BC Healthy Child Development Alliance

Special Needs Planning Group

Principles, Policy and Practice:

Supporting Children with Special Needs in British Columbia

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Additional information sources included: a planning symposium, a focus group on school inclusion, key informant surveys and interviews. The goals of the *Symposium for Children with Special Needs: BC Healthy Child Development Alliance* in Vancouver, BC, November, 2007 was to: 1) reflect on and discuss the major challenges impacting young children (i.e., age 0 to 6 years) and families with special needs in BC with other researchers, educators, medical specialists, leaders, parents and advocates in the field of child development; 2) learn and discuss what improvements, enhancements, and entitlements are needed for assisting and supporting these children and their families; and 3) describe the key features that needs to be incorporated in a policy position paper for presentation to the BC Healthy Child Development Alliance and the Provincial Government. The participants included:

Lorraine Aitken, , Supported Child Development Program, Provincial Advisor
Jane Blaine, Learning Disabilities Association of BC
Dana Brynelsen, Infant Development Program of BC, Provincial Advisor
Linda Clarkson, BC Aboriginal Child Care Society
Diana Elliot, Aboriginal Infant Development Program, Provincial Advisor
Alanna Hendren, Developmental Disabilities Association
Jill Houbé, BC Research Institute for Children's & Women's Health
Cyndi Gerlach, Parent
Hillel Goelman, The CHILD Project, Human Early Learning Partnership (HELP) UBC
Michael Guralnick, Center on Human Development and Disability, University of Washington
Christine Loock, UBC Pediatrics
Adrienne Montani, First Call
Jean Moore, First Call (CMHA)
Mari Pighini, HELP/CHILD/UBC
Jayne Pivik, HELP/CHILD/UBC
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Glenda Prkachin, BC ACDI & UNBC
Maureen O'Donnell, Children's & Women's Health Centre & Ministry of Health
Bruce Sandy, BCACDI, Provincial Advocate
Naznin Viri-Babul, Down Syndrome Research Foundation
David Wu, CHILD/HELP/UBC
Anat Zaidman-Zait, UBC
Susan Lane, BC Early Hearing Program, BC Family Hearing Resource Centre

Focus group members came from the following organizations: Aboriginal consultant, BC Centre for Ability; Burnaby Supported Child Development Program; Richmond Supported Child Development Program; Richmond Society for Community Living; Nechako, Stuart & Lakes Districts, Bulkley Valley and Hazeltons Area, Supported Child Development Program; Treehouse Early Learning Centre for Richmond, Society for Community Living (integrated school- 3-5 yrs.); Kindergarten teacher for students with visual impairments, Victoria, BC. Key informant surveys and interviews related to family and community based supports were conducted with parents, early childhood educators, interventionists and health professionals.

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The views, opinions and conclusions from this report are the sole responsibility of the author and do not necessarily reflect those of the BC Healthy Child Development Alliance

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Executive Summary

This review aims to examine best practices, both nationally and internationally, for children with special needs (CSNs) related to legislation, integrated systems of care, family support systems, physical and social inclusion, service provider and health professional support and cultural inclusion. These areas relate to a series of principles identified by participants from the *Symposium for Children with Special Needs: BC Healthy Child Development Alliance* in Vancouver, BC, November, 2007. Each of these principles were critically examined based on current practices or policy (or lack of) available from the scientific literature, governmental legislation, institutional briefs or position papers. From this examination, a series of recommendations are presented to support children with special needs in British Columbia. These include:

- **Recommendation 1:** Institute Legislation and a Policy Framework for Children with Special Needs that allows British Columbia to fulfill its commitments to the vision of equality and equitable access identified by Canada and the United Nations Convention on the Rights of the Child (1989).

  An integrated approach to adequately addressing our international and national commitments to CSNs is recommended that includes “rights based standards” enshrined in legislation and a “policy framework” that outlines priorities supporting the legislation. Like the United States *Individuals with Disabilities Education Act,* enacting legislation for CSNs will ensure access to services, create processes and procedures for those services and provide a safeguard for standards regardless of the government in power. The supporting policy framework would provide the opportunity to examine and revise existing services, acquire public consultation and develop an integrated system of care plan.

- **Recommendation 2.** Develop an integrated system of care plan for children with special needs that incorporates early identification and care, is family-centered, includes a coordinated and collaborative network with a single point of entry, and addresses the needs of the child from birth to 19 years.

  Essential to this system of care plan would be the need for a cross-departmental (family and child services, health and education) collaboration to address the entire spectrum of needs. Best practices indicate that an integrated service delivery system be family-centered, community-based, integrated, collaborative and inclusive. A coordinated and streamlined service system will provide access to all levels of care, from specialized tertiary care to general community based programs, in order to meet the needs of a broad range of children with special needs and their families. Continuity of services from birth to 19 years will address current transitional difficulties as the child ages and develops. Finally, a single point of entry will address duplication of services and assist coordination for multiple support services.

- **Recommendation 3.** Include in the system of care plan, programs and services that support families; ensuring availability and access to respite care, child care, information and special needs training for caregivers.

As the move toward community based care for CSNs increased, the burden for coordinating care and support also increased for families. Current reviews have shown that families need financial, physical and emotional support such as available and accessible day care, respite care opportunities and information about resources and services within their communities.

- **Recommendation 4.** Adopt the International Classification of Functioning, Disability and Health for Children and Youth *(*ICF-CY, *WHO, 2007)* guidelines for evaluating community-based barriers for children with special needs and develop inclusion plans to be integrated in British Columbia's Policy Framework for Children with Special Needs.

The need for supports within communities is recognized as an important factor influencing the physical and social inclusion of CSNs. The ICF-CY is an internationally agreed upon classification system for assessing the health of children and youth in the context of their developmental stage and the environments in which they live. Current research points to the need to address inclusion in schools, daycare centers, and public places such as parks and recreational centres.

- **Recommendation 5.** Develop, fund and evaluate best practice models that promote competency, interdisciplinarity and academic-community based education training for all individuals working with CSNs, focusing on actions which support recruitment and retention.

  To function properly, the system of care plan requires support for service providers and health professionals in the areas of education, training, funding, recruitment and training. Attention must be paid to all roles involved in providing services, ensuring the adequate availability of and funding for: physiotherapists, occupational therapists, speech language pathologists, therapy aides, social workers and behavioural interventionists and those involved in the diagnosis, assessment and development of supported community, school and home based programs. Interdisciplinary educational training that supports collaborative problem solving is recommended. Collaborations between academic and community based service organizations is vital.

- **Recommendation 6.** Ensure that all legislation, policy frameworks and practices specific to children with special needs are culturally safe, appropriate and relevant.

  Sensitivity to the cultural and linguistic requirements of children, families and communities is necessary. Learning from and working with individuals from a variety of cultures in developing the legislation, policy framework and integrated service delivery plan is essential for a Canadian solution that addresses the current systemic difficulties and gaps confronting CSNs and their families.

  These recommendations are ambitious but if implemented will place British Columbia as a world leader in complying with The United Nations International Convention of Rights of the Child and Canada’s stated values while providing the opportunity for children with special needs to develop to their full potential.

Background

The BC Healthy Child Development Alliance is a coalition that includes policy makers, academics, researchers, as well as other coalitions and associations of health professionals, child development and child care professionals and educational professionals. The Alliance aims to inform the development and implementation of policy that will promote the healthy development of infants, children, and youth in BC. After a provincial forum on healthy infant and early child development held in November, 2004, the Alliance was formed in response to the need for a steward of the work of the forum and the recommendations arising from the forum.

The Alliance aims to bring a focus on prevention, health promotion, and the early years and to enable and support the healthy development of all children in BC. Part of this work involves the need to develop the essential elements of a provincial framework for the early years, including key actions required to implement the framework. Some essential elements for an early years framework have been identified, including the need for:

- Good prenatal education, support, and care for women to ensure that all infants are born healthy;
- Accessible and quality child care for families;
- Early identification, intervention, and support for children and families with special needs;
- Accessible health promotion and prevention activities, including strategies to reach out to families with limited income and with diverse language and cultural backgrounds;
- Community- and neighbourhood-based planning and delivery of early childhood services;
- Promotion of physical, social, emotional, cognitive, and communication skills that are necessary for healthy child development and learning;
- An Aboriginal early child development plan;
- Collaborative planning and actions to develop shared, long-term, sustainable goals and an integrated, coordinated system for program delivery; and
- A systematic, long-term approach to monitoring and evaluating outcomes.

Current gaps in the system for children with special needs

A sub-committee of the Alliance was stuck to examine the impact of the current system for children with special needs (CSNs). This subcommittee used the following definition of CSNs:

> *Infants and young children with special needs include those children and their families who require additional specialized resources, intervention, and support because of the presence of a single or multiple, identified childhood developmental delay(s) or disability(ies). This could include an established condition or diagnosed disability that may persist over time and may prevent or limit participation in age-appropriate activities due to problems in function in one or more of the following areas: physical, cognitive, sensory, learning, communication, social and emotional, or behavioural.*

To examine the gaps in the system, the British Columbia Healthy Child Development Alliance Special Needs Planning Group held a symposium in 2007 with a large number of stakeholders supporting CSNs, including service providers, parents, and researchers. The systematic gaps identified for CSNs at this forum included:

1. The lack of a provincial strategic plan for addressing the unique needs of CSNs.
2. A service delivery system that is fragmented, system orientated (vs. child needs-based), provides uneven access, does not support transitions, and is not properly funded.
3. Excessive waitlists and wait times for services.
4. Lack of early screening and support for children with learning disabilities.
5. Lack of a coordinated case management system.
6. Insufficient training opportunities for professionals dealing with CSNs.
7. Recruitment and retention problems affecting professionals dealing with CSNs.
8. Poor informational support system for families.
9. Insufficient qualified child care for CSNs.
10. Lack of adequate funding, requiring service providers to “fight for the same pot” and families needing to buy services privately.
11. Difficulties providing culturally appropriate services.
12. Non inclusive environments and access to programs for CSNs.
13. Reduced funding to special educational programs and services.

Statistics support these conclusions. The currently system for CSNs in B.C. is not addressing the needs of 52,000 children and their families with special needs under the age of 6 years; the 90,000 children and families with special needs who are school aged; the 5,000 children with special needs in care and the 6,000 CSNs on waitlists for early intervention services.[1]

Purpose

As well as identifying systematic gaps, a series of principles emerged from the British Columbia Healthy Child Development Alliance Special Needs Planning Symposium. The following is a summary of those principles:

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[1] Demographics identified by the BC Association of Child Development & Intervention (see http://www.bcacdr.org)

Principle 1. Legislation specifically addressing children with special needs is required in British Columbia to fulfill our commitment to the United Nations Convention on the Rights of the Child (UNCRC, 1989), ensure consistent support and address the specific requirements of children with special needs.

Principle 2. A comprehensive, inclusive and collaborative system of care is required for children with special needs in B.C. Particular support given for Michael Guralnick's principles associated with early intervention[2]:

1. Adopt a developmental framework that informs all components of early intervention system and centres on families.
2. Integration and coordination at all levels of the early intervention system is essential.
3. Inclusion of participation of children and families in typical community programs and activities are maximized.
4. Early detection and identification procedures are in place.
5. Surveillance and monitoring are an integral part of the system.
6. All parts of the system are individualized.
7. A strong evaluation and feedback process is evident.
8. It is recognized that true partnerships with families cannot occur without sensitivity to cultural differences and an understanding of their developmental implications.
9. There is a belief that recommendations to families and practices must be evidence-based.
10. A systems perspective is maintained, recognizing interrelationships among all components.

Principle 3. Programs and services that support families of children with special needs are required.

Principle 4. Community-based programs and services that support physical and social inclusion for families of children with special needs are required.

Principle 5. A plan supporting service providers and health professionals that addresses

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[2] Guralnick, M.J. (2001). A Developmental Systems Model for Early Intervention, *Infants and Young Children, 14*(2), 1-18.

education and training needs, recruitment and retention and associated funding support is required.

Principle 6. Ensure that the Legislation and Policy Framework for CSNs are culturally competent; building on the unique values, preferences, and strengths of children, families and their communities.

The purpose of this review was to examine each of these principles from an evidence-based perspective; using "best practice" examples both nationally and internationally. The review focused on peer reviewed scientific papers, governmental legislation, policy briefs and provincial/municipal internet descriptions of programs and services. Areas covered included: legislation, integrated systems of care, family support systems, physical and social inclusion, service provider and health professional support and cultural inclusion.

Review

Legislation

Principle 1. Legislation specifically addressing children with special needs is required in British Columbia to fulfill our commitment to the United Nations Convention on the Rights of the Child (UNCRC, 1989), ensure consistent support and address the specific requirements of children with special needs.

In Canada, we have identified and supported the "ideals" in which to address the welfare of our children with special needs. These include the rights to full citizenship, inclusion, health, well-being and education. Most notably, Canada ratified *The United Nations Convention on the Rights of the Child*[3] (UNCRC, 1989) along with all other countries in the world except Somalia and the United States. Specific for CSNs, we agreed that children in Canada have the right to: the highest standard of health care (Article 24); the right for disabled children to enjoy life and participate actively in society (Article 23); the right to a standard of living adequate for the child's physical, mental, spiritual, moral

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[3] *United Nations Convention on the Rights of the Child* (see http://www.ohchr.org/english/law/pdf/crc.pdf)

and social development (Article 27); and finally, the right for children to express views freely and to be listened to (Articles 12 and 13).

> *"We will take all measures to ensure the full and equal enjoyment of all human rights and fundamental freedoms, including equal access to health, education and recreational services, by children with disabilities and children with special needs; to ensure the recognition of their dignity; to promote their self reliance; and to facilitate their active participation in the community"* Article 23, UNCRC

From an educational perspective, Canada also adopted *The Salamanca Statement* [4] (UNESCO, July, 1994), agreeing that: 1) " Schools should accommodate all children regardless of their physical, intellectual, emotional, social, linguistic or other conditions"; and " Regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all".

As well, in May, 2002, Canada signed the United Nations Declaration entitled *A World Fit for Children*[5]*,* where we agreed to develop a national action plan to ensure that Canadian children get the best possible start in life by supporting the physical, psychological, spiritual, social, emotional, cognitive and cultural development of children as a matter of national and global priorities" (Plan of Action Signatories to the United Nations General Assembly Special Session on Children, May 2002).

Canada has responded to these international conventions in a number of ways. In response to the *Convention on the Rights of the Child*, the federal government initiated the *Early Childhood Development Agreement*[6], developed to address the conditions of risk for children in the earliest stages of life. The principles guiding this initiative include: prevention, promotion, protection and partnership and are focused on integrated community-based initiatives supporting healthy child development.

As well, the *National Children's Agenda*[7] was initiated in 1997, whose focus was to serve as an action plan for ensuring that our children develop to their full potential as healthy,

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[4] *The Salamanca Statement* (see http://unesdoc.unesco.org/images/0009/000984/098427eo.pdf)

[5] *A World Fit for Children* (see http://www.unicef.org/specialsession/wffc/)

[6] *Early Childhood Development Agreement* (see http://www.socialunion.gc.ca/ecd/toc_e.html)

[7] *National Children's Agenda* (see http://www.socialunion.ca/nca_e.html)

successful and contributing members of society. One specific result of this initiative was the establishment of five Centres of Excellence for Children's Well-Being, whose mandate was to enhance the understanding of and responsiveness to the physical and mental health needs children up to age 18 years. The *Centre of Excellence for Children and Adolescents with Special Needs*[8] was established in 2000, with a focus on CSNs in rural and northern Canada. During the first five years, this Centre worked on the areas of nutrition, substance abuse, learning, communication and mental health. The Centre's focus on information dissemination, community collaboration and partnerships and a focus on Aboriginal children have been highlighted as achievements to date [9].

Canada's and B.C.'s legislation and policy addressing CNS are embedded in childhood initiatives associated with education, early learning and care and health. However, CSNs are rarely mentioned beyond statements related to inclusion. For example, Human Resources and Social Development Canada introduced the *Multilateral Framework for Early Childhood Development* [10] in 2003 which identified guiding principles for supporting young children. These include early learning and child care services that are: available and accessible, affordable, quality-based to promote development, supports parental choices and are inclusive. The principle specific for CSNs states:

> *Early learning and child care should be inclusive of, and responsive to, the needs of children with differing abilities; Aboriginal (i.e. Indian, Inuit and Métis) children; and children in various cultural and linguistic circumstances. Examples of initiatives that support inclusiveness could include special needs programming and supports, and culturally and linguistically appropriate resources and training.*

More recently, acknowledgement of additional supports needed for families that have children with severe disabilities or require financial support has been identified. In response to the *World Fit for Children*, the federal government released *A Canada Fit for Children*[11] (2004); a national action plan for supporting families and communities, promoting healthy lives, protection from harm and the promotion of education and learning. This document recognizes the additional burdens for families of CSNs in

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[8] *Centre of Excellence for Children and Adolescents with Special Needs* (see http://www.coespecialneeds.ca/?display=home)

[9] Varga-Toth, J. (2006). *Meeting the needs of children and adolescents with special needs in rural and northern Canada: Summary report of a roundtable for Canadian policy-makers.* Canadian Policy Research Networks Inc. and Centre for Excellence for Children & Adolescents with Special Needs. See http://www.coespecialneeds.ca.

[10] *Multilateral Framework for Early Childhood Development* in 2003 (see http://www.socialunion.ca/ecd-framework_e.htm)

[11] *A Canada Fit for Children* (see http://www.hrsdc.gc.ca/en/cs/sp/sdc/socpol/publications/2002-002483/canadafite.pdf)

relation to potential economic disadvantages and associated developmental risks. It outlines some of the tax benefits provided for families of children with severe disabilities and those in low to modest income brackets as well as details provincial efforts to establish ministries specifically for children and families in order to coordinate policy development (e.g., B.C.'s Ministry of Child and Family Development).

> *Canadians believe that children with disabilities should have equity of access to programs and services that allow them to reach their full potential and participate as they wish in society, along with other Canadian children and young people. Canadians also recognize the particular challenges faced by parents of children with disabilities and the extra supports they may require.*
>
> *Article* 83, *Canada Fit for Children*

The federal government of Canada does not have legislation that authorizes a coordinated and integrated policy approach for all children with disabilities or special needs. According to Valentine (2001) in his policy review of services, policy and legislation for children with disabilities[12], "programs are the responsibility of, administrated by and funded through a variety of disjointed policy instruments and regulatory frameworks" (p. 4). Instability is also a concern. As Turner[13], in his review of legislation examining children's rights to services in Canada indicates, "during conservative political times, services shrinks along with the government's financial commitment to social, health and educational services" (p. 154).

However, this situation is changing in some provinces, although not yet in British Columbia. Most notably, Alberta has recently legislated the *Family Support for Children with Disabilities Act* (FSCD)[14] which addresses better coordination and integration of services, is family-centered, provides improved access to information, more family-focused supports and services and transitional support and services up to age 22. This comprehensive legislation was developed based on extensive stakeholder feedback including families of CSNs and with the understanding that the unique needs of children

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[12] Valentine, F. (2001). Enabling citizenship: Full inclusion of children with disabilities and their parents. *Canadian Policy Research Networks Discussion Paper No. F/13*. Available at http://www.cprn.org/cprn.html

[13] Children's Rights to Services in Canada," in David Turner and Max. R. Uhlemann, (2007). *A Legal Handbook for the Helping Professional*, Sedgewick Society for Consumer and Public Education, School of Social Work, University of Victoria, BC.

[14] Alberta's *Family Support for Children with Disabilities Act* (see http://www.child.gov.ab.ca/whatwedo/fscd/pdf/Parents-%20regulations.pdf)

with disabilities and special needs could not be adequately addressed within child protection legislation. This legislation has been supported with the *Policy Framework for Children and Youth with Special and Complex Needs and their Families*[15], released in 2003, and with funding for regional support coordinators, the development of an integrated case management system and the development of a toll-free support line providing callers with information on provincial and community supports and services. This legislation and policy framework is a stellar example of a government listening and responding to their constituents, using evidence-based best practices and following through with an integrated plan and funding support.

No other province has developed legislation specific for children and youth with disabilities or special needs. Quebec's *Youth Protection Act*[16] (1979) provides legislation that protects children and youths' rights to services. Specifically, "The child and the parents are entitled to receive, with continuity and in a personalized manner, health services and social services that are appropriate from a scientific, human and social standpoint, taking into account the legislative and regulatory provisions governing the organization and operation of the institution providing those services, as well as its human, material and financial resources" (Article 8).

Saskatchewan does not have legislation specific for CSNs but does have a disability action plan with an associated *Disability Inclusion Policy Framework*[17] that addresses supports for people with cognitive and developmental disabilities, home care respite, child day care, housing, transportation, physical accessibility, employment, and income support. Specific to children are initiatives related to child day care (see www.sasked.gov.sk.ca) through the department of education, the *Cognitive Disabilities Strategy* (see www.health.gov.sk.ca) through the department of health and a respite program for families with children with intellectual disabilities through the Community Living Division.

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[15] Alberta's *Policy Framework for Children and Youth with Special and Complex Needs and their Families* (see http://www.child.alberta.ca/home/documents/ministry/User-Friendly_Policy_Framework1.pdf)

[16] Quebec's *Youth Protection Act* (see http://www.canlii.org/qc/laws/sta/p-34/20051216/whole.html)

[17] Saskatchewan's *Disability Inclusion Policy Framework* (see http://72.14.253.104/search?q=cache:0QhiVIp7KicJ:www.cr.gov.sk.ca/publications/disability-framework.pdf+%22Disability+Inclusion+Policy+Framework%22&hl=en&ct=clnk&cd=1

The last province with legislation supporting individuals with disabilities or special needs is Ontario, although again, it is not specific for children. Ontario's strategy for improving the lives of persons with disabilities focuses on promoting inclusion. Identified as the *Accessibility for Ontarians with Disabilities Act, 2005,*[18] this legislation aims to achieve accessibility for Ontarians with disabilities with respect to goods, services, facilities, accommodation, employment, buildings, structures and premises on or before January 1, 2025, by developing, implementing and enforcing accessibility standards.

The only legislation that British Columbia has in relation to children with disabilities or special needs is the right for educational placement in integrated settings (*School Act*, Ministerial Order 150/89)[19] and the right for an individual education plan (*School Act*, Ministerial Order 638/95)[20] . According to the Ministry of Children and Family Development[21] (MCFD), their mandate is to: assist individuals and families in order to promote their healthy development, provide child protection, community living services, services for children with special needs, child and youth mental health, youth justice, and early childhood development programs and services. The mandate specific for CSNs is effected through the *Child, Family and Community Service Act* [22] and its associated regulation, although there are no "definitions of any concepts related to special needs or disabilities" and "the policies can be changed at any time without requisite public notification" (MacDonald, 2003)[23].

MCFD is responsible for developing and implementing policy and programs for CSNs. Their *Community Support Services Policy Manual* details the services that are provided

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[18] Accessibility for Ontarians with Disabilities Act (see http://www.mcss.gov.on.ca/mcss/english/pillars/accessibilityOntario/)

[19] Integrated Placement, *School Act*, Ministerial Order 150/89 (see http://www.bced.gov.bc.ca/legislation/schoollaw/e/m150-89.pdf)

[20] Individual Education Plan, *School Act*, Ministerial Order 638/95 (see http://www.bced.gov.bc.ca/legislation/schoollaw/e/m638-95.pdf)

[21] British Columbia's Ministry of Children and Family Development (see http://www2.vpl.vancouver.bc.ca/DBs/RedBook/orgPgs/3/3351.html)

[22] British Columbia's *Child, Family and Community Service Act* (see http://www.qp.gov.bc.ca/statreg/stat/C/96046_01.html

[23] MacDonald, M. (2003). *Children and adolescents with special needs: A review of provincial British Columbian and Canadian federal law and policy direction*. Centre for Excellence for Children and Adolescents with Special Needs, University of Northern British Columbia: Taskforce on Substance Abuse.

specifically for CSNs, including: at home and respite benefits, the Infant Development Program, child and youth care worker services, behavioral support for children with Autism, homemaker/home support worker program, parent support for families with children with special needs; and professional support for children with special needs. Funding is also provided by MCFD for the Associate Family Program; the Early Intervention Program; School-aged Therapy Services, Summer programs for the Blind and Deaf and the Community Brain Injury Program, typically through contracts.

MCFD is also responsible for child protection, residential care, guardianship, foster care, permanency and adoption planning for children and youth permanently in care, community child and youth mental health services, community youth justice services, and services to strengthen and preserve families.

This long list of responsibilities for MCFD, the distribution of funding and the lack of supporting legislation has negatively impacted CSNs. For example, the message from the Minister, Tom Christensen, in his description of the 2007/08-2009/10 Service Plan[24] mentions a new model for Aboriginal child and family services; child protection as a key ministry priority; early learning and care initiatives including ActNow BC and StrongStart BC; the development of a youth advisory council, the implementation of the B.C.'s Child and Youth Mental Plan and continued efforts with Community Living B.C. for services for the developmentally disabled. No mention is made of other types of special needs; however, the development of an integrated service plan that addresses all children is identified.

The Service Plan does mention CSNs as one of its great goals, specifically Goal 3, to "Build the best system of support in Canada for persons with disabilities, those with special needs, children at risk, and seniors" though the delivery of child welfare services; implementing the Child and Youth Mental Health Plan; many cross ministry initiatives; and in implementing initiatives to assist youth at risk.

According to *A Canada Fit for Children* (2004), "the role of government and society with respect to children is to provide the legislative and policy frameworks, the institutional and organizational structures, the fiscal and other supports and services to enable

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[24] MCFD's 2007/08-2009/10 Service Plan (see http://www.bcbudget.gov.bc.ca/2007/sp/cfd/default.aspx?hash=5)

families to ensure their children's healthy development " (p. 5). Volpe [25] in his review of provincial policies for children's services (education, health and social services) and children's rights indicates that Canada has not fully adopted all of the UNCRC conventions and suggests establishing legal mechanisms that specify how it intends to comply. A clear, centralized provincial focus of accountability, planning, funding and coordination for all services for children and youth with special needs is required.

Recommendation 1: Institute Legislation and a Policy Framework for Children with Special Needs that allows British Columbia to fulfill its commitments to the vision of equality and equitable access identified by Canada and the United Nations Convention on the Rights of the Child.

An Integrated System of Care

Principle 2. A comprehensive, inclusive and collaborative system of care is required for children with special needs in B.C.

Although MCFD has recognized the distinct needs of individuals with developmental disabilities, children diagnosed with Autism Spectrum Disorder and children eligible for the At Home program through the development of *Community Living British Columbia* and, the needs of children and youth with mental health issues through the development and implementation of the *Child and Youth Mental Health Plan*; children with all other types of special needs are incorporated within general children's initiatives. The systematic gaps identified earlier suggests the need for a service delivery plan specific for all children with special needs, where they are not competing for the same funding support.

As the *Canadian Coalition for the Rights of Children* found in their review of Canadian policy in relation to the UNCRC, "There is insufficient funding for the early diagnosis of children with disabilities and appropriate programs and services, such as child care,

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[25] Volpe, R., Cox, S., Goddard, L., & Tilleczek, K. (1997). *Children's rights in Canada: A review of provincial policies*. The Dr. R.G.N. Laidlaw Research Centre: University of Toronto.

early education and early intervention. These services are often treated as discretionary expenditures, rather than as rights, and are subject to elimination or cutbacks during times of fiscal restraint. There are often long waiting lists for health services impeding early diagnoses and appropriate therapeutic interventions. There are wide variations in the provision of services across Canada, often within provinces, and services may be subject to a means test" [26].

As it stands now, one of the 2007/08-2009/10 Ministry Service Plan goals of MCFD is the development of a fully regionalized model of governance and delivery of services. Although the integrated framework is not expected to be completed until the middle of 2008, Deputy Minister, Lesley du Toit, in her presentation at the BC Healthy Child Development Alliance Forum (Nov. 21, 2007), indicated that this system will be: integrated, coordinated, focused on the early years, be child centered, focused on the child in the context of family and his/her community, will use a developmental and strengths-based approach and will be supported across multiple years. These principles are laudable and based on best practices and research[27].

However, the service delivery needs of CSNs are distinctly different from children without special needs, as noted by other jurisdictions (e.g., Alberta) and countries (e.g., US, UK) who have service delivery policy frameworks specific for CSNs. According to Prelock and colleagues[28] "children with special needs and their families have complex resource, service and support needs" (p.36). They visit health professions more often and more are likely to visit a variety of different health professionals. Statistics from the *Canadian Council on Social Development*[29] using data from Statistics Canada's PALS, 2001[30], reported that 69.9 % of children with disabilities visit family doctors/general practitioners and 47.1 % visit other medical specialists on a monthly basis. Other health professions visited on a monthly basis included: speech therapists (9%), physiotherapists (5.3%), nurses (3.2%) and psychologists (4.5%). Fifteen and a half

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[26] Canadian Coalition for the Rights of Children (see http://www.rightsofchildren.ca/report/page16.htm)

[27] Harbin, G., McWilliam, R.A., & Gallagher (2000). Services for young children with disabilities and their families. In J. Shonkoff and S. Meisels (Eds.). *Handbook of Early Childhood Intervention*, (pp. 387-415). Cambridge: University Press.

[28] Prelock, P., Beatson, J., Contompasis, S., Bishop, K. (1999). A Model for Family-Centered Interdisciplinary Practice in the community. *Topical Language Disorders, 19*(3), 36-51.

[29] Canadian Council on Social Development (see http://www.ccsd.ca/drip /research/drip20/index.htm)

[30] These statistics were for children 15 years and under.

percent of children with disabilities had unmet needs for health care services (4.9% for speech therapists, 6.8 % for other health care professions). Reasons for these unmet needs included long waitlists (54.5%), cost (40%) and the lack of local access (34.1%).

Other relevant statistics from this report relate to the coordination of care for CSNs. Seventy-five percent of the time, the child's mother was cited as the individual who coordinated their child's care (making appointments, phoning, visiting health professionals). Difficulties with care coordination were reported for 1 in 5 CSNs; including: difficulty obtaining appointments (57.1 %), lack of local availability (39.2%), not enough time (50.6%), work conflicts (49.1%), lack of information (35.7%) and lack of coordination between health care professionals (36.1%)[31]

So what is the most effective system of care for CSNs? For the purposes of this report, a system of care is defined as a broad array of services and supports that is organized into a coordinated network, that integrates care planning and management across multiple systems and that builds meaningful partnerships with families at service and policy levels.

Regional coordination and integrated service delivery

CSNs typically require health, education and social service supports for optimal social inclusion. In B.C., this would require the networking and collaboration between the three ministry partners (MCFD, education and health), regional authorities and service providers. According to the Ministry of Social Development in New Zealand [32], who evaluated successful models of regional coordination and integrated service delivery, the key principles include:

- Clarity of purpose and function
- Relationships and information sharing
- Taking into account the local context
- Appropriate mechanisms and processes
- Governance, leadership and accountability

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[31] Individuals often reported more than one difficulty associated with coordination of care.

[32] Review of the Centre Integrated Service Delivery: Regional Co-ordination - *Final Workstream Report, NZ State Services Commission and the Ministry of Social Development,* July 2003. (see http://www.ssc.govt.nz/roc-isd-final-workstream-report)

In their *Final Workstream Report* (2003, p.5), regional coordination is defined as:

> "a multi-agency collaboration at a strategic level. Its purpose is to provide an overview of needs and activities in an area, and engage in forward planning and alignment of resources across a whole region, population group or cross-cutting issue. The principle mechanisms are networks, which are relatively informal groups which focus on relation-ship building and information sharing; and partnerships, which are more formal arrangements with a focused objective around the production of strategies, systems and services".

> Integrated service delivery "involves organizations working together at an operational level. Its purpose is to develop the delivery of services requiring the input of more than one agency, focused on specific local areas, client groups, communities, families or individuals. Three models of integrated service delivery are identified. These are case management approaches, "one-stop-shop" single access points for service delivery and joint-funded contract service provision" .

In their review of the international literature and through a series of focus groups with policy makers, community members and the voluntary sector, key lessons learned are that: 1) the type of integrated service delivery approach must be tailored to the needs of the community; "no one type fits all" ,with multiple approaches sometimes being needed; 2) a central governing body is needed to promote collaborative practices and develop best practice guidelines; 3) Open information sharing, joint consultation processes and clear accountability mechanisms for meeting objectives and representing local communities are required; 4) a process for client and stakeholder feedback is needed; and, 5) outcome evaluations need to be conducted.

As New Zealand's system[33] indicates, no one system is applicable to all instances but must have a central body directing policy and programs and plans that reflect the regional needs. Alberta's system of care for CSNs identified earlier, is an good example of central planning and support (an integrated, collaborative, coordinated plan that is supported by legislation, a policy framework and funding).

The following models are examples of the three different approaches to the delivery of coordinated care: 1) the agency-based service integration approach; 2) a

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[33] *Mosaics - Whakaahua Papariki: Key Findings and Good Practice Guide for Regional Co-ordination and Integrated Service Delivery, and Integrated Service Delivery and Regional Co-ordination: A Literature Review* (see http://www.msd.govt.nz/documents/publications/strategic-social-policy/mosaics.pdf)

system/sector-based service integration approach; and 3) the client/family-based service coordination approach.

Agency-based service integration approaches

The *Developmental Systems Model for Early Intervention* developed by Michael Guralnick[34] is a community-based model focused on research evidence and systematic service provision that addresses early identification and care. This model provides guidelines for communities to organize resource supports, social supports and information and services that support CSNs and their families. The following is a list of implementation recommendations based on this model:

1. Identify or develop a systematic screening and referral process by examining existing screening programs, high-risk registries and available tools.
2. Develop protocols for a monitoring program linked to specific risk categories for those children who do not meet above screening criteria but require further monitoring.
3. Develop an accessible directory of interventionists (interdisciplinary assessment groups, preventative intervention programs, those in general early intervention) that is communicated to professionals, undated regularly and allows tracking of children via a centralized database.
4. Ensure availability of professionals who can complete a comprehensive interdisciplinary assessment addressing the child's developmental profile, diagnostic/etiologic information and recommendations.
5. Establish eligibility criteria for entry into early intervention programs.
6. Develop an inventory of early intervention programs that assists in providing a quick coordinated delivery of services, assigns a case manager and allows the assessment of child and family stressors.
7. Identify preventive type programs for children at risk that are ideally linked to the early intervention programs.
8. Identify or develop a set of protocols, surveys or questionnaires that assess familial/child stressors related to information needs, interpersonal and family distress, resource needs and confidence threats.
9. Develop and implement an individualized comprehensive program based on above and linking resource supports, social supports and information and services. Create a process and set of decision rules guiding this plan. Include various transition plans for developmental milestones (e.g., starting preschool).
10. Develop a monitoring system and evaluation plan examining the system's efficiency, parent and professional satisfaction levels and child outcomes.

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[34] Guralnick, M.J. (2001). A Developmental Systems Model for Early Intervention, *Infants and Young Children, 14*(2), 1-18.

The strengths of this model are that it is developmentally based, focuses on early identification and care, addresses family strengths and needs, is geared to the child's individual needs and provides a systems approach that can be tailored to specific communities.

The Infant Development Program of British Columbia shares many of the same principles. Specifically, it delivers family-centered services for children aged 0-3 who are at risk for developmental disabilities, based on the following principles: that the early years are important, that early intervention can alleviate the impact of delay or disability, and that the family unit is essential to the healthy development of the child[35] . As Goelman and colleagues note, the emphasis on family dynamics, parental responsiveness to their children and their well-being, the commitment to the provision of integrated services and the decision-making, monitoring and evaluation of the efficacy of specific programs and interventions are prominent features of both models[36].

System/sector-based service integration approach

The *Children's Treatment Network of Simcoe York* is an innovative and new initiative that provides a one-stop-shop single plan of care service model for CSNs[37]. Funded by the Ontario Ministry of Children and Youth Services, the Children's Treatment Network is a not-for-profit service delivery model for children with multiple disabilities and their families in the Simcoe County and York region. Network services are available to children and youth with a wide range of disabilities and complex conditions, such as cerebral palsy, muscular dystrophy, acquired brain injury, development and learning difficulties, spina bifida, autism or pervasive development disorder (PDD), and chronic and/or long-term medical conditions that require intensive therapy, specialized equipment or travel to treatment centres outside the community. Services coordinated through the Network include: occupational therapy, speech and language therapy, physiotherapy, recreation therapy, social work, psychology, nursing, orthotics,

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[35] Brynelsen, D., Cummings, H. & Gonzalez, V. (1993). Infant Development Programs. In Ferguson, R., Pence, A. & Denholm, C. (Eds.) *Professional Child and Youth Care, Second Edition*. British Columbia: UBC Press, 162-187.

[36] Goelman, H., Brynelsen, D., Pighini, M.J., & Kysela, G.M. (2005). The Infant Development Program's Early Assessment and Early Intervention Model In British Columbia. In M.J. Guralnick (Ed.), *A Developmental Systems Approach to Early Intervention: National and International Perspectives*, (pp. 439-454). Baltimore: Paul H. Brookes.

[37] The Children's Treatment Network of Simcoe York (see http://www.ctn-simcoeyork.ca)

audiology, seating and mobility, feeding and swallowing, augmentative communications and any other additional medical and child development services.

Parents or health care professionals can call a toll-free number to access a coordinator and a repository of over 40 healthcare, recreation, educational, social and community services. Based on information received from the parent, the child and family are then assigned a team to develop an individualized plan of care that includes coordinated services. All children with multiple disabilities in Simcoe and York will have an integrated care plan developed with coordinated services and monitoring of progress through the use of shared electronic record over the next three years. Benefits associated with this system include:

1. A coordinated team approach
2. Services that are tailored to the needs of the child and his/her family
3. Services that are updated regularly to address local access issues
4. Tools, processes and systems that are being developed to provide a single plan of coordinated care
5. Provides services for children birth to 19 years to address developmental and transitional phases
6. Children's progress is monitored through the use of a shared electronic record
7. Additional health care professionals have been hired (70 to date) to address the demand, including: physiotherapists, occupational therapists, speech language pathologists, communication disorder assistants, developmental pediatricians, inclusive recreationists and service coordinators
8. Resource centres are being built in different areas of the region to provide access to integrated services, professionals and specialized equipment
9. Training is provided to assist in understanding the tools, processes and systems
10. The single point of access helps reduce the burden on families and service providers
11. The model and system is being evaluated by a local university to examine impact and effectiveness

An evaluation of the system indicated that after one year in operation, wait times were reduced. Network funding enabled partners were able to conduct an additional 19,000 therapy sessions for over 2,400 children in need of services, including: 1) 8,105 occupational therapy sessions; 2) 5,087 speech and language sessions; 3) 4,623 physiotherapy sessions; 4) 284 inclusive recreation sessions; and 5) 1,524 additional sessions conducted for dietician services, developmental diagnostic consultations, and service coordination.

Another model with a single point of contact for families is the *Key Worker Model of Service Delivery*. This system of care is prevalent in the United Kingdom as a result of statutory guidance from the *Children's Act* (1989)[38] and enacted through Children's Trusts. The key worker or care coordinator facilitates services across different systems (health, social services, education, financial resources, transportation, recreation); providing support, resources and information to meet the individual needs of the child. Support from the key worker is also family–centered and tailored to their informational and support requirements. As well, emotional support, encouragement and counseling is often provided to families by the key worker. According to a review of the literature by Drennan, Wagner and Rosenbaum (2003) of the *CanChild Centre for Childhood Disability Research*, McMaster University[39], general principles for facilitating this system of care include:

Service-Specific Principles:

The key worker service should :

1. Be family-centered rather than child-centered;
2. Be needs-led rather than service-led;
3. Entail a flexible, individualized approach;
4. Be a formalized program so it is recognized by professionals/practitioners across all agencies;
5. Be evaluated, monitored, and able to adjust to meet needs;
6. Include an overall Service Coordinator (i.e., to coordinate key worker services);
7. Be supported by a multi-agency steering committee; and
8. Have buy-in and ownership from management for longevity and maintenance of the program.

Role-Specific Principles:

To support and empower key workers appropriately, the role should include:

1. Clearly defined job descriptions outlining roles, responsibilities, and limitations;
2. Protected time for the service, regardless of whether it is full-time or otherwise; and
3. Adequate support and training.

Key workers should : 1) be accountable to the family, not perceived as working for an agency; and 2) be a single contact, able to work across agencies.

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[38] UK's *Children's Act* (see http://www.england-legislation.hmso.gov.uk/acts/acts1989/Ukpga_19890041_en_1.htm)

[39] CanChild Centre for Childhood Disability Research, McMaster University (see http://www.canchild.ca/Default.aspx?tabid=130)

Client/family-based service coordination approach

Another system of care approach for CSNs is exemplified in the *Model for Family-Centered Interdisciplinary Practice in the Community*[40]*.* Developed by the Vermont Interdisciplinary Leadership Education for Health Professionals Program, this system blends training, family-centered services and academic-community collaborations to develop best practices. The interdisciplinary training component is comprised of advanced graduate students, postdoctoral fellows or professional level community fellows in medicine, nursing, physical therapy, speech-language pathology, psychology, nutrition, public administration and education working together in conducting community-based assessments and consultations. The principles of the community-based assessments and consultation process include: 1) the intake process comprised of family and provider interviews; 2) where the assessment takes place (in the home or the child's community); and 3) how the information is shared (interdisciplinary reports, community follow-up meetings and resource books).

The intake process typically involves a referral from a special educator or pediatrician to the clinical coordinator of the program. A family interview then takes place in the child's home or within their community and is centered around the questions and issues the family has concerning their child's needs. Following this, the referral source, school service coordinator and primary health care provider are contacted and interviewed by phone. Team members then use observations, interviews and record reviews to try and understand the child's needs within different contexts in the community (his/her school, home, playground, etc.). This information is then reviewed by the interdisciplinary team and three outputs are provided to the child's family and current service provider: 1) an interdisciplinary report; 2) a community-based follow-up meeting to address questions raised, review recommendations and develop an action plan; and 3) a resource notebook containing pertinent articles and recent research related to the child's diagnosis or challenges, handouts on intervention strategies, and contact information for services or resources. The information is tailored to the families knowledge base and skills. This entire process is led by a care coordinator (often the trainee) who organizes the teams, makes connections and plan the community consultation and assessment.

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[40] See Prelock, P., Beatson, J., Contompasis, S., & Bishop, K. (1999)- Ibid

The entire process includes an evaluation component focused on all of the individuals involved, including the trainees, care team, families, and service providers. The advantages to this model include: a strengths-based ecological approach, family-centered care, interdisciplinary teaming and collaboration, a training component and cultural competence.

The examples of different models provided above reflect the three major approaches to the delivery of coordinated care: 1) The system/sector-based service integration approach (Children's Network, UK system and key worker model); 2) the agency-based service integration approach (Developmental Systems Model for Early Intervention, US; Infant Development Program, B.C.); and 3) the client/family-based service coordination approach (Model for Family-Centered Interdisciplinary Practice in the Community*).*

According to King and Meyer (2006)[41] who reviewed the different approaches in relation to CSNs, these three approaches reflect different perspectives and purviews and attention to all three in the development of a framework will enhance the likelihood that services in a community will be integrated and coordinated. For example, a model which combines elements of all three approaches and is particularly useful in rural and northern communities is the inter-sectoral service delivery model "*Hook and Hub*" which combines early childhood care and development programs. See Figure 1 (pp. 39-40 for a description).

Accountability is an important feature to also consider. According to Dawn Steele, the parent of 14-year old with Autism Spectrum Disorder and a member of several Vancouver-based and provincial parent support/advocacy groups and networks, "we need prompt, easy and well-advertised channels to access an ombudsman/advocate who can intervene on a case by case basis and help families having trouble accessing services or not satisfied with the services they are receiving. This 'complaints' system should also have a clear mandate to work supportively within the system to identify and fix the roots of the complaint and systemic issues that may underlie it".[42]

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[41] King, G. & Meyer, K, (2006). Service integration and co-ordination: a framework of approaches for the delivery of coordinated care to children with disabilities and their families. *Child Care, Health & Development, 32*(4), 477-492.

[42] Interview, Dawn Steele on September 14, 2007.

Recommendation 2. Develop an integrated system of care plan for children with special needs that incorporates early identification and care, is family-centered, includes a coordinated and collaborative network with a single point of entry, and addresses the needs of the child from birth to 19 years.

Family Support Systems

Principle 3. Programs and services that support families of children with special needs are required.

The *Canadian Coalition for the Rights of Children* in their review of Canadian policy in relation to the UNCRC[43] also reported that "There has been a shift in recent years away from institutional care to providing services in the community. This has led to a growing number of children with disabilities living at home with their families. These families may require professional home care, respite care, income supports, child care and enhanced parental leave. Often, families do not receive adequate assistance and frequently find themselves financially, physically and emotionally exhausted by efforts to care for their children".

Financial Support

The lower income of parents with CSNs has been reported widely and relates to the costs associated with treatment and care and difficulty finding appropriate child care. For example, *The Canadian Institute of Child Health* in their latest profile, report that 30% of children under the age of 12 years with a disability fell into the lower two income quintiles and were at a slightly elevated risk of experiencing food insecurity (running out of money to buy food).[44] *The Canadian Council on Social Development,* in their report on the needs and gaps for children with disabilities reported that about a third of parents

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[43] Canadian Coalition for the Rights of Children (see http://www.rightsofchildren.ca/report/page16.htm)

[44] *The Canadian Institute of Child Health* (see http://www.cich.ca/PDFFiles/ProfileFactSheets/English/DisabilitiesEng.pdf)

of children with disabilities (over 50,000) require assistance with the costs related to their child's daily activities and 73% report these needs go unmet[45].

Irwin and Lero (1997)[46] conducted a national Canadian study on workforce barriers for parents of CSNs. They found that the demands of their child's health condition or disability resulted in a significant percentage of parents being either unemployed, underemployed or working part-time. Stress from trying to balance work and family obligations affected 90% of the sample, with 88% reported feeling tired and overloaded. Parents also reported a fear of losing already fragile community-based resources because of government cuts to social programs such as access to therapy, assessments, medications and assistive devices.

This study also examine the availability of inclusive child care programs. According to the authors, 53% of parents indicated that available programs could not accommodate their child's needs, 54% indicated they were too expensive, 69% reported too few trained and committed care givers for their children's needs and 71% indicated difficulty in finding appropriate child care. Recommendations from the study included developing progressive policies to assist parents of CSNs such as a national child care program and the promotion of employment and pay equity.

The *Canadian Coalition for the Rights of Children* recommended the following action item: "Additional assistance and financial help are needed to meet the extra needs of children with disabilities and to support their families, regardless of family income. This may include augmented maternity and parental leave policies, income support, respite care, child care options or training"[47].

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[45] *The Canadian Council on Social Development* (see http://www.socialunion.ca/pwd/title.html)

[46] Irwin, S.H. and Lero, D. (1997). *In Our Way. Child Care Barriers to Full Workforce Participation Experienced by Parents of Children with Special Needs - and Potential Remedies.* BretonBooks: Nova Scotia.

[46] The Canadian Coalition for the Rights of Children- Ibid

Informational Support

Another area of support needed for families is information about their child's condition, development and community-based resources. Gowen looked at the type of information parents of CSNs want and how they want it presented[48] . Parents were interested in information about how they could help their child adjust, build their self-confidence, enhance learning and academic skills and develop imagination. Parents were also interested in discipline issues, how to deal with the emotional aspects of parenting a child with special needs, community resources that they might access and their child's legal rights. Interventionists and teachers were the preferred choice for information about teaching children and finding community resources. Reading materials were identified as the best method for receiving information about communities and finances. As this study was conducted prior to the abundance of information available on the Internet, further research is needed on desired informational sources.

There is evidence that parents are capable of identifying difficulties or developmental delays and that relevant prescreening tools should be made available to them. For example, Glascoe [49] found that parental concerns about their child's motor, language, global cognition and school performance was 79% accurate when compared to psychological assessments.

Providing information to families about community resources, barriers for social exclusion and tools for prescreening (as well as training for service providers) are the objectives of a new initiative, *the Social Inclusion Project*, developed in concert with Social Development Canada, the University of British Columbia's Human Early Learning Partnership and The Infant Development Program of British Columbia [50]. According to the information listed on their website, the following will be available to professional community workers, parents and all interested and contributing members of each community within B.C.'s lower mainland (although funding is being sought to expand it throughout B.C.): 1) A website with a links/information of existing programs and resources; chat rooms where parents and community workers and professionals can

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[48] Gowen, J. (1989). *Informational needs of parents of young children with special needs: Technical report.* Handicapped Children's Early Education: Washington, DC

[49] Glasscoe, F. (1997). Parents' concerns about children's development: Prescreening technique or screening test? *Pediatrics, 99* (4), 522-528.

[50] Social Inclusion Project (see http://www.earlylearning.ubc.ca/sdpp.htm)

post/exchange information and share their experiences (links to translate information in several languages); 2) A resource book available to the community compiling existing services/programs available through the different agencies (available in several languages); 3) Electronic and print materials to assist parents of vulnerable children to be aware of early signs of vulnerability and how to contact appropriate early identification and intervention agencies; 4) Electronic and print materials to educate parents, professionals and community agencies on ways of identifying and reducing barriers to social inclusion; 5) Electronic and instructional materials to assist in the professional training of early intervention specialists in a variety of modalities (e.g., classroom instruction, practicum placements, distance education.); 6) Electronic and instructional materials to inform child care professionals, preschool and elementary school teachers about the nature and consequence of early vulnerabilities and their implications for classroom practice; and 7) Translation of materials (online and electronic translations to other languages prevalent in the community: Chinese, Vietnamese, Punjabi, Spanish, Arabic –available for parents and for community agencies/schools that provide services/instruction in these languages.

Not only is information being provided to parents, professionals and community members (with sensitivity to different languages), it also addresses awareness and training, provides an opportunity for parents to connect and provides advice on how to contact resources and services. Once fully functional, this program’s educational and informational benefits could serve as a model for other jurisdictions.

Recommendation 3. Include in the system of care plan, programs and services that support families; ensuring availability and access to respite care, child care, information and special needs training for caregivers.

Physical and Social Inclusion

Principle 4. Community-based programs and services that support physical and social inclusion for families of children with special needs are required.

In October 2007, The World Health Organization released the first internationally agreed upon classification code for assessing the health of children and youth in the context of their stages of development and the environments in which they live. The *International Classification of Functioning, Disability and Health for Children and Youth* (ICF–CY)[51], reflects a bio-psychosocial conceptualization of health that highlights the role of the environment as a crucial determinant in functioning and development, where access restrictions have a negative impact. Simeonsson and colleagues[52] recommend that the ICF be used as a universal standard to evaluate and realize the rights of children with disabilities under the UNCRC.

Harkness and Super[53] describe the influence of the environment on children's health status as the 'developmental niche'; composed of: 1) the physical and social environment (natural and built environments, social and cultural practices); 2) child rearing and child care customs; and 3) the values and beliefs that define parenting practices. This review will focus on the first aspect, specifically inclusion in the child's community, schools/day care, and access to programs and services.

As indicated earlier, families who have a child with a disability are more likely to live in poverty and must deal with inaccessible community/neighbourhoods, child care and schools. Park et al. (2002)[54] in their review of the environmental effects associated with poverty for children living with disabilities found that they were more likely to reside in overcrowded, unclean and non-functioning homes, e.g., with contaminants such as lead or no heat. Further, children living in poverty were more likely to experience unsafe neighborhoods (i.e., crime, violence, drugs) and are less likely to use local sport and leisure facilities (Finch et al., 2001)[55].

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[51] *International Classification of Functioning, Disability and Health for Children and Youth* (ICF–CY) see http://www.who.int/mediacentre/news/releases/2007/pr59/en/index.html

[52] Simeonsson, R.J., Leonardi, M., Lollars, D., Bjorck-Akesson, E., Hollenweger, J. & Martinuzzi, A. (2003). Applying the International Classification of Functioning, Disability and Health (ICF) to measure childhood disability. *Disability and Rehabilitation, 25* (11-12), 602-610.

[53] Harkness, S. & Super, C.M. (1994). The developmental niche: A theoretical framework for analyzing the household production of health. *Social Science & Medicine, 38*, 217-226.

[54] Park, J., Turnbull, A., & Turnbull, H. (2002). Impacts of poverty on quality of life in families of children with disabilities. *Exceptional Children, 68*(2), 151-167.

[55] Finch, N., Lawton, D., Williams, J. & Sloper, P. (2001). *Disability Survey 2000: Young* People with a Disability and Sport. London: Sport England.

Physical inclusion

Inaccessible communities and neighborhoods are also barriers. The physical barriers noted most often include: steep ramps, uncut curbs, uneven steps or surfaces, heavy doors and one-inch thresholds[56, 57]. Other reported environmental barriers for children with disabilities are noise and stress levels impacting balance and difficulties associated with access and physical reaching[58].

Inaccessible schools and day care centers are a particularly salient issue for children with disabilities considering the amount of time spent in these environments. Even after 30 years of educational reform (e.g., The Individuals with Disabilities Education Act in the US and the Canadian Charter of Rights and Freedoms in Canada), schools and day care centers that have CSNs are still riddled with accessibility and attitudinal barriers[59],[60],[61]. For example, in a review of 109 schools in Ontario, Canada, the average number of accessibility barriers in schools with students with disabilities was 20, whereas schools without students with disabilities had 23 barriers [51].

As Goelman and colleagues found in their report, *You Bet I Care!* [62]*,* high quality child care is impacted by the level and quality of education and training that early childhood educators receive. According to Crowther[63], less than half of the CSNs in Canada have access to an inclusive child care setting, in part due to the lack of legislation making it illegal to exclude CSNs, insufficient and inconsistent funding to support these children, inaccessible facilities and the lack of appropriate staff training.

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[56] Hutchinson, T. & Gordon, D. (2001). *Towards nationally useful definitions of disability: Final Project Report.* NHS Research and Development*:* Maternal and child health indicators. London: Department of Health.

[57] Law M. & Dunn W. (1993). Perspectives on understanding and changing the environments of children with disabilities. *Physical and Occupational Therapy in Pediatrics*, 13(3), 1-17.

[58] Hutchinson, T. & Gordon, D. (2001).- Ibid

[59] Pivik, J. (2005). The effect of role and salience on inclusive environmental assessments. *Doctoral Dissertation:* University of Ottawa, ON, Canada.

[60] Pivik, J., McComas, J., & Laflamme, M. (2002). Barriers and facilitators to inclusive education as reported by students with physical disabilities and their parents. *Exceptional Children, 69* (1), 97-106.

[61] Valentine, F. (2001). Ibid.

[62] Goelman, H., Doherty, G., Lero, D., Lagrange, A. & Tougas, J. (2000). *You Bet I Care! Caring and Learning Environments: Quality in Child Care Centres Across Canada.* Guelph, ON: Centre for Families, Work and Well-being, University of Guelph.

[63] Crowther, I. (2006). *Inclusion in early childhood settings: Children with special needs in Canada.* Toronto, ON: Pearson/Prentice Hall.

To evaluate the participation levels for CSNs, an examination of environmental contexts is needed. Capacity inventories describing environmental factors typically focus on different types of buildings, availability of recreational areas and green space, evidence of crime, and a general description of the environment such as crowding, noise levels, and street traffic[64-65] . Although all of these factors are important for all children, children with disabilities also require additional considerations such as: 1) sidewalks and curb cuts; 2) accessible playgrounds; 3) accessible schools; and, 4) opportunities for participation in sports and social programs. Pfeifer[66] found that children with disabilities have a variety of behaviors that indicate their active involvement with the environment that are not reflected in standard assessments. These may be related to functional activities required in the roles and in the environments in which they participate. More research is needed to clearly identify environmental contexts that support and exclude CSNs.

Social inclusion

CSNs also face social exclusion within community-based agencies. The *Canadian Council on Social Development*[67] surveyed 112 community-based agencies to determine their capacity to respond to the needs of CSNs. The following types of agencies responded: boards of education (n=25), provincial departments of education (n=6), community-based health agencies (n=17), community-based social services agencies (n=32), municipal recreational departments (n=20), provincial organizations serving CSNs (n=8) and national organizations serving CSNs (n=4). Seventy-six percent of these agencies reported that there were barriers impeding CSNs from accessing their services. The most commonly reported barrier was the lack of availability of trained staff, including specialists, aides, therapists and support workers (23%). Also reported were costs (21%), physical accessibility of the facilities (14%), transportation barriers (9%) and public and professional attitudes (7%).

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[64] Barnes McGuire, J. (1997). The reliability and validity of a questionnaire describing neighbourhood characteristics relevant to families and young children living in urban areas. J*ournal of Community Psychology, 26(6),* 551-566.

[65] Coulton, C., Korbin, J., & Su, M. (1996). Measuring neighbourhood contexts for young children in an urban area. *American Journal of Community Psychology,* *29*(2), 5-32.

[66] Pfeifer, T (1999). Exploration of agency in preschool children with disabilities. *Dissertation Abstracts International: Section B: The Sciences and Engineering.* Accession Number: 1999-95024-100.

[67] Canadian Council on Social Development (2001). *Children and Youth with Special Needs: Summary report of findings*. (see http://www.ccsd.ca/pubs/2001/specialneeds/specialneeds.pdf)

Recommendation 4. Adopt the International Classification of Functioning, Disability and Health for Children and Youth *(*ICF-CY, *WHO, 2007)* guidelines for evaluating community-based barriers for children with special needs and develop inclusion plans

Service Provider and Health Professional Support

Principle 5. A plan supporting service providers and health professionals that addresses education and training needs, recruitment and retention and associated funding support is required.

The paradigm shift reflecting "best practices" for CSNs including: family-centered care, early intervention and support, naturalistic approaches to intervention, the need for coordinated interdisciplinary services and an understanding of interactive approaches to child development and learning, all impact on the education and training requirements of those supporting CSNs[68]. Based on their review of the personnel training requirements for early childhood special education (ECSE), Klein and Gilkerson (2000, p.471) [62] identified the following educational competencies needed to support best practices:

1. The uniqueness of early childhood as a developmental phase.
2. All developmental domains, the application of developmental theories to at-risk to disabled children, and the role of developmental status in devising interventions.
3. Family systems theory and dynamics, roles and relationships within families and the community.
4. The significant role of families as key decision makers and full partners in early intervention.
5. Developmentally and individually appropriate practices in ECSE as a framework for organizing classroom activities.
6. Curriculum development and strategies for implementing appropriate instruction based on the identified needs of individual children.
7. Culturally competent professional behaviors and cross-cultural differences as they affect interactions with children and families.
8. The importance of collaborative interpersonal and interprofessional behavior for members of interdisciplinary teams, including how to build and maintain teams.

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[68] Klein, N.K. and Gilkerson, L. (2000). Personnel preparation for early childhood intervention programs. In In J. Shonkoff and S. Meisels (Eds.). *Handbook of Early Childhood Intervention*, (pp. 454-483). Cambridge: University Press.

9. Child and family assessment and program evaluation strategies, including the use of performance-based authentic assessments.
10. The historical, legal and philosophical bases of services for typical and atypical children and strategies for advocacy on behalf of young children.
11. The meaning and application of professionalism, that is, adherence to the highest levels of professional practice, as it relates to work with parents, children and other professionals.

Training

They go on to report that training opportunities to support these educational competences should include: 1) extensive field-based opportunities; 2) on-site observations, interviews and interactions with experienced practitioners, children and materials; 3) involvement with well-functioning interdisciplinary teams; 4) opportunities for practicing effective communication with families and other community members; 5) opportunities for selecting, administering and reporting child and family assessments; 6) experience in developing, administering and evaluating individualized plans for the child; 7) transitional planning and monitoring; and 8) opportunities for ongoing professional development and engaging in reflective practice and collaborative problem solving (p. 472).

Recommendations identified by Klein and Gilkerson [62] for facilitating training for early childhood special educators include:

1. Enhancing expertise of university faculty (e.g., through sabbaticals, conferences, self-study);
2. Developing collaborative partnerships across universities;
3. Establishing university/service agency partnerships; and,
4. Providing special education training to all early childhood educators.

Developing an interdisciplinary academic-community collaborative model such as that described earlier (*Model for Family-Centered Interdisciplinary Practice in the Community)* addresses many of these recommendations. Expanding on the model used by the Infant Development Program (IDP) of B.C. provides another option[69]. The IDP maintains strong links with post-secondary professional programs that provide ongoing training and support for staff, such as the ID/SC Certificate and Diploma Programs and the Summer Institutes, all of which are offered at the University of British Columbia.

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[69] Goelman, H., Brynelsen, D., Pighini, M.J., & Kysela, G.M. (2005)-Ibid

The five courses in the Certificate Program and the 10 courses in the Diploma Program are offered in a variety of different distance and face-to-face formats. The majority of consultants hold at least a bachelors degree. In some of the more isolated rural and/or aboriginal communities, IDP staff continue to develop professionally working towards the completion of a certificate or diploma equivalent level in infant development/early childhood programs. Overall, the IDP consultants are well trained, connected and supported, with ongoing professional development throughout the year according to Dana Brynelsen, the IDP Provincial Advisor.[70]

For improving knowledge of special education for school personnel, a focus group conducted by the author[71] recommended:

1. Educate the public, teachers, and all levels of school administrators about special needs.
2. School districts to provide training and awareness programs to teachers, school administrators and community about realities of children with different types of disabilities and capabilities.
3. Government to provide an on-line informational depository of available services and resources that have been assessed. Parents should be able to feed information into system which can then be vetted.
4. Sustainable funding for special education which is not impacted by political change.
5. Decisions about attending inclusive schools should be family-centered not decided by school board.
6. Individual Education Plans must be done inclusively with child's parents, teachers, therapist, support workers.
7. Government to develop guidelines for provincial consistency related to resources and services.

Recruitment and retention

Recruitment and retention of service providers for CSNs is another major issue and has been associated with poor pay and the lack of support. Whitaker (2000)[72] found that new special education teachers who had a special educator mentor (who met with them frequently, provided emotional and systems information and assisted with materials and

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[70] Brynelsen, D., Krausert, P.L., Oldfield, J., Stewart, M. & Wolverton, A. (2003) B.C. IDP PowerPoint Presentation. Vancouver, B.C. : Infant Development Programme.

[71] Focus group conducted May 22, 2007 with community service experts associated with CSNs, Innovative Assessment Workshop, University of British Columbia

[72] Whitaker, S.D. (2000). Mentoring beginning special education teachers and the relationship to attrition. *Exceptional Children, 66*, 546-566.

resources) was more likely to remain in special education. Boyer and Gillespie (2000)[73] also recommend supporting mentorships by providing them with: release time to observe new teachers, opportunities for regularly scheduled group sessions, and access to communication technology. They also recommend that new teachers are provided content training in: assessments, working with paraprofessionals, managing the behavior of CSNs to enhance learning, adapting the curriculum, determining appropriate accommodations, differentiating instruction and coordinating diagnostic results with the instructional methods.

British Columbia has made some strides toward increasing resources to professional training of early childhood educators. For example, wage enhancement grants and operating grants to child care programs that were implemented in the 1990, resulted in the highest quality of group child care programs in Canada[74]. Continuing and expanding this effort will help with recruitment and retention of service providers for CSNs.

Recommendation 5. Develop, fund and evaluate best practice models that promote competency, interdisciplinarity and academic-community based education training for all individuals working with CSNs, focusing on actions which support recruitment and retention.

Cultural Inclusion

Principle 6. Ensure that the Legislation and Policy Framework for CSNs are culturally competent; building on the unique values, preferences, and strengths of children, families and their communities.

According to the principles espoused by *Multilateral Framework for Early Childhood Development*, early learning and child care should be inclusive of and responsive to Aboriginal (i.e. Indian, Inuit and Métis) children and children in various cultural and linguistic circumstances. Consideration should also extend to cultural considerations of

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[73] Boyer, L. & Gillespie (2000). Keeping the committed: The importance of induction and support programs for new special educators. *Teaching Exceptional Children, 33*(6), 10-15.

[74] Goelman, Doherty, Lero, LaGrange & Tougas, 2000- Ibid.

these children's families and communities. As the *Many Hands, One Dream Summit* (2005) concluded, the vision of child health for Aboriginal people is comprehensive and holistic:

> *Physical, emotional, spiritual and cognitive health interacting with family, community, nation, world and spirit. Viewed from this perspective, health problems should be approached not just physically but emotionally, spiritually and cognitively as well. Interventions would involve not only the child, but also their family and community to ensure that everyone had the knowledge, wellness and strength to support the child in achieving and maintaining holistic health* (p. 5)[75]

The key principles identified for Aboriginal children's health from this Summit, attended by over 160 delegates are:

- **Self-determination** (Aboriginal people are in the best position to make decisions that affect the health of their children, youth, families and communities; the ability of families to define their own cultural identities must be respected; Aboriginal children and youth must be actively engaged in conversations about child and youth health)
- **Intergenerational** (Decisions about child health must look to the past for wisdom and to the future to ensure the needs of generations to come are also considered; Traditional health practices should be integrated and respected as an asset; Children learn healthy behaviors through role models…all community members have a responsibility to help children learn to live in ways that promote their health)
- **Non-discrimination** (Articulate tangible expressions of racism in the health system and work to counter race-based practice; Recognize the validity of Aboriginal health care knowledge and intellectual property; Aboriginal children and youth are entitled to equitable access to health and heath care services that are responsive to their needs; Health care services based on distinct Aboriginal cultures is the preferred option)
- **Holism** (Consider the impact of heath care decisions on the child, their family, and the community; Focus equally on meeting emotional, physical, cognitive and spiritual needs; Consider the impact of health care decisions across the life transitions of a child/young person; Actively support the

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[75] Blackstock, C., Bruyere, D., Moreau, E. (2006). *Many Hands, One Dream: Principles for a new perspective on the health of First Nations, Inuit and Métis children and youth* (see www.manyhandsonedream.ca).

earth—practicing in an environmentally friendly manner and taking full account of environmental impacts on child health)

- **Respect for culture and language** (Recognize and acknowledge the legitimate care that has been practiced by Aboriginal peoples for centuries; Acknowledge that mainstream health is culturally shaped and thus is not culturally neutral when interacting with peoples of different cultures; Because culture and language are ways of seeing and understanding the world, the health care system will be most effective when it can relate to Aboriginal children and youth and their families in that context)
- **Shared responsibility** (Mainstream system needs to make space for Aboriginal concepts of health and improve its capacity to work with Aboriginal children and families; Improve links between professionals working in child and youth health and communities; Encourage and support Aboriginal students to enter into the health or social services professions; Promote the continuity of care in Aboriginal communities; Develop new relationships with non-Aboriginal health care providers and organizations characterized by reciprocity, respect and a balance of power)

An example of these principles in action is the inter-sectoral service delivery model "Hook and Hub" which combines early childhood care and development programs in three First Nations communities.[76] See figure below for a description of this community-based model.

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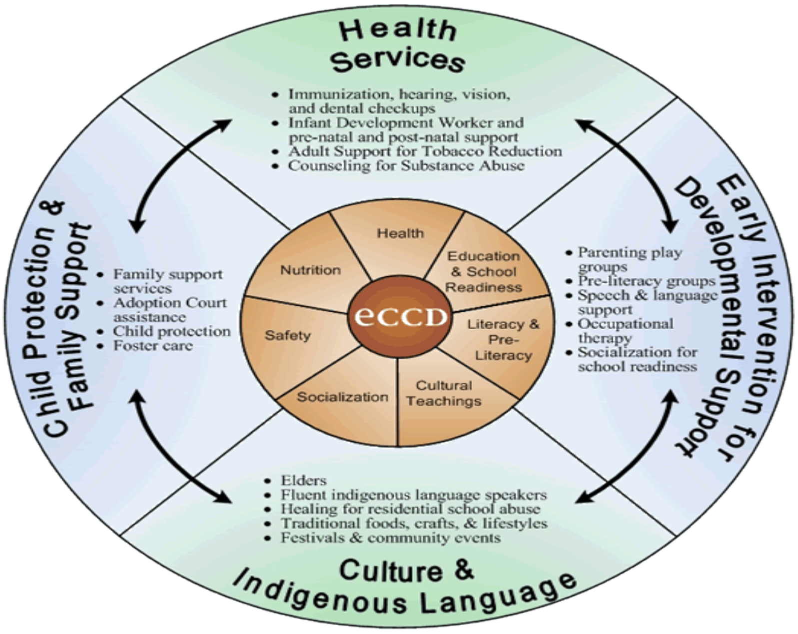
[76] Ball, J. (2005). Early childhood care and development programs as "hook" and "hub" for inter-sectoral service delivery in First Nations communities. *Journal of Aboriginal Health, 2*, 36-53 (see http://www.ecdip.org/docs/pdf/jah.pdf)



Early Childhood Care and Development as a Community-Based Hub

Twinning child care centres with development programs, supports an integrated case management of social and health services such as health monitoring and care, screening for special services, supported child care and early interventions. As Bell reports, this model is multidimensional, accessible, culturally safe, appropriate, and holistic[77]

A series of studies conducted under the auspices of the Consortium for Health, Intervention, Learning and Development at the University of British Columbia has also provided some practice and policy guidelines for ensuring cultural sensitivity with Aboriginal families and communities. For example, a “culturally appropriate practice means respecting parents, listening to parents, working to build positive relationships with parents, and only introducing formal observation, screening, or assessment when the parents are ready and signal their agreement through explicit consent” [78]. As well, advice from the *Aboriginal HIPPY Documentation Project* suggests providing resources for families beyond immediate programming for children such as opportunities for adults

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[77] Ball, J. (2004). Early childhood care and development programs as hook and hub: Promising practices in First Nations communities. University of Victoria (see http://www.ecdip.org/integratedservices/index.htm).

[78] Ball, J. (2007). *Screening and Assessment Practices in Aboriginal Early Childhood Programs in British Columbia (see www.ecdip.org)*

to interact with each other, and enrichment activities for adults and information on topics related to supporting children's healthy development[79].

Service delivery plans and policy must also address other cultures and language needs in British Columbia. An excellent initiative mentioned earlier that considers these needs was the *Social Inclusion Project* (p. 30) which provides information to families in Chinese, Vietnamese, Punjabi, Spanish, and Arabic. Understanding different cultural expectations related to health is another requirement needed to provide effective services.

Recommendation 6. Ensure that all legislation, policy frameworks and practices specific to children with special needs are culturally safe, appropriate and relevant.

What is your vision for children with special needs in BC?

All children with special needs and their families receive timely, personalized services, guidance and supports, based on individual need and best practices, from a single, fully-integrated and seamless provincial system that offers local "one-stop shopping" access and ongoing personalized/professional case management to help families support their own children, to avert crises proactively and to help these children themselves maximize their potential as productive, independent and integrated members of society, throughout their childhood and youth and into adulthood. Dawn Steele, Parent and advocate

Inclusion with appropriate supports to develop strengths, talents and interests to lead full and rich lives within their family and community.

Lorraine Aitken, Provincial Advisor, Supported Child Development Program

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[79] Le Mare, L., Beatch, M., & Harkey, T. (2007). The Aboriginal HIPPY Documentation Project. Presentation at the 2007 CHILD Forum, *Translating Early Child Development Research into Policy and Pratice*, Nov. 19, 2007, Vancouver, BC

A seamless, accessible system that values and supports an interprofessional team of health care providers that focuses on family and child centred care.

Lesley Bainbridge, Associate Principal, College of Health Disciplines and Director, Interprofessional Education, UBC

That they receive prompt identification, intervention and support by trained, qualified professionals to ensure maximum development and outcomes.

Alanna Hendren, Executive Director, Developmental Disabilities Association

A fully integrated system of care that supports effective transitions from one system of care to another (early intervention, school based, youth and adult services and supports). A wraparound service delivery model that is collaborative, team and community based for children and youth with special needs.

Nancy Gale, Executive Director, Cariboo Chilcotin Child Development Centre, Williams Lake

Conclusion

Identifying what has been effective for CSNs from the national and international literature is the first stage toward addressing "our vision" for CSNs and moving forward to address current systemic gaps. This report has provided different examples and models of legislation, integrated systems of care, family support systems, physical and social inclusion provision, service provider and health professional support systems and methods for promoting cultural inclusion. The next stage is to develop a strategic plan that operationalizes the recommendations specific to British Columbia.

Components of this strategic plan should include:

- Consultation and input from a wide variety of stakeholders;
- The establishment of clear goals, required resources, outcomes, deliverables and timelines for plan implementation;

- An evaluation plan with milestones for accountability;
- Dedicated and supported funding;
- Collaborate with a university research unit that:
  - Examines “best practice” service delivery models.
  - Completes a provincial study on the incidence and distribution of special needs in the preschool years and school age population.
  - Determines the current levels of service in each region for each program, and comparing the funding of services to the incidence numbers.
  - Develops a funding strategy that will effectively address the discrepancies between regions and between programs.
  - Identifies necessary funds required to support the delivery of services.

Gathering this information and developing concrete goals and milestones will assist in informing the specifics associated with the recommendations of this report. The various examples of different methods for services delivery plans, community and family support systems and cultural inclusivity can be mixed and matched to address the specific needs of CSNs in BC. By doing so, British Columbia will be a world leader in providing care and support for its vulnerable citizens and an example of a jurisdiction supporting its stated ideals of the right to full citizenship, inclusion, health and well-being.