 1990, 1993, 1996, 1999 and 2001 all stress that the structure and operation of the government is a major reason for the delays and modest results in addressing the concerns of Canadians with disabilities. Governments generally seem unable to deal effectively with cross-departmental or horizontal issues (Savoie, 1999; Tindal and Nobes Tindal, 2000; House of Commons, 2001). The realms of disability and children are two such horizontal issues.

As an early House of Commons report stated, "the crucial obstacles which prevent the Government of Canada from responding directly, appropriately, and continually to the needs of more than two million Canadians have nothing to do with motivation. They have to do with the systems of communication, organizations and decision-making within the Government of Canada, and within Canadian society in general" (1981a: 5-6). A 1990 report by the relevant standing committee made a related observation that the problem was not the absence of sincere intentions but, rather, it was primarily due to inconsistency of attention.

“The absence, within the federal government, of an effective and accountable mechanism for change is one important reason why Canada’s commitments to people with disabilities remain only partially fulfilled” (House of Commons, 1990a: 33). A subsequent report on Aboriginal peoples with disabilities was far more critical. It stated that the federal government had taken a “strikingly fragmented approach,” with responsibility scattered amongst different departments and programs, resulting in “turf wars among bureaucrats” and “definitely no concentrated focus on disability.” This fragmented focus was seen as “a clear illustration of the *ad hoc* approach that departments are taking to the needs of people ... with disabilities” (House of Commons, 1993: 13 and 17). The Scott Task Force report employed more temperate language, but the message was similar (Canada, 1996: 25):

Because disability issues cut across the federal government’s organizational lines, they often get lost in a bureaucratic shuffle. In some instances, a positive action by one department may be lost because of the inaction of another that unintentionally cancels out the first. In other cases, a department may have the will to act but needs the support and input of others to get the job done. While government departments are able to join forces to meet disability-related goals, it is important to establish clear lines of accountability at the federal level.

The most recent parliamentary committee reviews of federal disability policy, done in 1999 and 2001, focus mainly on the processes and structures of government. Again, the main conclusion is highly unfavorable. The committee reported a “lack of departmental responsibilities, an absence of strong program structures, fragmented service development and inconsistent standards” (House of Commons, 1999: 18; House of Commons, 2001: chapters 2 and 3). They found that matters of access and inclusion for children, youth and adults with disabilities are not routinely a part of legislative, policy and program development. The lack of input by disability and family organizations in setting goals and desired outcomes compounds this problem.

The departmentalized nature of government has a number of dysfunctional consequences. Hierarchies separate policy development from program administration within departments, with the result that departmental managers are accountable for the vertical rather than the horizontal management of programs. The same is the case for planning documents and performance reporting systems. Cross-departmental coordination and accountability are frustrated by the deep-seated reliance on individual departmental portfolios and ministerial responsibilities.

The need for a strong government-wide accountability mechanism is again noted. “One of the major problems in implementing disability policies and programs is that no one has ever been clearly accountable for results.” The committee acknowledged that even the lead minister for disability issues, presently the Minister of Human Resources Development, has a difficult job since lead ministers cannot force action.

4.0 A Way Forward – Lessons, Goals, and Choices

This paper had two main purposes. The first was to describe and analyze the governance regime in Canada for children with disabilities and their families. This has been done. The second was to identify the governance and accountability structures that will allow an agenda of childhood development, family support, and social inclusion for children with disabilities to move forward in Canada. That is the task of this final section.

We first draw several lessons from the previous mapping exercise of the five sectors. Then, we articulate a set of preferred values and goals with respect to a substantially reformed governance regime. Finally we offer a set of choices for reforming aspects of all five sectors and their interrelationships. The ultimate intent is to encourage changes on multiple fronts that will improve governing practices such that when we say “all children” we truly mean all children.

4.1 Seven Lessons from the Disability Domain

Before moving forward and proposing a reform agenda, it is instructive to reflect on where we have come from and where we now stand. Seven key lessons can be drawn from this analysis of the governance regime for children with disabilities and their families:

1. Canadian social programs and services for families with children generally, and for families who have children with disabilities more specifically, embody assumptions about the responsibilities and capacities of families, informal helping networks, voluntary groups, communities, and other social arrangements. These assumptions must be surfaced and critically examined as to their effects and appropriateness.
2. Reforms to the governance regime are desirable from both an individual and societal perspective, in order to address power imbalances and to promote fuller citizenship for children with disabilities and their families. Given disparities in economic and social status, reforms are wanted and expected by families, parent groups, youth, disability organizations, other voluntary sector groups, service providers, and Aboriginal communities.
3. The public sector has primacy in shaping the governance regime in terms of setting policy and establishing a legal and fiscal context within which other sectors operate. At the same time, it is inaccurate to think that the traditional approach to disability issues involved only government responsibility (that is, the public sector) and that the new vision is to move towards shared responsibility by all sectors. In fact, the approach always was, and still is, multi-sectoral.
4. Minor tinkering with programs and structures will simply perpetuate the frustrating pattern seen over the past generation, with disability issues seemingly trapped in a circle. Fundamental reforms in several arenas are essential for advancing the vision of full citizenship and inclusion for *all* children, including those with disabilities, and their families.
5. An overarching policy discourse, while useful, is far from enough to ensure horizontal coordination. What are also needed are agreed-upon outcomes, indicators, and information systems to track, assess and report on performance results.

6. There is no universally “best” governance regime for Canada’s children with disabilities and their families. Debates over the mix of roles among the sectors will never be settled, as there will always be disagreement about the proper balance to be reached. However, there are many practices deemed highly unsatisfactory, others regarded to be effective, and still others viewed as promising directions for future development.
7. Many reforms to disability programs and services have not withstood the winds of change, probably because the reforms were neither legislated nor designed as entitlements, but rather were created as discretionary benefits. Any effective strategy for reform must recognize where power is located in governments, and on how power is mobilized and then exercised.

4.2 A Transformed Governance Regime – Preferred Practices and Desired Outcomes

What might a more inclusive and integrated governance regime look like? What would be its overall vision, key goals and desired outcomes? The vision expressed in the *In Unison* paper, the most up-to date intergovernmental consensus, is that (Federal-Provincial-Territorial Ministers Responsible for Social Services, 1998: 1):

Persons with disabilities participate as full citizens in all aspects of Canadian society. The full participation of persons with disabilities requires the commitment of all sectors of society. The realization of the vision will allow persons with disabilities to maximize their well-being through access to required supports and the elimination of barriers that prevent their full participation.

This vision is based on the values of equality, inclusion, and independence, as well as on the principles of rights and responsibilities, empowerment, and participation. As the overarching idea for this vision, citizenship has the goal of mobilizing all sectors to enhance the full and equal participation of persons with disabilities, to make as inclusive as possible all domains of society. The policy direction agreed to by governments is to amend and adopt policies that promote access to generic programs and services.

A friendly amendment to the vision, a vision after all that came from the disability policy sector rather than the child and family policy domain, might be as follows:

All sectors in Canada support a governance regime that values, supports and enhances the citizenship, human rights and lives of all children, youth and their families in whatever communities they live.

Desirable features of this addendum are the explicit references to citizenship and human rights, to children and youth, and to the diversity of communities. From these aspects, come the principles of interdependence, equity and a sense of belonging. As a British policy analyst has observed, “children [with disabilities] need to develop a new relationship in which they are not excluded as having ‘special needs’ but seen as girls and boys with a range of hopes, wishes and dreams like any others” (Middleton, 1999: 121).

The link between community and citizenship, and rights and duties, was impressively made by T. H. Marshall (1973: 84), who wrote:

Citizenship is a status bestowed on those who are full members of a community. All who possess the status are equal with respect to the rights and duties with which the status is bestowed. There is no universal principle that determines what those rights and duties shall be, but societies in which citizenship is a developing institution create an image of an ideal citizenship against which achievement can be measured and towards which aspirations can be directed.

Citizenship for *all* children and their parents in Canada certainly continues to be a developing institution, and the image or vision of an ideal citizenship status has been expressed in a number of reports by different governments, professional associations and advocacy groups. As noted throughout this document, these reports include the *United Nations Convention on the Rights of the Child*, the National Children's Agenda, and the *Social Union Framework Agreement*.

Yet, as a Canadian parliamentary committee recently observed, "no single policy framework that exists within the federal government adequately addresses the needs of children with disabilities and their families" (House of Commons, 2001: 21). The same can be said of provincial, territorial and municipal governments. In Box 24, we provide one example of a framework for family support initiatives, which articulates principles intended to strengthen adults in their multiple roles as parents, and to support healthy child development.

Box 24
Principles for Family-Focused Supports

Focus on the entire family.

Change as the family's needs, roles and ages change.

Encourage families to express their own needs and direct decisions on how their needs are met.

Treat people with disabilities and their families with dignity by respecting their individual choices and preferences.

Respect cultural, economic, social and spiritual differences.

Encourage families to use the natural/informal community resources.

Provide a convenient and central access to services and resources.

Source: The Human Services Research Institute, cited in McAulay (1995: 5-6).

Recall that in Box 4, the prevailing governance practices in the family, child welfare, and disability domains were presented. To present a transformed regime, Box 25 follows the same pattern of governance practices, but substitutes a set of preferred practices and desired outcomes that reflect the vision and principles outlined above.

Box 25

Preferred Governance Practices in a Transformed Regime

1. Individual and family involvement and participation by youth, parents, and a wide range of community groups in policy development is encouraged through funding, training and other forms of capacity building, buttressed by “entitlement to participate” legislation.
2. Policy-making and decision-making decentralized and, at the same time, integrated within and across sectors. Legislative bodies are strengthened with support from representative advisory councils and watchdog agencies.
3. Mandates focus on social integration, accessibility and human rights. Disability seen as a diverse and common part of the human condition. Service systems have single access points and portable eligibility requirements. Organizations involved in child care, education, health, recreation and other social services are linked together by cross-governmental and cross-sectoral coordinating bodies.
4. Staff and professionals act as facilitators of independence working for children and families. Personal supports are a right for everyone in need, rather than a discretionary benefit.
5. Service and benefit provision is person, family, and community centred, as appropriate. Individual funding is a widely used model allowing for flexible and portable service choices decided upon by the consumer or their advocate or guardian.
6. All family members, as well as the role of neighbours and friends, are recognized and valued. Funds for service provision (i.e., personal care benefits) could go to individuals in a person’s informal support network.
7. Intergovernmental relations are characterized by joint planning, consultations, and dispute avoidance mechanisms, while respecting the different jurisdictions of the orders of government, in the spirit of the *Social Union Framework Agreement* and other recent accords.
8. Policy and programs recognize and respect the diversity of Aboriginal peoples in Canada (First Nations, Métis, Inuit, Innu, and others). Established structures enable regular and meaningful input by Aboriginal leaders and groups to government structures and processes. Treaties are negotiated based on mutual respect, recognition and sharing. Services are developed by and for Aboriginal families and communities that are accessible, affordable, portable and culturally appropriate. An intended outcome of initiatives such as Aboriginal Head Start would be the sustenance of cultural and spiritual practices, and their transmission to the next generations.
9. An interactive set of accountabilities exist, which are transparent, participatory, timely, and make use of qualitative as well as quantitative information.
10. Evaluations and the publication of results are done routinely, with the establishment of outcomes and indicators. Pilot projects and program demonstrations are undertaken on a regular basis to learn what works and to share effective practices. Comprehensive and longitudinal data sets on families and social care are built and analyzed.

The challenge of governance integration is far from unique to disability policy in general, or to children with disabilities and their families in particular. That existing programs and services are a patchwork is a critique common to social policy fields. Most social policy areas lack a coherent and comprehensive national approach. This does not necessarily mean, however, that these fields lack a long-term vision or sense of direction. In deed, much of Canada's post-war social policy making was guided by what may be called "directed incrementalism" (Rice and Prince, 2000).

It is useful to note what an integrated governance regime does *not* mean, as well as what it may entail. Integration, as applied to the governance regime for children with disabilities, does not mean an absence of differences in programming approaches or an absence of conflict between governments or even sectors. This is to expect fantasy in our public world of federalism, which enshrines simultaneously the principles of unity and diversity. As the Scott Task Force explained (Canada, 1996: 17):

Canadian governments can work together to establish pan-Canadian objectives, principles and, perhaps most importantly, common values so that all can be inclusive of and accessible to people with disabilities. This does not have to involve any level of government telling another what to do. These objectives, principles and values can be negotiated and developed jointly by the federal, provincial and territorial governments with input from the citizens they affect. They can also reflect regional variations. The discussions would focus on the means that will be used to ensure equity and equality of opportunity and to ensure that all Canadians have full rights. The key point is that they would provide for consistent outcomes, not that provinces and territories would provide exactly equivalent programs and services.

Just as governance involves more than government, integration is about much more than coordination among government departments and agencies. Integration, in institutional and sociological terms, is multidimensional. It happens on an everyday or episodic basis, in formal and informal ways, and on interpersonal, organizational, interagency, intergovernmental, and intersectoral levels. In policy terms, integration has an important dualism. First, it means building disability considerations into mainstream programs and policies in all the areas that are listed in Box 1. At the same time, the integration of people with disabilities means there is a need to supplement mainstream programs, where necessary, with complementary services and supports for addressing the additional disadvantages faced by children, youth, and adults with disabilities.

An integrated governance regime would work towards more, rather than less, collaboration among sectors. In addition, it would institute dispute resolution mechanisms, rather than treat conflict as abnormal. It would encourage actions by individual governments or institutions that were complementary, rather than contradictory, and would strive toward shared aims and desired outcomes for citizens and communities.

Governing in an integrated fashion is not a thing or endpoint that is attained, but instead is an ongoing process – indeed, a national project in progress – involving a complex array of relationships, individuals, groups, organizations, and sectors. There would be, therefore, ways and means to record, assess and report on experiences in order to learn collectively about what works for whom, how and why. As well, there would be systems instituted to involve families, voluntary groups, Aboriginal and commercial or professional representatives, and others in a regular and meaningful way in setting visions, policy parameters and performance measures, and in interpreting program and service outcomes.

To ensure the inclusion of *all* children and families, meaningful and lasting reforms must address *all* parts and levels of government, *all* processes of governing, and *all* sectors of Canadian society. A package of multiple reforms (see Appendix A), that is publicly determined, implemented, and evaluated, is essential to realizing the vision of human rights and full citizenship.

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Appendix A

An Overview of Governance Reform Proposals

Table 1 presents a menu of governance reform proposals for the disability domain. The reform ideas range from smaller to broadest in scope, from government to state to civil society. The full menu fits with a socio-political ecology of disability policy and the view that all sectors, not only governments, are responsible for improving the living conditions and opportunities for children with disabilities and their families. Each level offers a different context and distinct way of looking at governance for individual issues, reform ideas and proposals. Each level also contains an implicit notion of integration. At the departmental level, for example, integration refers vertically to programs within a given portfolio, and possibly horizontally to programs in other departments in the same government. At the level of the executive, integration usually means horizontal coordination across the entire government. As well, it can mean ensuring that congruency exists between the priorities of the first minister and cabinet on one hand, and the activities of the public service on the other.

In keeping with the concepts of governance and governing used in this study, the reform proposals extend beyond the public sector to the four other sectors. The proposals relate to the processes of policy initiation, policy development, and policy evaluation (Lemieux, 2000), as well as others examined here, such as capacity building, consultation and participation. At the inter-sectoral level, then, governing in an integrated fashion would entail coordination across some or all five sectors, depending on the actual and preferred division of responsibilities. While reform proposals are organized by level of analysis, a reality of all the sectors is their fuzzy boundaries. Reform ideas interact with and overlap organizational levels and societal sectors. Thus, numerous reforms listed in Table 1 could be adapted to operate at any of the levels, determined by the intention and ambition of policy makers.

This table is intended as a foundational overview of possibilities for change, most of which have been advanced over the past few decades by disability groups, child and family organizations, and other actors. Reflecting the growing priority of this domain, new reports on disability issues appear on a frequent basis. In May 2001, the Alberta and Manitoba governments both released disability strategy papers. Both are entitled *Full Citizenship* (Alberta, 2001; Manitoba, 2001), and both involve opportunities for community input and refinement of the stated policy vision and recommendations. At the federal level, the latest report on disability and children appeared in June 2001 (House of Commons, 2001). More details on the rationales and possible design features of all the ideas presented in Table 1 can be found in various reports listed in the Bibliography.

Table 1
A Menu of Governance Reform Proposals for the Disability Domain

Level of Analysis	Institutional Focus	Governance Processes	Reform Proposals
Departmental	<ul style="list-style-type: none"> • Government ministries and departments, Crown corporations, regulatory boards, and related public agencies 	<ul style="list-style-type: none"> • Policy development • Program delivery • Accountability • Resource allocation 	<ul style="list-style-type: none"> • Tying Cabinet Ministers' and Deputy Ministers' pay to performance results on disability strategy • Small disability directorates, secretariats or units • Disability/Family liaison officers in each key department and agency • Appeal mechanisms
Executive	<ul style="list-style-type: none"> • Central agencies • Cabinet ministers 	<ul style="list-style-type: none"> • Coordination • Accountability • Creating structures and assigning mandates 	<ul style="list-style-type: none"> • Disability Lens/Family Lens Policy Frameworks • Legislative review process and omnibus reforms • Central Unit and Senior Official in Privy Council Office • Lead minister designated with statutory powers • First Minister's Council for Persons with Disabilities • <i>Canadians with Disabilities Act</i> and equivalent laws in the provinces and territories • Enhanced research program on pilot projects and programs for community living
Parliamentary	<ul style="list-style-type: none"> • Legislative committees and sub-committees • Legislative offices and officers • Roundtables 	<ul style="list-style-type: none"> • Accountability • Including the public • Policy review • Advocacy • Changing attitudes and behaviours 	<ul style="list-style-type: none"> • Office of a Commissioner for Persons with Disabilities • Office of a Commissioner for Children • Annual reports to Parliament on disability issues and children's issues • Permanent standing committee or sub-committee on disability issues, with a wide mandate • Joint meetings of standing committees/sub-committees • Improved <i>Human Rights Code</i> compliance

Table 1, continued

Level of Analysis	Institutional Focus	Governance Processes	Reform Proposals
Intergovernmental	<ul style="list-style-type: none"> • First Ministers conferences • Meetings of responsible ministers • Working groups of F-P-T officials • <i>Social Union Framework Agreement</i> • National, provincial, and treaty Aboriginal organizations • Provincial-municipal and related processes 	<ul style="list-style-type: none"> • Managing interdependence • Policy planning • Including stakeholders • Capacity building with First Nations and other Aboriginal communities 	<ul style="list-style-type: none"> • Outcome reports and social audits • F-P-T advisory committees • Expanded scope of Court Challenges Program to include provinces and territories • Canadian Council on Aboriginal Peoples with Disabilities
Inter-sectoral	<ul style="list-style-type: none"> • Joint Table processes between governments and the voluntary sector • Roundtables • Mass media with social marketing • Sector coalitions and umbrella organizations 	<ul style="list-style-type: none"> • Managing interdependencies • Accountability • Strengthening civil society • Supporting citizen participation by families in all stages of the policy process • Changing attitudes and behaviours • Forming new strategic alliances 	<ul style="list-style-type: none"> • Capacity building (support for associations of families, national voluntary organizations, Native Friendship Centres) • Regulatory reforms • Royal Commission or similar comprehensive national inquiry on disability issues • Disability Awareness campaigns • Annual roundtables on disability issues with a broad range of stakeholders, which include follow-up action plans, implementation, and evaluation of the actions taken or not

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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CPRN Funding Sources

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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