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

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Executive Summary

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Executive Summary

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

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

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

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

Drawing on a series of broad policy scans reflected in the inventory tables and boxes provided in Appendix A, this report demonstrates that governments have yet to provide a pan-Canadian vision for all children with disabilities and their families. The activity surrounding the *Agreement on Early Childhood Development Initiatives* (ECDI) signed between the federal government and the provinces (except Quebec) and territories demonstrates an emerging pan-

Canadian vision for children from birth to age six, of course, and such developments can only be applauded. Nonetheless, school-aged children with disabilities are not a central policy focus of governments.

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

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

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

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

Adequate Income

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

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

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

Effective Parenting

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

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

Supportive Community Environments

The third enabling condition required for positive child outcomes is supportive community environments. The notion of a supportive community environment includes a number of

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

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

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

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

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

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