

# Specialink

..... THE NATIONAL CENTRE FOR CHILD CARE INCLUSION



## Background

**Specialink:** The National Centre for Child Care Inclusion works to expand the quality and quantity of opportunities for inclusion in child care, recreation, and other community settings, for young children with special support needs and their families. Since our founding in 1989, we have put researchers, trainers, policy makers, parents, early childhood educators and centre directors in touch with the best inclusive practices on the frontlines of child care. As such, we address services, systems and policies related to our goals and our focus is on capacity development and knowledge exchange. Specialink has contributed to the research, the policy debate and the training of child care staff on strategies and practices that makes inclusion of children with special needs a more common reality. Specialink utilizes an inter-disciplinary, cross-sectoral approach that includes participants and stakeholders from research, training, policy, disability organizations, related service providers, child care professionals and parents themselves.

We are regularly invited to strategy meetings held by various organizations and government departments and are frequently invited to serve on task-groups and committees. In turn, we use the expertise of these various stakeholder groups and their ongoing feedback to continue to fine-tune and evaluate our strategies and products. We welcome their advice about real-world problems regarding inclusion in child care. Our name recognition is a drawing card across Canada — attracting attention to our products, training, consultations and workshops. Over 200 agencies, college and university programs, and centre-based professionals have already contacted us for pilot versions of our most recent resource, ***The Specialink Child Care Inclusion Practices and Principles Scales*** (Irwin, 2005) and over 2000 early childhood professionals have personally taken our training that teaches them to improve their quality/inclusion efforts. There is now growing interest in train-the-trainer/leadership institutes to further our impact and reach. The first of these was offered collaboratively with the University of Winnipeg and Community Living Manitoba in July 2006.

Specialink operates a resource centres (books, videos, journals, assessment tools) and shares its resources Canada. There are approximately 6000 items (videos, books, journals, kits, vertical files, etc) related to child development, childcare, inclusion, disability, and policy in this comprehensive resource centre which is in the process of being relocated to the University of Winnipeg.

Specialink works cooperatively with provincial and territorial governments and the federal government on the development of and enhancement of inclusive child and family social policy. We are pleased to provide recommendations to the House of Commons Standing Committee on Finance pre-budget consultation process by addressing the specific questions posed and demonstrating the role that inclusive high quality child care services can play in supporting children with disabilities and their working parents. No other organization speaks for children with special needs and their families, or for the way the lack of child care for children with special needs has a huge impact on the work and training possibilities for the children's families. In our presentation and companion brief, we will weave in real stories about real Canadians who have been in touch with Specialink over the years, telling us their stories, and asking us for help.

We understand the theme of these consultations is "Canada's Place in a Competitive World" and so we will also try to contextualize our remarks by making international social policy comparisons on the indicator of disability. Where children with special educational needs are concerned, the Organization for Economic & Cooperative Development (OECD) that reviewed Canada's childcare system witnessed in Canada some skilled examples of inclusiveness within public provision. However, according to OECD (2004a), data on provision of service to young children with special needs is not readily available or even tracked by many jurisdictions, which suggests that legal rights to access and state investments in inclusion may be weak at this level.<sup>1</sup>

**1. What specific federal tax and/or program spending measures should be implemented in the upcoming budget to ensure that our citizens are healthy, have the right skills, etc. for their own benefit and for the benefit of their employers?**

In a time of increasing labour shortages, it is ironic that a significant subset of the Canadian population – eager and ready to work – is doubly ghettoized. 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 the community could not meet the special needs of his child...

Children are our youngest of citizens--and the most vulnerable--and of these young citizens, children with disabilities may be the most vulnerable of all. On their behalf, Specialink has worked at getting municipal councils to support access and transportation for children with special needs, at getting school boards and teachers to welcome our children into the regular classroom, getting

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<sup>1</sup> From OECD - Early Childhood Education and Care Policy: Canada Country Note - October 2004, chapter 5 recommendations

child care centres to strive for affordable quality child care with the kind of flexible hours parents of children with special needs require so that they can join the workforce, participate in education and training, or involve themselves in the community in other ways.

Similarly, SpecialLink lobbied hard when the Liberal Party of Canada first started to talk about their QUAD principles for early learning, because the notion of “inclusion” was significantly missing. We counted it as a great success when the **U** in QUAD became “*universally inclusive*” because we felt the needs of children with disabilities and their parents would finally begin to be a factor in the development of policy and programs.

SpecialLink was pleased that the Conservative Government’s 2006 Federal Budget delivered on commitments made to persons with disabilities in the 2005 Federal Budget, but we were also greatly dismayed by the cancellation of the bilateral agreements for early learning and child care effective March 31, 2007. We call upon the federal government to ensure that Budget 2007 includes a broad comprehensive disability strategy that moves past tax measures and concentrates on program expenditures. Beyond the focus on the universal child care benefit and the undefined nature of the space creation initiative, the needs of children with disabilities may once again be overlooked without very specific direction to community groups and governments, such as that which was articulated, province by province, and captured within their bi-lateral agreements with the Government of Canada.

While we appreciate the important policy goal of offering families direct financial support to help raise their preschool children, Canadian research shows that an estimated 10% of children have special needs that require some level of additional supports and/or consultation and training to assure their full participation in community based, “regular” programs. Extra money for their parents is just not enough.

Canadian and international research confirms the extraordinary struggle these parents face in juggling work, family and child care. Their 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). We know that children with disabilities have never been at the top of the list when political spending decisions are made, and that as a result, their parents are regularly denied opportunities to participate in the workforce. International research confirms this conclusion, noting 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.

As such, Specialink was encouraged that the bi-lateral agreements on early learning and child care had commitment by all 10 provincial and federal governments to public reporting through specific indicators and measures for inclusion of children with disabilities. Similarly, we want to see the same kind of rigorous accountability that tracks the outcomes of the current Government's policy decisions tracked as well, particularly on these indicators:

- The number of children with special needs in child care programs
- Evidence of children with a range of needs and levels included
- Number of centres accepting children
- Reduced incidence of children with special needs being turned down
- Higher retention ... No Expulsion
- Inclusive quality indicators and quality improvement over time, as a condition of funding for spaces and operations

### **Funding and financing recommendations**

The OECD team confirmed long waiting lists exist in community services in several jurisdictions in Canada, including those centres that accept children with special needs. Their recommendation was to substantially increased funding of services to young children. Most OECD countries have already done so, and within the last ten or twenty years, have greatly increase their investments in ECEC system building. For example, in the UK since 1998, the child care budget has more than doubled. Significant budgetary increases have also been envisaged to meet the extra costs of appropriate inclusion of children with special needs into mainstream education.

We fear that without the leadership of the federal government on the rights of children with disabilities, congruent with our Charter of Rights and Freedoms and Article 23 of the UN Convention on the Rights of the Child, any progress made towards more inclusive early learning and care opportunities for families raising children with special support needs will be lost.

We believe that we must prioritize investments in building an inclusive children's public policy agenda in order to meet the social development needs and aspirations of children with disabilities and their families. While we absolutely support the responsibility of the provinces and territories in the delivery of child care services and agree that a one-size-fits-all strategy will not work; disability crosscuts all income groups and is life-long. Our research shows that turning children away based on 'disability' still appears to be one of the accepted forms of discrimination in Canada and will be further discussed under question 3.

**2. What specific federal tax and/or program spending measures should be implemented in the upcoming budget to ensure that our businesses are competitive?**

In 1997, Dr. Donna Lero of Guelph University and Dr. Sharon of SpecialLink, the National Centre for Child Care Inclusion published **In Our Way: Child Care Barriers To Full Workplace Participation Experienced By Parents Of Children With Special Needs -And Potential Remedies**, a Canadian national study on workforce barriers for parents of children with special needs. Since then, we have worked collaboratively with the disability and childcare community and with employee and employer groups to profile this issue.

All parents in the paid workforce face challenges balancing their work and family responsibilities. But for parents of children with special needs, the juggling act also 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. The study was the first Canadian research on how employed parents of children with special needs, estimated to comprise 6 to 10% of children in Canada, juggle work and family responsibilities. It was sponsored by the Canadian Union of Postal Workers.

The researchers surveyed 151 postal worker and non-postal worker families across Canada whose children have special needs. They 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.

- 39% reported their employment status had been affected;
- 26% reported that their choice of occupation had been constrained;
- 46% said their work schedules had been affected;
- 68% had turned down overtime;
- 27% had to forego opportunities for promotion; and,
- 64% of two-parent families with one parent unemployed reported their child's special needs were a major factor in the unemployment.

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.

Moreover, 88% 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. Typically, children were cared for by parents or a caregiver in the child's own home, and parents had few backups in case a child care arrangement ended or broke down temporarily. Parents also worried about whether the caregiver or program could be flexible when needed, the high cost of care, and whether the care provided was the best for the child.

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.

"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."

The postal workers union commissioned the study after a needs assessment of its members revealed that child care for children with special needs was a major issue. The shift work, extended hours and weekend work at the Post Office magnify the child care challenges faced by traditional "9 to 5" workers. The union feels that negotiated workplace supports are critical to help parents in the workforce meet their family and work obligations.

Dr. Irwin confirmed that they originally thought "that the postal worker parents and those in the reference group would be very different. But there were lots of parents in the reference group who also worked back shifts, split shifts, left regular jobs and had to opt for non-traditional employment arrangements to meet their child's needs."

### **A variety of supports needed:**

The study shows that while parents of children with special needs face the same problems as other employed parents, the intensity, availability, cost and duration of their child care needs are different. Parents said they needed a mix of flexibility, services and support to help them cope, including:

- formal workplace policies and benefit provisions, such as extended health plans to cover additional expenses for their children's special needs;
- paid special leave for emergencies and paid family responsibility leave, since many parents use their sick or vacation leave, or take unpaid leave for emergencies, or when their child is ill or has a medical appointment;
- flexibility in schedules and workload;
- stability in work scheduling for temporary or casual workers to help them plan child care;
- assistance with child care provision and child care costs; and,
- increased awareness and sensitivity of employers, unions, co-workers and the public to the challenges of parenting a child with special needs.

Parents also expressed fears about losing already fragile community-based resources because of government cuts to social programs. These cuts threaten

the access of children with special needs to therapy, assessments, medications and assistive devices.

The study recommends the development of progressive public policies to help parents juggle family and work. These policies include a comprehensive national child care program, promotion of employment and pay equity, and honouring ILO conventions on the rights of workers with family responsibilities to equitable treatment in the workplace, and equitable treatment of persons with disabilities.

Dr. Donna Lero concluded that "The basic child care issues parents face in today's social and economic climate, and the additional challenges faced by parents of children with special needs, require much more than ad hoc solutions. We need strong, comprehensive family-supportive policies that help all families in Canada meet their work and family obligations."

Specialink encourages the federal government to measure the inclusivity of their child and family social policy decisions to ensure these family realities are finally addressed.

### **3. What specific federal tax and/or program spending measures should be implemented to ensure that our nation has the infrastructure required by citizens and businesses?**

British research<sup>2</sup> 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 as described earlier have taken steps to evolve their child and family policy accordingly.

Sadly, Canadian research<sup>3</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 found that almost one-third of these families (31%) reported that one parent had not taken 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 for many families with children with disabilities, this is often not an option for a family with a child with special needs. Almost two out of ten families (19%) reported that one parent quit work to care for the child and 34% report that one parent had to reduce the number of hours worked because of these caring responsibilities. For 18% of families, there were

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<sup>2</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>3</sup> Government of Canada, Statistics Canada, 2002 Participation and Activity Limitation Survey, 2001

financial problems reported in the 12 months prior to the conduct of PALS as a result of their child's condition.

For 64% of two-parent families with a child with a disability, one parent has to leave the labour market to care for their child, 40% of parents with children with disabilities find themselves only able to work at reduced hours, and over 70% pass up promotions.<sup>4</sup>

We all understand and appreciate the value played by child care and school not only as educational settings for children but also as an employment support to their families, yet the gaps in services are not as well understood. The OECD team recommended that Canada should “in so far as possible, include children with special educational needs in public early development/ education service.” The team pointed out that 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. SpecialLink research confirms this observation, and we note it can be extremely difficult for parents to obtain appropriate child care for children with disabilities, since staff lack training, buildings are not adapted, and funding is lacking. Building on the OECD comparison of Canada to other wealthy countries, SpecialLink recommends the federal government develop:

- **Policies that affect availability & access for children & parents**

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 continue its leadership role in developing policy and as a funder. For example, while the Federal Government’s proposed community investment fund will offer a \$10,000 credit to businesses or community groups that establish programs, our research shows that \$20,000 per space is required for initial start up costs, and that ongoing operating costs for children with disabilities requires a sustained \$20,000 annually per space.

- **Policies that ensure all programs are physically accessible with design features appropriate for care**

We encourage your government to set aside specific dollars for capital investments for accessible programs. Since accessibility and physical structure are so closely related to both inclusion quality and global quality, all new centres must be purpose built to meet current standards, and older centres must be eligible for capital grants to increase accessibility. Federal ‘retro-fitting’ grants to

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<sup>4</sup>An Anti Poverty Agenda for Persons with Disabilities, Equality Fact Sheet 3, NUPGE, n.d.



existing programs should not be counted as new space creation, but tracked separately as infrastructure support.

At the provincial and program delivery levels, we encourage policies that support

- Education / training requirements for director & staff related to inclusion
- 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
- Monitoring of adequacy of resources, including caseloads of resource consultants, responsiveness

Chairperson of the House of Commons Standing Committee on Finance, Honourable Brian Pallister can certainly confirm that here in Manitoba, our provincial government has been able to announce and then begin to fund these kinds of very specific inclusion goals within its proposed infrastructure-the action plan for our ELCC investments. Without the federal funds to the provinces to implement these plans, what guarantees will any of us have that these policy goals will be met?

**4. What specific federal actions should be taken to ensure that the government is able to afford the tax and/or spending measures needed to ensure that Canada's citizens and businesses can prosper in the world of the future?**

Over the years, SpecialLink has appeared in front of many different taskforces and committees. In the 1980's, we were mainly talking about the doubly ghettoized mothers of children with special needs who wanted to be in the paid workforce, but could not find adequate child care. A generation later, and Canada faces an escalating labour shortage and child care is part of the social architecture and infrastructure that is sorely missing. Many parents of children with special needs want to and/or need to work. Their employers need them. 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." There are obvious paybacks to our taxation system through all of these outcomes. Children with disabilities need to be able to grow up with viable optimistic futures, as do all Canadian children. Their parents want to be able to work and be contributors to the society that is helping them care for their children. A focus on the early years provides one of the best returns any investor can hope for.

## **Conclusion**

The prioritization of children with disabilities in the federal government's social policy goals for Canadian families must be meaningful and contribute to lasting, life-long patterns of inclusion. As such, we call upon the members of this House of Commons Standing Committee on Finance to recommend that the Government of Canada honour the spirit and intention of the ten bi-lateral agreements on Early Learning and Child Care, made with all ten Canadian provinces, who agreed on shared role and authentic support to the youngest citizens of Canada and their families. We particularly call upon you to act as champions for children who so assuredly deserve our efforts to create and sustain an inclusive and welcoming community and to help remove the many employment barriers faced by their families. Thank you for allowing us to share our most sincere and long lasting vision of how we will get there together—beginning in the early years.