



DEBRA MAYER

## Disability and Inclusion: Changing Attitudes — Changing Policy

**A**s we move towards the end of the first decade of the 21<sup>st</sup> century, Canadian families continue to be stymied by the lack of a national early learning and care system, and policy makers continue to be confounded by the concept of a “rights based” rationale for children’s entitlement to early learning services separate from their parents employment status. This policy quagmire, detailed by others in this volume, is especially problematic for families raising children with special needs, defined by the OECD as “all children...who require additional public or private resources beyond those normally required to support healthy development. This definition includes children...who require additional resources because of exceptional gifts and talents, physical, sensory, cognitive and learning challenges, mental health issues as well as problems due to social, cultural, linguistic or family factors.”<sup>21</sup>

We require a fundamental shift in attitudes among our policy makers, funders and service providers to ensure that all children with disabilities and other special support needs have their rights guaranteed and respected, and have the supports they need to live, grow, and thrive in their families and communities. The concepts of inclusion, accessibility, and universality must be

enshrined within a national early learning and child care act that fulfills those commitments and legal requirements under the law.

How far off is that “shift”? And what is required in order for it to occur?

There is good recognition of the relationship between early childhood education and care and the concept of “social inclusion” for all children, including those with special support needs. Early learning services enhance children’s well being, development and prospects for life-long learning.<sup>2</sup> Friendly reminds us that this “...inclusive approach to children with disabilities requires alternative (not merely normative) ways of considering

developmental outcomes and learning.” Early learning services support children’s families in their ability to work, study and become included in society, and help to counter family poverty and marginalization. They are particularly

**Early learning services support children’s families in their ability to work, study and become included in society, and help to counter family poverty and marginalization.**

important for mothers of young children, especially those with disabilities, and contribute to equity of women as a basic citizenship right, and to the rights of children with disabilities as a fundamental social justice issue.

Despite the lack of a national early childhood learning and care system, the Canadian context for early childhood inclusion seems to be supported by legislation and conventions at both the national and international levels. Canada is of course a signatory to the UN Convention on the Rights of the Child whose Article 23 specifically addresses the human rights of children with a disability by promoting dignity and self-reliance and by facilitating the active participation of children with disabilities in their communities. Yet children with disabilities are frequently denied service by home care providers, child care centres, preschools, family resource programs, and other community supports for young families, for a variety of reasons, including lack of trained staff, attitude and bias, inaccessible spaces, and lack of professional resource consultation (such as speech therapists, physiotherapists etc).

So how then do children with disabilities fully participate in community-based early years programs when they are hard to find or afford? How do children with special needs receive maximum benefit from centres which are so poorly resourced that their programs are not physically accessible or not appropriate for the very children who would so benefit from their early intervention components? How do their families receive the supports they are seeking?

According to the Canadian Association for Community Living, families describe an accepting and inclusive community as one that provides leadership in valuing families and the roles they play; and one that recognizes that the responsibility for being included in the community does not rest with the family, the individual or disability and service organizations. CACL stresses that the community as a whole and its members share in this responsibility.

That kind of responsibility is framed by the 1st international human rights treaty of the 21<sup>st</sup> century, the UN Convention on the Rights of Persons with Disabilities (ratified by Canada on March 30, 2007). It recognizes that a *change of attitude in society* is necessary if persons with disabilities are ever to achieve equal status. As a result of ratification, we are now required to progressively work toward measures that ensure full citizenship for persons with disabilities. This of course includes children with special needs. Many Canadians believe that the change of attitude that will ensure full citizenship begins with children's entitlement to inclusive early learning programs.

In March 2007, Canada signed the Convention and indicated ratification would follow which will further require us to progressively work toward measures that ensure full citizenship for persons with disabilities. This of course includes children with special needs. Many Canadians believe that the change of attitude that will ensure full citizenship begins with children's entitlement to inclusive early learning programs.

So despite all the language about inclusion, access to inclusive early childhood education is not an entitlement for children with disabilities and is not mandated through federal government legislation (as it is in the U.S.). When the Organization for Economic and Cooperative Development (OECD) reviewed Canada's child care system, they witnessed some skilled exam-

ples of inclusiveness within public provision. However, according to the OECD (2004a), although Canadian provinces promote and mandate inclusion in the school system, there was no data available on children receiving additional resources at pre-primary level. They found that in the child care sector, data on children with special needs is even more rare, which suggests that legal rights to access and state investments in inclusion may be weak at this level. This makes involvement with early childhood services potentially difficult for families who have children with disabilities.<sup>4</sup>

SpeciaLink research confirms this observation, and we note it can be extremely difficult for parents to obtain appropriate child care for children with disabilities: staff lack training, buildings are not accessible and funding is lacking.

Further compounding the challenges faced by some parents of children with special needs is the complexity of funding and services from one province to another<sup>5</sup> or even one municipality to another. Most provinces and territories in Canada have some stated commitments to inclusion in their educational reforms and in some cases to their child care plans, but because we lack a universal system for early learning and care, policy responses are not uniform and the experience of a parent raising a child with autism in Vancouver can be very different from that of a similar family in Winnipeg or Toronto. Services for families in Northern Canada can be even harder to access and even less predictable.<sup>6</sup>

Beyond our concern about our children's right to inclusive early childhood learning where early intervention can be offered in a timely manner, consider for a moment the realities faced by their parents. In a time of increasing labour shortages, it is ironic that a significant subset of the Canadian population — one that is eager and ready to work — is doubly ghettoized. Few of us can imagine the extraordinary struggle these parents face in juggling work, family and child care and how they are often denied opportunities to participate in the workforce. International research confirms that those parents who are able to work often do so below their skill level and capacity, because of their need to find work compatible with the requirements of caring.

Over the years, SpeciaLink has heard from a single mother in Whitehorse who had to leave a training program that would

have brought her economic self-sufficiency, because the local child care program could not deal with the catheterization needs of her child and there were no health resource personnel available to the early childhood program. A northern community lost its only doctor because that community could not meet the special needs of his child. In 2005, CBC TV News covered the challenges faced by a parent of a child with cerebral palsy who searched for two years before finding a spot for her child at the preschool centre in Fredericton, N.B.<sup>7</sup>

Canadian research shows that an estimated 10% of children have special needs requiring some level of additional supports and/or consultation and training to assure full participation in community based, “regular” programs. The Government of Canada’s current policy to transfer funds directly to parents via the universal child care benefit (\$100 per month) negates the unique needs of children with disabilities and their families and puts the onus of responsiveness upon an under-resourced child care community. Without very specific direction to community groups and governments to meet the national and international commitments previously outlined, the needs of these families and their children are unlikely to ever be met.

As an organization with national reach, we have been tracking this issue for well over a decade. In 1997, we published *In Our Way: Child Care Barriers to Full Workplace Participation Experienced by Parents of Children with Special Needs — And Potential Remedies*.<sup>8</sup> This provided us with the opportunity to work collaboratively with the disability and child care communities and with employee and employer groups to profile and address the issue of workforce barriers for parents of children with special needs.

This study was the first in Canada that documented how employed parents of children with special needs — estimated to comprise 6% to 10% of children in Canada — juggle work and family responsibilities. Most parents in the paid workforce face challenges balancing work and family responsibilities. But for mothers of children with special needs, the juggling act also

**In a time of increasing labour shortages, it is ironic that a significant subset of the Canadian population — one that is eager and ready to work — is doubly ghettoized.**

## OUR SCHOOLS/OUR SELVES

involves economic penalties in the form of extra expenses and foregone employment income, as well as added stress because of inadequate child care, workplace and social supports. We found that a significant percentage of parents were either unemployed, underemployed or worked part time because of the demands of their child's disability or health condition.

Eighty-eight percent of parents said they felt tired and overloaded, and 90% said they were stressed about balancing work and family obligations. A major cause of stress was the lack of access to appropriate, affordable licensed child care.

Many parents in dual-earner families reported working opposite shifts to provide economic stability and meet the special needs of their child. But they had little time for themselves or as a couple. As well, they were often exhausted, especially those working regular night shifts, whose daytime child care responsibilities left little time for sleep. Mothers' employment was far more likely to be affected by their children's needs for care and support, and the extra logistics of balancing work and family responsibilities. "It takes a long time to feed her and dress her because of her cerebral palsy," said one parent. "Then, after school, which ends at 2:30, she really requires a lot of tutoring and extra help from me, if she's going to keep up at all. I never get enough sleep."

Sadly, more recent Canadian research<sup>9</sup> paints a similar picture of the negative impact played by the presence of a child with a disability on the economic status of the family. In 2001, Statistics Canada in the Participation and Activity Limitation Survey (PALS) found that almost one-third of these families (31%) reported that one parent had turned down a job in order to take care of the child. 23% reported that one parent quit their job to care for the child and 26% of families reported that in the 12 months prior to the conduct of PALS, there were financial problems as a result of the child's condition. While dual wage earner families have become the norm in Canada, this is often not an option for many families with children with disabilities. Almost two out of 10 families (19%) reported that one parent quit work to care for the child and 34% reported that one parent had to reduce the number of hours worked because of these caring responsibilities. For 18% of families, there were financial problems reported in the 12 months prior to the conduct of PALS as a result of their child's condition. Furthermore, for 64% of two-

parent families with a child with a disability, one parent had to leave the labour market to care for their child, 40% of parents with children with disabilities found themselves only able to work at reduced hours, and over 70% passed up promotions.<sup>10</sup>

So what happens to these families and their ability to care for their own children? Is welfare the answer? British research of unemployed families raising children with disabilities shows that welfare benefits did not adequately compensate for loss of earnings and the extra costs associated with disability. The earnings thresholds on benefits, combined with the difficulties in sustaining secure but flexible work, trapped many families in poverty. The British research team confirmed that lack of opportunity to work results in personal and financial hardship and increase stress for parents and more recently have taken steps to evolve their child and family policy accordingly.<sup>11</sup>

Many other studies have examined the effect of family caregiving responsibilities on maternal workforce participation, and the relationship between child care services, maternal workforce participation and work/family balance. Existing research often uses gender-neutral terms, which may obscure women's primary role in caregiving and hide the high costs they bear. Of even concern is that mothers in atypical family situations — those who are “mothering at the margins” — are even more likely to be invisible within the data that is collected (Garcia Coll, Surrey & Weingarten, 1998). We do know that mothers of children with disabilities face greater care-giving tasks, making them more likely to stay out of the paid labor market. Statistics Canada reports that mothers most often experienced such impacts on their employment situations. For example, of the 84,000 children aged five to 12 whose family's employment situation was affected, seven out of 10 reported that the mother experienced such impacts because of the child's condition. According to PALS, approximately 20% of parents of preschool children report having been refused child care due to their child's disability.

SpeciaLink's research shows that turning children away based on “disability” still appears to be one of the accepted forms of discrimination in Canada and this forms the basis for our work to promote a zero reject policy in Canadian early learning and care programs.<sup>12</sup> A primary focus for us has been upon the training expectations we have for early childhood educators

which has some significant gaps when it comes to preparing staff for the task of creating inclusive settings. The Child Care Human Resource Sector Council (2007) states that providing an

**Specialink recommends the federal government develop policies that affect availability and access of inclusive early learning programs for children with special needs and their families.**

inclusive environment for children with disabilities requires a workforce with appropriate developmental training, understanding and support but at least 1/3 of graduating students do not feel well enough prepared to work with children with special

needs.<sup>13</sup> American evidence similarly suggests that early childhood professionals may not be adequately prepared to serve young children with disabilities enrolled in inclusive programs. So the training barrier is a profound one which must be addressed to assure better outcomes for children.

Building on the OECD comparison of Canada to other wealthy countries, Specialink recommends the federal government develop policies that affect availability and access of inclusive early learning programs for children with special needs and their families. We believe that building the capacity of communities is essential to meeting the needs of children and families and this is where the federal government must resume a leadership role both in developing policy and as a funder. At the provincial and program delivery levels, we encourage ministry budgetary increases to meet the extra costs of the appropriate inclusion of children with special needs. These should include a focus on the education/training requirements for director and staff related to inclusion; the resources to provide additional trained staff beyond ratio as needed; resources allocated for in-service training and on-going support to centre; staff and regulated home child care providers; and the monitoring of adequacy of resources, including caseloads of resource consultants and their responsiveness to requests for help from the community. All jurisdictions must do a better job at collecting data and planning and funding accordingly.

When inclusive child care *is* available, it allows both mothers and fathers to continue to work, which can be crucial to meeting disability-related expenses and to the mother's economic and psychological well-being, both in the short term and the long

term.<sup>14</sup> Furthermore, when their children attend inclusive early years programs with typically developing children, all learn at the youngest of ages about our inclusive, welcoming society. The OECD team confirmed that “Apart from the human rights perspective (Article 23, Convention on the Rights of the Child), additional costs for special needs children in early education are more than recuperated through downstream savings on special education units, remedial teaching and social security.”<sup>15</sup> Children with disabilities need to be able to grow to be able to work and be contributors to the society that is helping them care for their children. A focus on inclusion in the early years provides one of the best returns any Canadian can hope for.

\* \* \*

**Debra Mayer, MA**, is Director of SpecialLink, the National Centre for Child Care Inclusion, located at the University of Winnipeg, where she also teaches ECE leadership courses.

## ENDNOTES

<sup>1</sup> Organization for Economic and Cooperative Development, 2000. *Statistics and Indicators on Students with Learning and Behaviour Difficulties and Disadvantage*, Paris: Author.

<sup>2</sup> Martha Friendly, (n.d.) *A New Way of Thinking? Towards a Vision of Social Inclusion*. Social inclusion through early childhood education and care. (<http://www.ccsd.ca/subsites/inclusion/bp/mf.htm>).

<sup>3</sup> From OECD – Early Childhood Education and Care Policy: Canada Country Note – October 2004, chapter 5 recommendations.

<sup>4</sup> Llewellyn, G., Thompson, K., & Fante, M. (2002). *Inclusion in early childhood services: ongoing challenges*. Australian Journal of Early Childhood, 27(3), 18-23.

<sup>5</sup> Campaign 2000, 2003. *Diversity or Disparity? Early Childhood Education and Care in Canada (ECEC) Provincial and Territorial Responses to Inclusion*.

([http://www.campaign2000.ca/ci/issue/SocialInclusion\\_ISSUE.pdf](http://www.campaign2000.ca/ci/issue/SocialInclusion_ISSUE.pdf))<sup>6</sup> Judi Varga-Toth, 2006. *Meeting the Needs of Children and Adolescents with Special Needs in Rural and Northern Canada: Research Report F | 54*, Family Network, Centre of Excellence for Children & Adolescents with Special Needs Summary Report of a Roundtable for Canadian Policy-Makers.

## OUR SCHOOLS/OUR SELVES

<sup>7</sup> [http://www.cbc.ca/news/background/daycare/canada\\_snapshot.html](http://www.cbc.ca/news/background/daycare/canada_snapshot.html)

<sup>8</sup> <http://www.specialinkcanada.org/books/inourway.html>

<sup>9</sup> Government of Canada, Statistics Canada, 2002 Participation and Activity Limitation Survey, 2001  
(<http://www.statcan.ca/Daily/English/030729/d030729b.htm>)

<sup>10</sup> National Union of Public and General Employees, n.d. *An Anti Poverty Agenda for Persons with Disabilities, Equality Fact Sheet 3.*

<sup>11</sup> *Caring to Work: Accounts of working parents of disabled children.* Carolyn Kagan, Suzan Lewis and Patricia Heaton, The Family Policy Studies Centre, Joseph Rowntree Foundation, York, UK, 1998.

<sup>12</sup> Bulletin of the Child Care Human Resources Sector Council. Spring 2007  
(<http://www.ccsccssge.ca/english/pdf/research/2007/CCHRSCspring07-final.pdf>)

<sup>13</sup> National Professional Development Center on Inclusion. (2007). Research synthesis points on early childhood inclusion. Chapel Hill: The University of North Carolina, FPG Child Development Institute, Author.

<sup>14</sup> Government of Canada, 2007. Chapter 9: Young Children with Disabilities, in *The Well Being of Canada's Children.*  
([http://72.14.205.104/search?q=cache:597ev3k18F8J:www.socialunion.ca/well\\_being/2007/en/chapter\\_9.shtml+child+disability%2Bworking+mothers&hl=en&ct=clnk&cd=20&gl=ca&client=firefox-a](http://72.14.205.104/search?q=cache:597ev3k18F8J:www.socialunion.ca/well_being/2007/en/chapter_9.shtml+child+disability%2Bworking+mothers&hl=en&ct=clnk&cd=20&gl=ca&client=firefox-a))

<sup>15</sup> OECD – Early Childhood Education and Care Policy: Canada Country Note – October 2004.