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***Governing in an Integrated Fashion:
Lessons from the Disability Domain***

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Executive Summary

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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.