

Children with Disabilities and  
Their Families in Canada

A Discussion Paper

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Disabilities

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## Prologue

*“Get to know him ... he is a member of the community ... he needs supports to utilize his talents to be a contributing member of the community. Any money spent on him is an investment in the community.”*

A Mom, from the “Beyond the Limits: Mothers Caring for Children with Disabilities” study, Roeher Institute, 2000.

This Discussion paper explores the data and research available to us regarding children with disabilities. It describes how children with disabilities are doing in Canada, how families are faring in terms of caring for children with disabilities and how communities, services and systems measure up.

Canadian children with disabilities are a diverse group – some are of Aboriginal identity or come from other countries, some live in two-parent, some in lone-parent families, some live in large cities, some in isolated communities. They come from a variety of cultural and faith backgrounds.

Children with disabilities and their families are influenced by all of the macro-trends that influence all Canadian children. Their families are under increasing stress, along with many Canadian families, working hard to stay afloat economically, and juggling their work and family life. Beyond that, these children are also influenced by systems outside the family – these systems are also changing, and some are under strain. School environments are under increased pressure with fewer resources. The health care system is under stress. Social services are not always organized with the needs of individual children and families in mind. Local communities are struggling to provide the supports their residents need. These stresses and strains – faced by all Canadian children and families – are exponentially felt by children with disabilities and their families. This discussion paper will explore this and some of the reasons for it.

At the Roundtable we are going to begin a dialogue which will help us focus on solutions, so that Canadian children with disabilities and their families can do better. We will explore issues regarding family supports, work/family policies, family economic security, child care, the education system, recreation – among many others.

Canada is a signatory to the *UN Convention on the Rights of Children*. The Convention recognizes the rights of children with disabilities. It recognizes their right to protection and promotion of equality; their right to special care, including family support, early education, child care and early intervention; their right to access services, including education, employment training, health care and rehabilitation; and their right to recreation and play. Furthermore, the *Charter of Rights and Freedoms* guarantees equality rights for people with disabilities. The Canadian government has made a number of commitments to children with disabilities and their families. *In Unison: A Canadian Approach to Disability Issues*, released in 1998, is an accord of federal and provincial/territorial governments (except for Québec) which provides a blueprint for

policy development in the area of disability. It makes a commitment to “full citizenship” of people with disabilities. It identifies building blocks to guide policy development – disability supports, income supports and employment supports. The *Social Union Framework Agreement*, signed in February 1999, provides shared principles and approaches to advance social policies for all Canadians – including children with disabilities. *Future Directions* outlines the directions the Government of Canada believes it must take to move towards full citizenship for people with disabilities – with the intent of removing barriers and enhancing the opportunities for children with disabilities and their families to participate fully in all aspects of Canadian life. In “The Canada We Want”, as outlined in the most recent Speech from the Throne, the Government of Canada re-iterated its commitment to children, and specifically to children with disabilities. The ground work is done, the commitment is stated, and it is time to take action.

## Introduction

The objective of the National Roundtable on Children with Disabilities is to identify policy issues through the lens of children with disabilities and their families. The purpose of this discussion paper is to provide some context for these discussions based on research. It is hoped that this paper will stimulate thought and discussion. It is not intended to be the final word on the state of affairs of children with disabilities and their families, but rather to raise important issues that have been identified through the literature and published reports in Canada. It is hoped that issues and information not addressed in the paper will be identified by Roundtable participants.

### The framework of the paper

Children with disabilities develop in unique ways, as well as in relation to others. Environmental influences are key to their development. Therefore, this paper examines children with disabilities in the contexts of their families and their communities. The obvious pressures within those environments point to needed policy approaches.

## Who are children with disabilities?

According to the Canadian Institute of Child Health (CICH), based on the 1996-97 National Population Health Survey (NPHS), approximately 565,000 children and youth between birth and 19 years of age have disabilities (CICH, 2000). The NPHS was not specifically designed as a disability survey. However, respondents were asked: “Because of a long-term physical or mental condition or health problem, are/is you/he/she limited in the kind or amount of activity you/he/she can do?” Answering yes to this question indicated the presence of an activity limitation or disability. Based on this question, 7.7% of children and youth have disabilities – similar to the 7.2% determined by the 1991 Health and Activity Limitations Survey.

The CICH identifies that this is an imperfect approach to measuring childhood disability, as some types of activity limitations do not constitute disabilities, whereas some disabilities are not necessarily identified as limiting activity – for example learning disabilities. This definition is different than that in the Health and Activity Limitation Survey (HALS) and is thought by some to underestimate the prevalence of childhood disability (Roeher Institute, 2000b). In fact, the Roeher Institute estimates that an additional 143,000 children and youth could be “found” in the NPHS data if more variables were examined (CICH, 2000). A comprehensive survey, designed to investigate the health and well-being of children and youth with disabilities, is needed to further understand who these children are and how they are doing (CICH, 2000, p. 228). The CICH recommends that such a survey needs to examine environmental factors impacting activity limitation for children, social engagement and the role played by parents and other volunteers. There is also a need for information regarding meaningful participation of children with disabilities; youth specific issues; respite and home care;

the impact of learning disabilities; and the inclusiveness of Canadian communities (CICH, 2001).

Children with disabilities and their families are diverse – as are all Canadian children and families. And, each child with a disability is unique. Children differ by gender, ethnicity and culture, personality and interest. They are members of a variety of types of families in various socio-economic, geographic and community contexts (Roehrer Institute, 2000b). While we are lacking specific numbers on disability and race or cultural origin, in Canada, we know that children with disabilities are ethnically and racially diverse. Overall, five percent of all children are First Nations, Inuit or Métis, five percent were born in another country, and 7.5% speak neither French nor English as a first language (CCSD, 2001a; Roehrer Institute, 2000b). According to the Aboriginal Peoples Survey, 22% of Aboriginal youth (aged 15 to 24) were reported to have a disability – this was more than three times higher than that of non-Aboriginal youth seven percent (Demas, no year).

There are many different types of disability. According to the CICH, the most common type of long-term condition among young Canadian children (0 to 14 years) reported in HALS, 1991 was a learning disability – with just over 17 of every 1,000 children reporting this type of impairment. Boys were more likely than girls to have learning disabilities (CICH, 1994). In fact, according to the Learning Disabilities Association of Canada (LDAC), one in ten, or three million Canadians have learning disabilities. They report that typically, many children with learning disabilities are unidentified (LDAC, 2002b).

Again according to HALS, over eight children per thousand had a behavioural or emotional condition, and nearly seven per thousand had an intellectual disability (CICH, 1994). Overall, four percent of youth (15 to 19 years) had some form of learning disability, mental, emotional, psychiatric disability or developmental disability in 1991. Just over two percent had a mobility disability, another two percent had a disability affecting their agility and nearly three percent had a disability which affected their speaking, hearing or vision (CICH, 1994).

Not only do children live with many different types of disability, the levels of severity differ. Again, according to 1991 HALS data, of the 7.2% of Canadian children under 19 who were disabled, 85% had a mild, 11% had a moderate and four percent had severe levels of disability (CICH, 1994). However, CICH cautions that the number of children with complex health care needs living in communities across Canada is unknown. Practitioners report that technological and medical advances have improved survival rates for children born with life-threatening physical conditions and, correspondingly, increased the number of children requiring specialized community-care. The impacts of disability on their lives and the lives of their families have been explored through small research studies – and their needs are enormous and many of them unmet (CICH, 2000).

## Why be concerned about children with disabilities?

Historically, many children with disabilities were not visible. They lived in large institutions, away from their families, and communities. Now, most children with disabilities live at home with their families in communities across the country. However, this change has not resulted in children with disabilities being full and active members of our communities. Their needs have sometimes been forgotten when 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 needs of parents caring for children with disabilities have also been overlooked. And for some children with disabilities – for example, for Aboriginal children with disabilities and their parents – the situation is even more pronounced (Valentine, 2001).

Many children with disabilities and their parents are not fully included in all aspects of society and do not enjoy full citizenship. What does it mean to be fully included in society? It means children and families are able to participate with choice. It means that individual children are involved in activities and social structures in a way that is meaningful to their own unique experience. It means that they truly belong, have community, and are equal participants in that community (Frazee, in press). Rather than making it the responsibility of children and families to fit the ‘program’, real inclusion starts from the experiences of the child and challenges society to provide a meaningful place for them. Inclusion values diversity, and recognizes and values commonalities in people’s lived experiences and aspirations for themselves and their children (Freiler, 2002).

*“Inclusion is characterized by a society’s widely shared social experiences and active participation by a broad equality of opportunities and life chances for individuals and by the achievement of a basic level of well being for all citizens.”*  
(Amartya Sen)

Inclusion starts with the values in communities. Inclusive communities value children with disabilities and their families for the roles that they play. They recognize that the responsibility for being included in the community does not rest with the family, the individual or disability and service organizations, but within the infrastructure of the community and all its members (CACL, 2002). Today there is a lot of discussion in Canada about ‘investments in human capital’. Children are often seen as those ‘investments’ – and policy is shaped on this basis. At the same time, our society often sees children with disabilities as a ‘deficit’—considered to be inferior or a burden. That flies in the face of an inclusive society.

## Family Life

*Families with children with disabilities are like other families in many respects – with their own style, family dynamic, culture and preferences. However, there are certain experiences that families in this circumstance have in common.*

*Roehrer Institute, 2000b, p. 9*

Most children with disabilities are valued members of their families. They grow within loving relationships with their parents and their brothers and sisters. They share the joys and sorrows of family life. While in the past many families were told their children should be institutionalized if they were disabled, today most children with disabilities live at home with their parents and siblings – and they are likely to do so for most of their childhood (Roehrer Institute, 2000b). This trend benefits children and families in many ways. The mothers in The Roehrer Institute's study, *Beyond the Limits: Mothers Caring for Children with Disabilities* talked about the positive impacts their children have brought to their lives. They described the ways they have grown – saying they have become stronger, learned skills and tended to look at life in new ways. They report that their experiences as mothers of children with disabilities have made them better people, increased their awareness of a wide range of issues and taught them to look at the world and other people differently. They believe that they have been given greater insights, learned acceptance, become more sensitive to others' differences, learned new talents, and gained a sense of fulfillment (Roehrer Institute, 2000a).

When asked what they want for their child, most parents will say that they want their children to be happy, loved, safe and nourished. There is ample evidence that nurturing and supportive parenting is a critical factor contributing to the healthy growth and development of all children (Willms, 2002; Landy and Tam, 1996). Parents who have a child with a disability have the same goals as all parents in caring for their children – however, meeting these basic needs for their children is sometimes very difficult or even beyond their control. Through consultations with families, the Canadian Association for Community Living, (CACL), revealed that they assume an unrelenting level of responsibility and accountability for the quality of their child's life. Parents take on responsibility not only for the care related to their child's disability but also for creating friendships and building acceptance in the community. The responsibilities which other parents are able to share with the community, neighbours and society are often borne exclusively by parents who have a child with a disability. This is overwhelming for many (CACL, 2001a).

### Families and Economic Security

While children with disabilities may live in families in various economic circumstances, children with disabilities are more likely to be poor than other children. The Roehrer Institute has drawn on data from the National Population Health Survey which point to some alarming realities for many families of children with disabilities -- children with disabilities are more likely than other young people to be in families at the lower end of the income scale – 29% of children with disabilities live in households where the total

income is in the lower-middle and lowest income quintiles, compared with 17% of children without disabilities (Roeher, 2000b). Furthermore, poor children are more likely to have disabilities – children who live in low income households are 2.5 times more likely to have a problem with vision, hearing, speech or mobility than are children in high-income families (Ross and Roberts, 1999; Roeher Institute, 2000b).

One of the most basic outcomes of poverty is hunger. The recent *Progress of Canada's Children* (CCSD, 2002) indicated that child hunger is a serious and increasing problem in Canada – and children with disabilities are more likely to experience hunger. According to the National Population Health Survey, families with children who have disabilities are more likely than other families to have run out of money needed to buy food (16% compared with 8%) (Roeher Institute, 2002).

What is the dynamic between poverty and children with disabilities – does being poor increase the likelihood of disability or does having a child with a disability result in families being poor? Research indicates that it works both ways. Poverty leads to disability in a number of ways. People living in poverty tend to live in circumstances that may increase the risk of injury. They may have less access to health services, and lower literacy levels. Poor children are also more likely to be labelled as having a disability than children from more privileged families (Roeher Institute, 2000b).

Disability also leads to poverty – in a number of ways. For example, families with children with disabilities are more likely than other families to experience family breakdown – and the most significant predictor of poverty is lone-parent status. In fact, according to the Canadian Council on Social Development, (CCSD), based on analysis of the National Longitudinal Survey of Children and Youth (NLSCY), 21% of all children with special needs<sup>1</sup> live in a lone-parent family, compared with 15% of children with no special needs (Hanvey, 2001). Parents of children with disabilities face barriers to labour force participation or to advancing their careers. Parents also face additional financial costs related to disabilities – for tutors, special diets, special clothing, transportation, babysitting, medications, supplies and equipment, and home adaptations (Roeher Institute, 2000a).

While poverty is the most blatant form of economic insecurity, we have good evidence in Canada that many Canadian families – particularly those in the middle class – are barely surviving, and just one piece of bad luck away from economic disaster. For example, between 1984 and 1999 while the richest families in Canada saw their net worth, their assets, or their 'money in the bank' increase by 43%, middle-income families saw their wealth grow by only three percent (CCSD, 2002). Combine this with the extra costs associated with caring for a child with disabilities, and the outcomes are very tenuous.

## [Families and Work](#)

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<sup>1</sup> Children who have been diagnosed by a health professional within a six-month period prior to the survey as possessing a chronic condition or activity limitation.

Challenges faced in the paid labour force are certainly a major contributor to the economic insecurity of children with disabilities. While research addressing issues of working parents of children with disabilities is limited, it has given us insights into the barriers these parents face.

According to the CCSD, among children aged 6 to 11 in two-parent families in 1994, 35% of those with special needs had both parents working in the paid labour force, compared to 46% of children with no special needs (CCSD, 2001b). However, parents' work life is challenging. In 1997, a study by Irwin and Lero found that 39% of parents whose children were disabled worked reduced work hours; 46% worked altered schedules; 68% turned down overtime and 72% passed up promotions because of their caregiving responsibilities (Irwin and Lero, 1997).

According to this study, the ultimate result was often that one parent would leave the paid workforce to stay home to care for their child full time. Sixty-four percent of two-parent families with a child with a disability reported one parent losing or giving up their job to provide supports to their child. Most often it was the mother. This parent then experiences reduced income, loss of pensionable earnings, stress and isolation from staying at home, loss of career opportunities, and challenges upon re-entering the workforce at a later date (Irwin and Lero, 1997).

There is even less research on single parents of children with disabilities – therefore, we know very little about how they are managing. If parents in two-parent families suffer serious stress and exhaustion from the role of working and caring for a child with disabilities, the challenge for single parents must be that much greater (Roehrer, 1999).

Parents experience a number of barriers to working – the main one being access to high quality, affordable and inclusive child care. This issue will be explored later in the paper. There are other barriers as well. The particular needs of the child (e.g., medical appointments) and the unpredictability of those needs; the willingness and ability of employers to accommodate the parent (e.g., workplace flexibility); and additional physical and emotional demands of caring for a child with disabilities are some of the other factors that have an impact on a parent's capacity to seek and retain paid employment (Roehrer, 1999).

There are a number of caregiving-related barriers to workforce participation of parents (especially mothers) of children with disabilities. For example, extreme costs in time, money, and personal effort related to caregiving. A parent may simply not have time to participate in the workforce. Wages are insufficient to support the needs which result from disability – some (especially single) parents must rely on social assistance since it provides for the coverage of health care needs and prescription medications. Provincial health may not cover many of the costs related to disability (Roehrer Institute, 2000c).

Many women work part-time. A Roehrer Institute study found that of the 60% of mothers who care for children with disabilities and participate in the paid workforce, almost half worked part-time hours. Although many felt that working part-time caused financial

strain on the family, they felt that they had little choice but to stay home for caregiving purposes (Roehrer Institute, 2000a).

Parents of children with disabilities face many workplace-related barriers when attempting to juggle the responsibilities of caregiving and workforce participation. Research by The Roehrer Institute (1999) outlines a number of these, such as:

- *Unsupportive and inflexible supervisors* who may expect their caregiving employees to work from home, or may frown upon the need for such things as flexible work hours, using the phone for personal reasons, or leaving the workplace in times of emergency;
- *Inconsistent practices within different work environments* concerning flexibility with work hours, time off for medical appointments, special leave benefits.
- *Pressure from co-workers*, who may be unable to empathize with the caregiving situation, or who may resent the uneven availability of the caregiver/employee;
- *Inflexible workloads and schedules* and refusal to accommodate special needs, especially for those who are involved in shift work;
- *Limited formal benefits* such as extended medical plans, health coverage that is available to children with disabilities and employees who work part-time, and paid personal leave.

Canadian research has made it clear that major roadblocks to labour force participation of parents with disabilities exist in the workplace. While there is a need for additional investment in accessible child care, there is also a need for greater awareness on the part of employers about the particular situation of parents with children with disabilities. Flexibility in hours and location of work, recognition of particular needs in benefits packages, and awareness on the part of managers and co-workers are essential.

However employers will not be able to bring about labour force inclusion for parents caring for children with disabilities all on their own. There are a number of factors in the broader policy environment that limit the supports that families need such as:

- Lack of federal-provincial cooperation to secure tax and fiscal policies that support families caring for children with disabilities;
- Disincentives to enter the paid labour force because of inadequate home supports;
- Labour standards legislation that does not recognize the unique situation and needs of these parents; and
- Welfare programs' growing emphasis on parents to make the transition from social assistance to paid employment without providing needed supports.

### **Families and social assistance**

Some parents prefer – or simply have no other option – but to put their energies into caring for their children rather than into paid employment. It is estimated that 90% of women with children with disabilities who are not in the workforce do not seek employment because of their caregiving responsibilities. Parents, especially single parents, often need to rely on government support. Young people with disabilities are

nearly twice as likely as other young people to live in families that depend on government, not employment, for their main source of income (17% compared with 8%.) This includes social assistance, workers' compensation and employment insurance. For many families of children with disabilities it makes more sense to use social assistance than to take a job with low wages, since they are entitled to receive more disability-related supports when on welfare. Thus, many parents simply cannot afford to work (Roehrer Institute, 2000b).

*Finding a Way In: Parents on Social Assistance Caring for Children with Disabilities* (Roehrer Institute, 2000c) concluded that financial supports for families on social assistance who have children with disabilities are very inadequate. In this study, it was not uncommon for mothers to go without food so that their children could eat. Many, already living in poverty, experienced reductions in social assistance payments as a result of provincial social assistance cuts. They felt penalized and humiliated due to the financial impacts of choosing to care for a disabled child at home. It was also clear in this study that the amount of support required to enable parents to return to the paid workforce is considerable, and in some cases not feasible.

While recognizing that social assistance enabled them to survive, parents in this study described the negative side of social assistance. Not having enough money, never being able to catch up with bills, having to scrimp in every way possible including using food banks, all took their toll. Some of the children required special diets that were not adequately covered. Children with disabilities also often required special equipment and other aids (e.g., orthotics) that were not covered by welfare or health care. Parents reported that social assistance did not take into account the real costs involved in meeting the needs of children with disabilities. And, nothing was allowed for the caregiver or siblings. Parents were concerned about the psychological impact of welfare and poverty on their children. They felt that being on social assistance not only damages their own self-esteem, but that of their children. There was considerable bitterness and anger relating to the stigmatization of social assistance (Roehrer Institute, 2000c).

### Families and Caregiving

Parents are responsible for much of the direct support for children with disabilities. Many studies show parents have multiple responsibilities as nurses, service coordinators, case managers, advocates, trainers and educators (Roehrer Institute, 2000a). Those roles require time and skill, and are often taxing on parents. As in other Canadian families, the bulk of caregiving work in families with a child with a disability is still provided by women. While some community based supports are available, families are expected to fill in the gaps in service that result from funding cuts and shifting models of care, despite an increasing need for employment income. So, while families are happy to have their children at home, many parents, especially mothers, are stressed out and exhausted by their many responsibilities. This affects the health and well-being of mothers and entire families (Roehrer, 2000b).

*Beyond the Limits: Mothers Caring for Children with Disabilities* found that parents, particularly mothers, spend an incredible amount of time caring for and supporting their

children. On average, they spend 50 to 60 hours per week on personal care, advocacy, coordination of services and transportation directly related to their child's disability. This includes an average of 14 hours per week in advocacy and coordination related to their child's education. All of this is in addition to time they put into general domestic responsibilities and paid work. In order to do so, they have taken on a number of roles that greatly increase their responsibilities and impact on their physical, emotional and social status. In some cases these external roles actually impede or undermine effective parenting (Roeher Institute, 2000a) and for many families these responsibilities do not end. For parents of children without disabilities, as their children move through their teens and into young adulthood, the rigorous day-to-day physical caretaking and responsibility lessens – that is not the case for many families with children with disabilities.

Mothers' health and well-being are compromised by their workload. They report high levels of physical and emotional stress, and look to support from friends, medications, and counselling to deal with it. However, mothers are clear – stress is caused by lack of support, not their child (Roeher Institute, 2000a).

### Families and Relationships

Parents of children with disabilities love them and value them highly. They tend not to blame their stress and fatigue on their children, but rather on not having enough support (Roeher Institute, 2000a). Parents also point to many of the positive gains of caring for a child with a disability. They describe their experiences as deeply rewarding and satisfying, finding a “new appreciation for life” through their relationships with their children, and becoming stronger and more resilient to life's difficulties (Roeher, 2000b). We have less information about the children's own experiences and perceptions of their relationships with their families, since we do not have a population-based study that focuses on children with special needs. Based on data from the NLSCY (1994), looking at children with special needs, the CCSD found that the majority of children with special needs get along well with their parents and siblings. However, they were somewhat less likely to do so than were their peers without special needs. Eighty-nine percent of all children aged 6 to 11 without special needs got along with their parents well or very well, compared with 82% of children with special needs (Hanvey 2001).

The stresses of multiple responsibilities, lack of adequate support, and the juggling of multiple roles take a toll on many families. In some cases, insufficient support may lead to the placement of a child in a residential setting or in foster care which greatly increases the cost to society. In one survey of 117 parents of children with disabilities conducted by the Canadian Association of Community Care, half the parents cited denial of respite and child care services as reasons for out-of-home placement (CACC, 1995; CCRC, 1999; Roeher Institute, 2000b). In an Alberta study of 100 children in care of the child welfare system, 57% had accessed disability-related services in the past 12 months and 65% were diagnosed as having at least one disability (Alberta Family and Social Services and the Alberta Association for Community Living, 1997). The Canadian Coalition for the Rights of Children (CCRC) reports that foster parents of children with disabilities

typically receive better financial support from provincial authorities than natural families do (Canadian Coalition on the Rights of Children, 1999).

Another possible consequence of family stress due to insufficient support is family breakdown. As cited earlier, children with disabilities are over-represented in lone-parent families. In this situation, families become even more vulnerable as the risk of poverty is higher for lone-parent families than for two-parent families (Roehrer, 2000b).

## The Community

Community is important to children with disabilities in two important ways. First, it can provide children with disabilities and their families a sense of belonging – through the informal social support networks and participation in community life, children and families learn and grow. Second, it is the source of supports such as child care, education, disability support services, health services and recreation. We have ample evidence that children who live in well-resourced communities have a better chance of reaching their full potential than do those who live in poorly-resourced communities.

However, children with disabilities must be full participants in these communities to benefit from them. Frazee cites the *Eaton v Brant County Board of Education* legal case to describe how children with disabilities can be excluded from their communities:

*“Exclusion from the mainstream of society results from the construction of a society based solely on “mainstream” attributes to which disabled persons will never be able to gain access. Whether it is the impossibility of success at a written test for a blind person, or the need for ramp access to a library, the discrimination does not lie in the attribution of untrue characteristics to the disabled individual. Rather it is the failure to make reasonable accommodation, to fine-tune society so that its structures and assumptions do not result in the relegation and banishment of disabled persons from participation, which results in discrimination against them.”*

Eaton v Brant County Board of Education, 1997 (Frazee, in press)

## Housing

Stable, affordable housing in a child-friendly neighbourhood is essential for healthy child development. Yet low vacancy rates, rapidly rising rental costs, and reduced social assistance rates have made decent housing unattainable for many families. Governments, who once made a key contribution to housing supply, vacated the market and private developers have not filled the gap. In 1993, the federal government froze funding for social housing. By 1996, it had transferred responsibility for its existing housing stock to the provinces and territories. Most provincial governments withdrew from building new housing and some down-loaded their new responsibility to local governments with no additional resources. Ottawa has since taken a step back into affordable housing,

committing \$680 million over four years in 2001. While the provinces and territories have signed a framework agreement with the federal government for the new initiative, the majority have yet to contribute their own funding to make the agreement work (Campaign 2000, 2002).

In 1996, 15% of households with children were in substantial need – that is the housing was too expensive for their income, was in disrepair and/or was over-crowded. Families with children with disabilities were particularly susceptible to living in such difficult housing conditions. According to the CCSD, children with special needs are more likely to be living in problem housing. Of all children with special needs, 12.2% live in housing in need of major repairs, compared with 7% of children without special needs (CCSD, 2000; Hanvey, 2001).

### Child Care

Child care is important for children and families. Quality early childhood education and care provides children with a stable and healthy environment in which to learn, grow and develop relationships with other children. Child care enables parents to work, rest, study or attend to their other responsibilities. However, Canada has no comprehensive system of child care, despite rising numbers of women working outside the home and a decline in extended family support as family and community patterns shift (Roehler, 2000b).

Many studies have pointed to the necessity of affordable child care to enable parents to participate in the workplace. Gina Browne's study found that good free child care, along with recreation programs, enabled single mothers to leave welfare at double the rate of the welfare population not receiving such assistance (Browne et. al., 1998; Roehler, 2000b). Yet there is a scarcity of affordable child care in Canada. In 1998, there were 516,734 regulated child care spaces in Canada. This meant that only 10% of children up to age 12 had a regulated child care space available for them (CCSD, 2002). Despite the understanding of the importance of early childhood care and education, most governments in Canada have failed to capitalize on the opportunities to use child care programs as a developmental resource for children with disabilities. (Irwin, Lero and Brophy, 2000).

For parents of children with disabilities, accessing child care is very challenging. In their research, Irwin and Lero reported that 73% of parents reported difficulties finding appropriate care for their child. Seventy percent had difficulty finding trained and committed caregivers and 68% had difficulty finding back-up care when they or their child was ill (Irwin and Lero, 1997). Access is limited as a result of too few spaces, high cost and lack of inclusion.

While all provinces and territories have made some provision for inclusion, in no jurisdiction is it illegal to exclude a child from child care on the basis of disability or other special needs. And while many provincial officials and child care consultants have worked diligently to make inclusion a reality in their jurisdictions, written policies, training requirements, and resource allocation seldom suggest systematic, stable support

for inclusion. Consequently, it often falls to individual child care centres to choose whether to include or exclude these children (Irwin, Lero and Brophy, 2000).

Despite the lack of pro-active legislation and policy that would prohibit exclusion and facilitate the effective inclusion of children with disabilities in child care, many centres have done so. Research suggests that regular Canadian child care programs, when adequately resourced, can provide appropriate care for children with special needs. What supports inclusive child care? Irwin, Lero and Brophy found that early childhood educators' actual experiences with inclusion, not their general attitudes and beliefs, most strongly influence their commitment to inclusion, their acceptance of a broader range of children with disabilities being included, and their comfort and confidence in working with children with disabilities. Positive experiences for the staff and children depend on having additional resources to support inclusion (e.g., appropriate training, additional staff, time to plan and work collaboratively with parents and community-based professionals, and sometimes structural modification if the program is not accessible) that build on a base of high quality care (Irwin, Lero and Brophy, 2000).

However, the research findings also demonstrate that continued under-funding, cutbacks, lack of training, and a lack of clear governmental directive compromise the capacity of even the most experienced and committed child care programs to continue to provide effective inclusive care and developmental stimulation to children with special needs (Irwin, Lero and Brophy, 2000).

It is not only child care for young children that is at issue. For many parents, child care outside of school hours is also challenging – this is particularly so for parents of children with disabilities. It is difficult for many parents to work if they cannot find child care after school, before school and in the evenings. A recent study of 50 families of children with disabilities found that only 12% of the parents reported having access to after school care (Roehrer, 2000a).

## [Recreation](#)

One particularly important resource in children's communities is recreation, including sports, physical activity, arts, culture and clubs. There is good evidence that access to recreation is important for children's development. Participation by young people in structured recreation is important in many ways. It plays an important role in fostering active citizenship, social inclusion, improving physical and mental health, increasing self-esteem and encouraging better academic performance. Childhood obesity is increasing at an alarming rate among young people in general – the rates nearly tripled among boys and more than doubled among girls between 1981 and 1996 (Tremblay and Willms, 2000). Daily physical activity is one important solution to this problem. For many children facing academic challenges, recreation provides a level playing field where they can excel, develop leadership skills, and make and keep friends.

It is important for children with disabilities, as it is for all children, to belong to a community and to be able to take part in social and leisure activities with other young

people. This involves being able to access community spaces, such as stores, shopping malls, parks, playgrounds and public sidewalks. Children and youth with disabilities may face barriers engaging in even these simple activities that many take for granted (Roehrer, 2000b).

In 1991, according to HALS, 7% of children had difficulty taking short trips outside their home (CICH, 1994). According to the Institute, 27% of children 0 to 4 years and 58% of children aged 5 to 14 years with disabilities participated in community physical recreation programs in 1991.

Children living at low-income levels are less likely to participate in structured recreation activities – and we know that children with disabilities are over-represented in low-income families. A significant proportion of children with disabilities (four in ten) are not participating in community recreation activities as much as they would like, and almost half want to be more physically active (Canadian Coalition for the Rights of Children, 1999).

There is mounting evidence that the access to recreation for all children in Canada is deteriorating. A survey of municipal recreation departments across Canada indicated that most recreation departments charge user fees for all of their programs and user fees are going up (CCSD, 2001a).

The accessibility of community/public spaces is inconsistent. Building and other accessibility standards and codes exist, and are applied to many new spaces as they are constructed. However, even when efforts have been made for accessibility, the codes were designed with adults, not children in mind. There are no data which suggest the percentage of urban or rural spaces that are barrier free, in general or specifically for children. Anecdotal evidence suggests that many barriers exist, but accessibility may be improving over time as the public becomes more aware of these issues (Roehrer, 2000b).

Some recreation opportunities exist which are designed specifically for children with disabilities. However, these programs often lack the supports that municipal programs enjoy. These are not funded by any particular agency, but rather count on their own fundraising to survive. Many child and youth organizations, municipal parks and recreation programs, and sporting organizations have made efforts to be inclusive. However, progress has been inconsistent. Though access to these programs seems to be gradually increasing, children continue to face barriers. Typically, barriers to recreational activities include lack of specialized equipment, a lack of accessibility standards for play spaces, and insufficient staff training and staff ratios. Even when a program is inclusive, children may have a difficult time getting there because of a lack of accessible transportation (CCRC, 1999).

## Education

### **Children's participation in education**

All Canadian children have the right to attend school – and in fact are legally obligated up to age 16. Most children with disabilities do attend school. Young preschool children with disabilities may be less likely to access preschool or kindergarten than their non-disabled peers. While local education authorities in all provinces are funded to provide one year of preschooling, there is little support for children with disabilities (Roehrer, 2000b). However, attendance at school does not tell the whole story. In order to benefit from the education system, and to reach their full potential – socially and academically – children with disabilities need to participate fully – in their own unique way – in their schools.

Data indicate that once in the education system, children with disabilities face difficulties. According to the Canadian Institute of Child Health, 44% of children aged 5 to 14 with disabilities reported that their disability interfered with their education. Seven percent began school later than most children; eight percent said their schooling was interrupted for long periods; and 29% said they took longer to achieve their present level of education (CICH, 2000b). According to the CCSD, children with special needs are more likely to miss days at school and are less likely to be reported by their parents as doing well at school than are their non-disabled peers. The majority of children with disabilities say they like school a lot and look forward to going to school. However, again, they are less likely to feel that way than students without special needs. The majority of children with special needs rarely or never feel left out at school – only eight percent do so – but this compares to four percent of children without special needs (Hanvey, 2001).

Advances have been made recently in closing the education gap between older children with and without disabilities. Among young people aged 12 to 19, the vast majority are at school, college or university – 85% of young people with disabilities compared with 87% of their non-disabled counterparts. On balance, the education level of young people with disabilities is almost equal to other young people. About 20% of both groups have graduated from secondary school or have moved on to pursue post-secondary studies according to the 1996 NPHS (Roehrer Institute, 2000b).

The proportion of students with disabilities in full-time studies is lower than among other students (91% compared with 98% respectively). Some students may be choosing part-time study to accommodate their issues of health, physical stamina or learning difficulties. Others do so because of inaccessible transportation, because they have difficulty securing adequate personal and technological supports for participation in educational programming or because they simply have a more difficult time securing the needed financing for education where disability is an issue (Roehrer, 2000b).

### **The education system**

There is mounting evidence in many jurisdictions that education is under-resourced and struggling – this has a tremendous impact on children with disabilities. In a number of provinces, concerns about funding and delivery of special education services have been raised. A recent study by the CCSD found that only 19% of key informants surveyed felt that children with special needs were having those needs met in the education system.

Over ninety percent reported that the number of children requiring special education services had increased over the last five years – while 82% said that funding was inadequate to meet the needs of these students, in spite of increases in 80% of the cases. The majority (88%) reported that there are not enough specialists who are specifically equipped to support children in special education. More than half, 53%, said that the number of special education teachers has dropped over the last five years. In addition, there are not enough teachers' aides and assistants, psychologists, and speech therapists (Gibson, Kierstead and Hanvey, 2001).

In Ontario, People for Education in Ontario reported that the number of schools with specialist teachers in the province has declined steadily over the last five years and waiting lists for special education services increased by 14% from 34,700 in 1999/00 to 39,700 in 2001/02. Only 55% of schools have access to psychologists, 56% have access to social workers and only 24% have access to speech therapists (People for Education in Ontario, 2002).

There is debate and discussion in communities, among researchers, among policy makers, parents and educators about including all children with disabilities in regular classrooms. In Canada, there are provincial and territorial commitments to 'inclusive education', however, not all children are included in a regular classroom in their own neighbourhood. Those who support inclusive education cite academic and social benefits to the children. Those who are concerned raise issues about inclusive education not always recognizing the uniqueness of each child. They fear that inclusive education is commonly under-resourced, and the standards are resultantly low. While not all students benefit from full inclusion – at least not the way it exists in many jurisdictions – there is a danger that setting up segregated classrooms for children who need them could be used to exclude students who should be included. Conversely, the philosophy of inclusion can be used to justify cuts to special education – with the argument that you do not need extra resources, just the right attitude and good basic teaching. What is clear, however, is that certain factors are necessary for inclusion to work. There needs to be: adequate funding; open attitudes welcoming students with special needs and their parents; training for all teachers to manage inclusive classrooms; properly trained and allocated resource teachers who provide the assistance classroom teachers need; and the political will to put resources in place. These elements do not currently exist in Canada (Hoffman, 2002/03).

In most provinces and territories, inclusion in regular classes is determined on a case-by-case basis, and some children are more likely than others to be included. For instance, schools are more likely to include children with physical disabilities than those with multiple, developmental or emotional disabilities. It is reported that other factors impact these decisions as well – race, language or family income could play a role in decisions to include a child in a school (Canadian Coalition on the Rights of Children, 1999).

### **Aboriginal children**

There are even more challenges in the education system for Aboriginal children. Many First Nations communities control their education programs. However, often the funding available to communities to support the needs of students with disabilities is lacking,

partly as a result of the definition of disability. This results in communities lacking the required number of qualified professionals. Therefore, progress in integrated education in Aboriginal communities has not moved forward. Furthermore, jurisdictional problems further complicate young people's access to education when they move on to post-secondary education (Demas, no year).

### **Children with learning disabilities**

Children with learning disabilities face their own unique challenges in the education system. The LDAC reports that only three percent of school-age children with learning disabilities receive special services within their schools – the majority of students with learning disabilities are either unidentified or receive minimal service (Learning Disabilities of Canada, 2002b).

Supports for children with learning disabilities appear to be deteriorating. Compared with two or three years ago, provincial and local affiliates of the LDAC have reported that:

- Regular teachers are less likely to have the skills and knowledge needed to meet the needs of students with learning disabilities in the classroom. They have less one-on-one time with these students, and are therefore experiencing more difficulties in responding to their needs.
- Specific educational services for children with learning disabilities are less available, as are the services of school psychologists to assess their needs and to address the behavioural issues the students can present where their educational needs are not effectively addressed.
- School boards are having more difficulty raising the money needed to meet the educational needs of students with learning disabilities.
- Parents are experiencing increased financial pressures to meet their children's educational needs. They are resorting to private schools along with privately purchased special education and assessment services because they are less available in the publicly funded sphere.
- Society generally seems to hold more negative or sceptical attitudes and perceptions toward students with learning disabilities.
- As a result, parents are increasingly turning to courts and to provincial Human Rights Commissions to address the problems they face (Crawford, 2002).

While the costs of learning disabilities to individuals, families and to society are considerable – estimated at \$1.95 million per person from birth to retirement – effective educational and social supports for these children and their families could help to improve outcomes later in life. Research has shown that educational attainment is a key factor in the success in paid employment of people with disabilities. Generally, young adults with learning disabilities who have educational experiences that are not fraught with major delays and disruptions have better economic outcomes as young adults and are less likely to be attached to the disability income system (Crawford, 2002).

## [Health Services and Homecare](#)

The health care sector is one publicly-funded service in Canada that is supposed to be universal and available equally to all. However, based on the 1996 NPHS, The Roeher Institute found that 12% of young people with disabilities aged 12 to 19 reportedly did not receive the health services they needed in 1996. Only 2% of non-disabled young people experienced a similar lack of access to health services.

Other research conducted by the Roeher Institute has found that the health care system is not as well-gearred to the needs of young people with disabilities and their families as it is to others. It is important to address discrepancies in health service availability, access and adequacy for children with and without disabilities. It is equally important not to confuse disability and ill-health. Young people with disabilities do tend to report more chronic health problems than other young people and tend to report that they are somewhat less well in terms of general health than other young people. This might be expected. Overall, however, the vast majority of young people with disabilities – 88% – are reportedly in good, very good or excellent general health (Roeher, 2000b; Roeher, 2000f).

The shift to community- and family-based care, without providing adequate resources to support it, has made it difficult for families with disabled, sick or injured children to provide necessary homecare without threatening family incomes. The Children and Youth Homecare Network (CYHN) reports that there is not a system of homecare for children with special needs (CYHN, 2002). They cite a recent study that found services to be fragmented and unequally distributed from community to community. They found gaps in services, leaving many families with limited supports to assist them in caring for their child at home. The CYHN also reports human resource problems. Homecare providers are often paid less, are casual or part-time workers, and are faced with working conditions that vary considerably – even though the children they care for require the same specialty training as they would in hospitals. Without adequate access and funding, individual family members must absorb a lot of the costs of care – financial, emotional and physical costs (CYHN, 2002).

The CYHN identifies that there are substantial inter-provincial and intra-provincial differences in how home and community services are funded, allocated and delivered to children. They identify a desperate need for an integrated system of homecare for children. Children and youth requiring care in their home and community experience the best results when services and supports are integrated at every level, including the overall system level. Such a system needs to encompass formal and informal services and supports, flowing from institutions to home, school, day care, and back to institutions, when appropriate (CYHN, 2002).

## [Family Supports](#)

Families of children with disabilities may be able to access special funding or tax credits and community-based services such as respite or homecare to help them support and care

for their children with disabilities at home. However, these programs tend to have limited funding and provide access on a discretionary basis. Families do not have the clear entitlements to social services that they do for health care and education (Roehrer Institute, 2000b). Families say the means tests that determine eligibility are too rigid, and do not sufficiently consider individual family circumstances and disability-related costs. They also report that access to services varies between families and between regions, they are discouraged by long waiting lists, and that they often cannot afford the costs of short-term relief care transportation and equipment costs (CACC, 1995; Roehrer Institute, 2000b; CCRC, 1999).

Provincial governments have various programs to financially assist families with the extra costs associated with disability. According to the CCRC, a national study reported that in most parts of Canada, there is little financial support for family members who are primary caregivers of persons with disabilities. In fact, they report that most provinces and territories have no publicly-funded income support program for caregivers of children with disabilities (CCRC, 1999).

In the literature on family support, a major recurring theme is the lack of community resources produced by government cutbacks in health and social services. Since the replacement of the Canada Assistance Plan with the Canada Health and Social Transfer, publicly-supported social service agencies have been forced to streamline operations in order to serve as many people as possible. In order to maximize the use of available resources, service providers may only intervene in crisis situations, and may refuse service to clients with high levels of need. This only increases the caregiving burden on the families of people with disabilities (Roehrer Institute, 2001b).

Furthermore, the process of accessing services is problematic. Based on key informant research with mothers raising children with disabilities, it was found that the majority of programs force these women to constantly portray their child in a negative and deficit-based manner, continuously justifying their request for supports and jumping through endless hoops. Bureaucratic processes that insist that parents describe their children in a devaluing manner perpetuate feelings of betrayal of their own child. Parents report they are required to use intrusive and degrading language to obtain the services and supports they need. Children and families are often penalized for advances or gains made by the child, with the result of a reduction of supports and services (Douglas, 2001).

Families consistently report needing more respite care. Respite care involves services aimed at giving parents or guardians time off from caregiving. National statistics on access to respite care are not easily available, but numerous smaller studies consistently indicate that the availability of respite services is inadequate. In one study of 50 families, 90% stated that respite care was one of the top things they need to support their children in the community, but the need is not being met (Roehrer Institute, 2000a). Despite a large body of literature that shows the importance of respite in promoting well-being for families and community inclusion, issues related to respite have changed little in the last few decades. Access is particularly difficult for families in rural areas and for children

who have particular support needs like complex health issues, or behavioural disabilities (Roehrer Institute, 2000a).

Families are looking for ‘family-to-family’ support – forums, opportunities and networks in which they can meet and share experiences with other families. Family-based organizations and family networks are important ways in which families provide support, information and learning to each other. Building the capacity of families builds the capacity of communities, and of society. However, it is important that this essential element is strengthened and not left as an additional task and responsibility that rests on the shoulders of these families (CAACL, 2002).

### [Friends](#)

Children and youth rely on their friends – they can and do act as positive role models and demonstrate appropriate social behaviours. Peers often listen to, accept, and understand the frustrations, challenges and concerns associated with being young.

Friends provide an opportunity for young people to have their needs met, to feel capable, to belong, to be respected and to have fun. While young people often experience these needs being met within the family, their peer group provides unique and different opportunities. While many families assist their children to find out who they really are and to feel proud and confident of their unique traits and abilities, the peer group may often be more accepting of their feelings, thoughts and actions associated with this search for self-identity.

A study of youth aged 11 to 16 with disabilities in Ontario found that 82% of them said they had more than one close friend and 64% said they feel loved and appreciated most of the time. Only 44% said they feel needed and useful most of the time, and almost one in five felt left out often (Steele et. al., 2000).

According to interviews with young people with disabilities, when asked what social inclusion meant to them, *friendship is the distinctive and defining feature of inclusion* – friendship that is expressed freely as a dimension of being, and exchanged without measure or consideration. In the experience of these young people, the link between their own sense of well-being and inclusion is straightforward. The question of how they feel and think about themselves is inextricably linked to feelings of being included. Research by Jenkins and Keating (1998) confirms that robust networks of social relationship such as peer friendships correlate strongly with the development of childhood resilience and the ability to cope with external stress. Operating as a kind of “natural intervention”, feelings of connection to others have been demonstrated to contribute to a sense of security, integration and purposefulness. Young people with disabilities identified themes of cooperation, trust and mutual support as the benefits of inclusion. Inclusive friendships do not differentiate along lines of physiology or demonstrable intellectual capacity; rather they are based upon values and standards of conduct (Frazee, in press).

### [Safety and Security in the Community](#)

Violence against people with disabilities is recognized as a serious and pervasive problem. Abuse may involve sexual, physical or emotional maltreatment. The Roeher Institute recognizes that some forms of abuse may be subtle, and not as easily recognized by the law – for example, restricted movement, invasive “therapy” or rough handling while receiving personal care. Abuse could come at the hands of parents, teachers, health professionals and others (Roeher Institute, 2000b).

Children and youth with disabilities are more likely than other children to be physically or sexually abused. The Roeher Institute estimates that:

- 39 to 68 percent of girls with intellectual disabilities will be subject to sexual abuse before the age of 18;
- 16 to 30 percent of boys with intellectual disabilities will be subject to abuse before the age of 18; and
- 39% of children with multiple disabilities admitted to a psychiatric hospital have suffered maltreatment (mainly physical abuse) (Roeher Institute, 2000b).

Parents have expressed real concern for the safety of their children at school, with caregivers and in the community generally. For many parents, the safety and vulnerability of their children is a constant worry which makes meeting the other needs of their child and the family difficult (CACL, 2001).

Population-based surveys confirm these concerns. According to the CCSD, children with special needs are more likely to be bullied at school, they are more likely to report that other children say mean things to them, and they are less likely to feel safe at school than their non-disabled peers (Hanvey, 2001). According to the National Population Health Survey, only 51% of youth with disabilities aged 12 to 17 in Alberta say they ‘always’ feel safe in their community, compared with 57% of other young people. Only 52% always feel safe at school compared with 60% of their non-disabled counterparts, and only 78% always feel safe at home while this is true for 86% of other young people. While many children are at risk of abuse in their homes, children with disabilities may be at greater general risk because of the difficult circumstances common to their families (Roeher Institute, 2000b).

### [Supports for Aboriginal children with disabilities](#)

Community supports for Aboriginal children with disabilities are of particular concern. The federal government provides services to status Indians on-reserve and to the Inuit, while the provinces provide services to Indians living off-reserve, non-status Indians and Métis. Community organizations also provide services. Despite the large number of Aboriginal children affected by disability, service delivery is consistently poor or non-existent in Aboriginal communities. Many Aboriginal people live in rural or remote areas, so access to community-based services is even more difficult (Canada House of Commons, 1993; McDonald, 2000; CCRC, 1999).

Jurisdictional issues complicate health and social service delivery to Aboriginal children with disabilities. Provincial governments have refused to provide services to Aboriginal people on-reserve and the federal government does not provide all the necessary services.

In 1993, the federal Standing Committee on Human Rights and Disabled Persons observed that both levels of government appear to have forgotten the needs of Aboriginal people and that strong program structures were lacking, services were fragmented and standards were inconsistent (Canada House of Commons, 1993).

### Children living in northern and rural communities

The Centre of Excellence for Children and Adolescents with Special Needs has reported that over 40% of Canada's children and adolescents live in communities with less than 100,000 people. All children and adolescents in Nunavut, the Yukon, the Northwest Territories, and Prince Edward Island, over 60% of youth in Newfoundland, Nova Scotia, New Brunswick, and Saskatchewan, and at least 72% of Aboriginal youth live in small, rural, and remote communities. They state that children and adolescents with special needs in those areas face unique challenges because of where they live. These are due to the difficulty of attracting and retaining professionals and para-professionals in health, education, and related areas, the challenge of developing and delivering effective and fiscally responsible programs and training across vast distances and to sites where only one child with special needs may exist, declining populations in many rural and northern areas, and the fact that in most small, rural, and remote communities a culture of policy discourse does not exist, hampering the development of local solutions to local problems (Centre of Excellence for Children and Adolescents with Special Needs, 2002).

The Centre reports that the cultural and linguistic diversity of the peoples of northern Canada requires that resources and services for children and adolescents with special needs are culturally and linguistically appropriate. Currently, knowledge about the cultural and linguistic contexts of special needs in northern Canada is not well established and few resources that respond to cultural and linguistic requirements are available. The challenges presented by geography, cultural and linguistic diversity have not been adequately addressed. Children and adolescents with special needs in rural and northern communities are extremely under-served and their needs poorly represented in policy and services derived from large metropolitan populations (Centre of Excellence for Children and Adolescents with Special Needs, 2002).

## Moving into policy

The Roeher Institute has identified specific policy goals to ensure inclusion of children with disabilities and their families in the National Children's Agenda as:

- Establishing inclusive values, rights and approaches for healthy child development;
- Enhancing family economic security;
- Ensuring needed child and family supports – at home and in the community;
- Fostering inclusive communities; and

- Strengthening civil society (Roeher Institute, 2000g).

The Canadian Policy Research Networks (CPRN) has identified three enabling conditions required for positive child outcomes:

- Adequate income;
- Effective parenting; and
- Supportive community environments.

These recommendations have common elements.

Economic security and adequate income are critical in creating positive child outcomes. The research reviewed for this discussion paper makes clear, however, that parents of children with disabilities face unique financial challenges and, for most, making financial ends meet is difficult. 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 not available (Valentine, 2001).

Parents and families need supports to do their job. 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 children and parents are frequently not receiving the scope and level of support required. (Valentine, 2001).

The notion of a supportive community 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 offering inclusive services such as child care, health, respite services, homecare education and recreation – that enable all families to participate as full citizens. It means constructing a fully accessible environment so all children can go to the shopping centre, go to the movies, and attend swimming lessons at the community pool. It means family-friendly and disability-sensitive social policies – including employment policies, maternity/parental leave policies, collective agreements and employment contracts. 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 (Valentine, 2001).

Provincial governments have made gains in coordinating and integrating generic children's policies, but the Canadian Policy Research Network reports that 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 under-funded. 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 (Valentine, 2001).

Many Canadian studies have concluded 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, there is no coherent vision for achieving the best possible policy mix for children with disabilities and their parents (Valentine, 2001). Few provinces have such a vision for their own jurisdiction, and no consensus exists as yet for the country as a whole.

The most recent Speech from the Throne recognized the importance of children with disabilities and their families. The challenge ahead lies in framing policies that recognize the social context of the lives of these children, do not define disability in a deficit context and result in all children being included in society.

## References

Alberta Family and Social Services Child Welfare and the Alberta Association for Community Living. *Children with Disabilities and Care*. Edmonton, 1997. Cited in Canadian Coalition for the Rights of Children. *The UN Convention on the Rights of the Child: How Does Canada Measure Up?* Ottawa: The Canadian Coalition for the Rights of Children, 1999.

Assembly of First Nations. *To the People Who are Able: A Perspective on First Nation Children and Disability: A Discussion Paper*. Ottawa: The Author, 2000.

Avard, Denise. *Children and Youth with Disabilities in Canada: The 1986 Health and Activity Limitation Survey*. Ottawa: Canadian Institute of Child Health, 1994.

Browne G, Byrne C, Roberts J, Gafni A, Watt S, Haldane S, Thomas I, Ewart B, Schuster M, Underwood J, Flynn Kingson S, Rennick K. *Benefiting All the Beneficiaries of Social Assistance is "Within Our Reach": A RCT of the Two-Year Effects and Expense of Subsidized versus Non-subsidized Quality Child Care/Recreation for Children on Social Assistance*. Hamilton: McMaster University, 1998.

Campaign 2000. *The UN Special Session on Children: Putting Promises Into Action: A Report on a Decade of Child and Family poverty in Canada*. Toronto: Campaign 2000, 2002.

Canada House of Commons. *Completing the Circle. A Report on Aboriginal People with Disabilities*. Ottawa: Ontario, 1993.

CACC (CACC). *Home Based Care for Medically and Psychologically Fragile Children*. Ottawa: The Author, 1995.

Canadian Association for Community Living (CACL). *Don't Exclude our Children*. Toronto: The Author, 2001a.

Canadian Association for Community Living (CACL). *Building a National System of Family Support: A Shared Responsibility. Preliminary Framework*. Toronto: The Author, 2001b.

Canadian Association for Community Living (CACL). *Translating Needs into Policy Directions: A Community Paper*. Winter, 2002.

Canadian Coalition for the Rights of Children (CCRC). *The UN Convention on the Rights of the Child: How Does Canada Measure Up?* Ottawa: The Author, 1999.

Canadian School Boards Association. *Social Inclusion: The Role of School Boards*. Ottawa: The Author, 2001.

Canadian Council on Social Development (CCSD). *The Progress of Canada's Children*. Ottawa: The Author, 2002.

Canadian Council on Social Development (CCSD). *The Progress of Canada's Children*. Ottawa: The Author, 2001a.

Canadian Council on Social Development (CCSD). *Disability Information Sheet No. 3*. Ottawa: The Author, 2001b.

Canadian Council on Social Development (CCSD). *Housing Canada's Children*. Ottawa: Canadian Mortgage and Housing Corporation, 2000.

Canadian Institute of Child Health (CICH). *The Health of Canada's Children*. 2nd Edition. Ottawa: CICH, 1994.

Canadian Institute of Child Health (CICH). *The Health of Canada's Children*. 3rd Edition. Ottawa: CICH, 2000a.

Canadian Institute of Child Health (CICH). *Children and Youth With Disabilities*. Ottawa: The Author, 2000b

Canadian Institute of Child Health (CICH). *Report on the Consultation on Childhood Disability Surveys*. Prepared on behalf of Human Resources Development Canada. Ottawa: The Author, 2001.

Canadian Policy Research Networks (CPRN). *Services for Children with Special Needs in Canada: A Report Prepared for the CACC and Health Canada*. Ottawa: The Author, 1997.

Canadian Policy Research Networks (CPRN). *Enabling Citizenship: Full Inclusion of Children with Disabilities and their Parents*. Ottawa: The Author, 2001.

Campaign 2000. *Putting Promises Into Action: A Report on a Decade of Child and Family Poverty in Canada*. Toronto: The Author, 2002.

Centre of Excellence for Children and Adolescents with Special Needs. *Revised Proposal*. February, 2002.

College of Family Physicians of Canada. *Our Strength for Tomorrow: Valuing our Children: Report on Child Health*. <http://cfpc.ca>, 1997.

Children and Youth Homecare Network (CYHN). Submission to the Commission on the Future of Health Care in Canada. Ottawa: The Author, 2002.

Children with Disabilities. *Child and Family Canada Home Page*. <http://www.cfc-efc.ca>, September 6, 2002.

Crawford, Cameron. *Learning Disabilities in Canada: Economic Costs to Individuals, Families and Society*. Prepared for the Learning Disabilities of Canada by the Roeher Institute, 2002.

Demas, Doreen. *One Voice: The Perspectives of Aboriginal People with Disabilities*. Assembly of Manitoba Chiefs.

Doherty Social Planning Consultants Ltd. *Family Support Services for Children who are Physically Disabled, Sensory Impaired, Brain Damaged, or Medically Fragile*. Ottawa: The Author.

Douglas J. *The Impacts of Policy on the Health and Well-being of Women Raising Children with Disabilities*. Toronto: Canadian Association for Community Living, 2001.

Federal/Provincial/Territorial Advisory Committee on Population Health. *The Opportunity of Adolescence: The Health Sector Contribution*. Ottawa: The Author, 2000.

Fraze, Catherine, *Thumbs Up! Inclusion, Rights and Equality as Experienced by Youth with Disabilities*. Toronto: Laidlaw Foundation, in press.

Freiler, Christa. *Understanding Social Inclusion*. Toronto: The Laidlaw Foundation, 2002.

Gibson Kierstead, Angela and Hanvey, Louise. *Special Education in Canada*. Perception. 25(2): 10-12. Ottawa: Canadian Council on Social Development, 2001.

Hanvey, Louise. *Children and Youth with Special Needs*. Ottawa: Canadian Council on Social Development, 2001.

Hertzman, Clyde. *Leave No Child Behind! Social Exclusion and Child Development*. Toronto: The Laidlaw Foundation, 2002.

Hoffman, John. It Takes All Kinds. *Today's Parent*, December 2002/January 2003.

Home Based Care for Medically and Psychologically Fragile Children. *Child and Family Home Page*. <http://www.cfc-efc.ca>. September 6, 2002.

Irwin S. *Including All Children*. Child and Family Canada Website. <http://www.cfc-efc.ca>, 2002.

Irwin S, Lero D, and Brophy, K. *A Matter of Urgency: Including Children with Special Needs in Child Care in Canada*. Nova Scotia: Breton Books, 2000.

Irwin S and Lero D. *In our way: Childcare barriers to full workforce participation experienced by parents of children with special needs – and potential remedies*. Sydney, NS: Breton Books, 1997.

Irwin Sharon Hope. *Integration of Children with Disabilities into Daycare and Afterschool Care Systems*. Ottawa: Health and Welfare Canada, 1992.

King, AJC; Boyce, WF; and King, MA. *Trends in the Health of Canadian Youth*. Ottawa: Health Canada, 1999.

Laidlaw Foundation, *Perspectives on Social Inclusion Working Paper Series*, 2002.

Landy, S and Tam KK. Yes, parenting does make a difference to the development of children in Canada. In *Growing Up in Canada: National Longitudinal Survey of Children and Youth*. Ottawa: Human Resources Development Canada and Statistics Canada, 1996.

Learning Disabilities Association of Canada (LDAC). *Full Inclusion is not in the Best Interest of Children with Learning Disabilities*. Discussion Paper only, 2002a.

Learning Disabilities Association of Canada (LDAC). *Fact Sheet: Statistics on Learning Disabilities*. Child and Family Canada Website. <http://www.cfc-efc.ca>, 2002b.

MacMillan, Harriet, Walsh, Christine, Jamieson, Ellen, Crawford, Allison, Boyle, Michael. *Children's Health: First Nations and Inuit Regional Health Surveys*, 2002.

McDonald RAJ. *To the People Who are Able: A Perspective on First Nation Children and Disability*. A Discussion Paper Prepared for the Assembly of First Nations Social Development Secretariat, 2000.

Lupart Judy L. *Students with Exceptional Learning Needs: At-Risk, Utmost*. Paper prepared for the Pan-Canadian Education Research Agenda Symposium: Children and Youth at Risk, Ottawa, 2000.

McCreary Centre Society. *Adolescent Health Survey: Chronic Illness & Disability Among Youth in BC*. Burnaby: McCreary Centre Society, 1994.

Nessner, Katherine. "Children with Disabilities". *Canadian Social Trends*. 19:18-20, Ottawa: Statistics Canada, 1990.

Oderkirk, Jillian. "Disabilities Among Children". *Canadian Social Trends*. 31:22-25, Ottawa: Statistics Canada, 1993.

People for Education in Ontario. *Elementary Tracking Report*. The Author, 2002.

Psychosocial Paediatrics Committee, Canadian Paediatric Society. "The Child with Multiple Impairments." *Paediatrics and Child Health*. 5(7): 397-402. Reference No. PP 2000-02. Canadian Paediatric Society Home Page. <http://www.cps.ca>, 2000.

Roehrer Institute. *As If Children Matter: Perspectives on Children, Rights and Disability*. North York: L'Institut Roehrer Institute, 1995.

Roehrer Institute. *Disability, Community and Society Exploring the Links*. North York: L'Institut Roehrer Institute, 1996.

Roehrer Institute. *Supported health planning: A model to assist people with disabilities and complex medical needs and their families in planning for community inclusion*. North York: L'Institut Roehrer Institute, 1998.

Roehrer Institute. *Labour force inclusion of parents caring for children with disabilities*. North York: L'Institut Roehrer Institute, 1999.

Roehrer Institute. *Beyond the limits: Mothers caring for children with disabilities*. North York: L'Institut Roehrer Institute, 2000a.

Roehrer Institute, *Count Us In: A Demographic Overview of Childhood and Disability in Canada*. North York: L'Institut Roehrer Institute, 2000b.

Roehrer Institute. *Finding a way in: Parents on social assistance caring for children with disabilities*. North York: L'Institut Roehrer Institute, 2000c.

Roehrer Institute. *Moving In Unison into action: Towards a policy strategy to improve access to disability supports*. North York: L'Institut Roehrer Institute, 2000d.

Roehrer Institute. *Toward an inclusive approach to monitoring investments and outcomes in child development and learning*. North York: L'Institut Roehrer Institute, 2000e.

Roehrer Institute. *When kids belong: Supporting children with complex needs – At home and in the community*. North York: L'Institut Roehrer Institute, 2000f.

Roehrer Institute. *Agenda for Action: Policy Directions for Children with Disabilities and Families*. North York: L'Institut Roehrer Institute, 2000g.

Roehrer Institute, *Effective Supports to Families: A Review of the Literature*. North York: L'Institut Roehrer Institute, 2001a.

Roeher Institute. *Linking Formal and Informal Disability Supports: A Review of the Literature*. North York: L'Institut Roeher Institute, 2001b.

Guarnieri, Albina and Godfrey, John. *Interim Report of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities*. Ottawa: Sub-Committee on Children and Youth at Risk of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities.

Statistics Canada and the National Day Care Research Network. *The 1988 National Child Care Survey Information Manual*. Ottawa: Statistics Canada, 1998.

Steele, C; Bortolussi, J; Healy, H; Jutai, J; and Kalnins, I. *Healthy Living for People with Disabilities*. Bloorview Children's Hospital Foundation, unpublished, 2000.

Torjman, Sherri. *Will the 'Children's Budget' Include Kids with Disabilities?* Ottawa: Caledon Institute of Social Policy, 1999.

Tremblay M and Willms JD. Secular trends in the body mass index of Canadian children. *Canadian Medical Association Journal*, 163(11): 1429-33, 2000.

Valentine, F. *Enabling Citizenship: Full Inclusion of Children with Disabilities and their Parents*. Ottawa: Canadian Policy Research Networks, 2001.

Voices for Children. *Children With Special Needs: Fact Sheet # 18*. Toronto: The Author, 2002.

Voices for Children. *Shrinking School Space Affects Children and Youth*. Toronto: The Author, 2002.

Willms, JD. *Vulnerable Children*. Edmonton: University of Alberta Press, 2002.