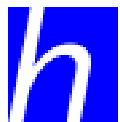
**Home Care and Pharmaceuticals Division,
Health Policy and Communications Branch,
Health Canada**

Analysis of Interfaces Along the Continuum of Care

Technical Report 5: Services for Children with Special Needs and Their Families

February 2002



Hollander Analytical Services Ltd.

Home Care and Pharmaceuticals Division,
Health Policy and Communications Branch,
Health Canada

Analysis of Interfaces Along the Continuum of Care

Technical Report 5: Services for Children with Special Needs and Their Families

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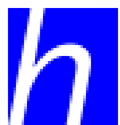

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EXECUTIVE SUMMARY

This report focuses on home and community care for children with special needs and their families. It is one element of a larger study, funded by Health Canada's Advisory Committee on Health Services, and initiated by the Working Group on Continuing Care, which examines the interfaces along the continuum of care for four populations: seniors, adults with disabilities, and adults requiring mental health services and children with special needs.

In this report, as in the larger study, we address key issues identified by Health Canada related to the promotion of integrated home and community care for children and their families, the supports that are essential to the success of home/community care, and the policy options required to strengthen the interfaces between and among service sectors.

In addressing these questions, we consider:

- Explicit and implicit barriers to integrated service delivery for children and families;
- How services are currently funded and how funding flows with children as they move from sector to sector;
- Efficiencies and inefficiencies and gaps in services; and
- Ways to optimize available resources to achieve better outcomes for children and families.

Our methodology made extensive use of interviews conducted with key informants in government, service provider organizations, and consumers in all provinces and territories. Policy implications of the findings focus on two common themes: the need for a broad range of services tailored to the specific needs of children and families in all jurisdictions and the coordination and integration of services, both within the health care sector, and between health and other related sectors such as social services, education, justice, and housing. There was a broad consensus among key informants that what makes a system a system are the coordinating, integrative functions that link services together. It was stressed that we must start somewhere to address expanded, well integrated services for children and families before families and communities are weakened and service costs spiral unchecked. The major policy options for strengthening the interfaces among service sectors are identified in our discussion.

System or Not? There was no jurisdiction in Canada in which key informants reported a fully integrated or complete system of services for children and families. Participants repeatedly cited examples of missing or weak services, long wait lists for services, lack of coordination of available services, and breakdowns in communication. The "silo" organization of services by ministry, departments, and regions often sets up barriers to integration and communication. While different services for children and families were often available, particularly in urban areas, inter-relationships, coordination, and linkages between available services were seen to be insufficient, and in many cases, there were significant gaps in available, publicly-funded services. Across Canada, publicly-funded formal supports and services are liberally supplemented by informal, volunteer services, which are seen to be essential for families living with a child with any kind of chronic condition, disability, or special need. In every jurisdiction, key informants

suggested reforms to minimize problems and time-expenditures for parents, optimize the use of limited resources, and reduce bureaucratic/administrative inefficiencies.

Accessing Services. Many children enter the service "system" directly from hospital or by referral from physicians or community nurses. Outside of these entry points, parents of children with special needs may experience long waits before needs are acknowledged and acted upon. Long wait lists for assessments were identified as a major issue across Canada. There were differences among key informants about the value and practicalities of single or central entry points to services, but pilot projects are being watched with interest. Related to this are the reported concerns about the impact of regionalized service delivery. It was thought by some that the push to regionalize services could dilute the available expertise needed to care for children with special needs since in any region, they constitute a small minority of those requiring services. Concerns were also expressed about the manner in which decisions are made about regionalization, the preparation of decision makers in pushing these initiatives forward, and the need to base decisions on research, evaluation, or other sound evidence.

Coordination and Integration of Services. There is neither care coordination (case management) nor effective coordination available for children and families in many jurisdictions although key informants indicated that it could be useful to parents and service providers alike. In a few jurisdictions, a case manager assists when the child enters the system, but disengages when the initial services are established and underway. As children's conditions change positively and negatively over time, families are frequently in the position of having to actively seek new and/or different services, without assistance or adequate knowledge, when they are under stress. There are also service and coordination gaps at key transition points in children's lives, especially from child to adult services and from preschool to school. There are also changes related to the acuity or characteristics of the condition. In many situations, the burden of coordination is left to parents.

Education systems rated well in some jurisdictions for their positive attempts to communicate with other elements of the service delivery system, including health, social services, and justice, and to actively encourage coordination among services (e.g. allowing rehabilitation or speech and language therapy at school, teaching the affected child's peers about the condition(s) and care in order to enhance socialization). Another component identified as being helpful to parents in enhancing care coordination were the parent-to-parent links. Support groups and one-to-one consultations among families who share similar issues greatly assisted parents to "learn the ropes" and begin and maintain coordination of their children's care. The Internet, long distance telephone, and print/other media contacts also worked well.

Rural/Urban Disparities. Inequities in the availability of, and access to, specialty services between rural areas and urban centers constituted a major issue. This raises questions of population density and the point at which there is a "critical mass" of children large enough to warrant specialized services and service providers. Since health and social service funding is linked to population numbers, where people are sparse so are services. Frequently, families feel forced to leave their homes in rural or northern areas or small communities and relocate to more expensive urban centres close to the services their children require. In rural and northern

communities, formal and informal carergivers can often “pull together” effectively around an individual child’s and family’s needs, but are simultaneously significantly hampered by lack of service options because policy does not support specialized services where a “critical mass” of clients is low.

Funding Issues. There were strong perceptions among informants that funding for services for children and families is currently inadequate, and that inadequate funding constitutes a major barrier to a fully integrated, smoothly functioning system of services. Funding shortfalls are particularly pressing in the community sector. Not receiving or waiting for home and community services are serious problems, so funding improvements were seen to be an important way to improve community based care for children and families across Canada. Funding policies need to be reformed to increase flexibility as children move within the system, and as their conditions and situations change. Key informants also identified challenges faced in northern jurisdictions where isolation and travel distances may raise the costs of care and where cultural differences make service delivery more complex.

Human Resource Shortages. Human resource shortages are becoming acute. The need for health and social care professionals specialized in pediatrics was identified as a major issue by key informants in every province. No category of workers is exempt, and are needs for workers cross the acute care sector and community based care sector. Such shortages exacerbate waiting lists for services and often compromise the quality of care since overburdened providers have insufficient time to follow established treatment protocols. Moreover, a lack of pediatric specialists means that even when care is available, it cannot be tailored to the specific social, psychological, developmental and physiological needs of children and their families.

Lack of Respite Care. Another significant gap across jurisdictions is the need for respite, both in-home and out of home. Family caregivers are reported to be taking on increasing burdens of care as fiscal pressures constrain home and community services in many jurisdictions, while at the same time more children are discharged from institutions with higher-level, more complex needs. To support families, and avoid “burn out”, respite services that allow children and their family caregivers to take life sustaining breaks are essential physically, socially, and economically.

Paucity of Research. A consistent theme for key informants across all categories, provinces and territories concerned the pressing need to begin to gather systematic data and evidence regarding the funding, allocation, and delivery of services to children with special needs and their families. It was generally perceived that a growing awareness of children’s and families’ needs has not been matched by data to guide policy, the establishment of actual services to meet needs, or the training of health professionals with specialized expertise in pediatric care. In particular, there is seen to be an urgent need to promote research related to outcomes of home and community care for children and families, and develop and evaluate protocols for care for children with special needs.

An Integrated System of Services for Children and Families. Survey respondents urge improvement in the delivery of services for children with special needs and their families in

Canada's communities. They identify the need for both qualitative and quantitative strengthening of the "system" of services: establishing and providing an essential "basket of services" in all jurisdictions, including rural and northern regions and, most importantly, developing superior means of linking services to one another among and across ministries, departments, agencies, and municipalities/communities. Examples of linking mechanisms include:

- Single or central point of access/entry (and re-entry) to the "system" of services;
- Availability of *Care Coordinators* (case managers) who have the mandate and authority to coordinate services across ministries and/or departments;
- Ministerial Tables, inter-ministerial committees and task forces, intra-health district, inter-departmental committees with strong, non-hierarchical leaders, clear mandates and power, and established structures;
- Care/case conferences that include families and/or other caregivers;
- Flexibility in funding and guidelines so parents can direct or manage their child's care;
- Established processes for communication with other elements of the service delivery system, including health, social services, education, and justice;
- Ongoing education for all workers about the service work of others in the "system";
- Attention to the improvement of parent-to-parent links and the roles of advocates; and
- It is the linkages that make a system a system.

Policy Implications for Children with Special Needs. Study findings suggest that to build a true system there needs to be an overall policy framework for children. This might be one that gives one ministry or department the mandate, authority, and funding to oversee children's services in an integrated fashion. Or, if ministries and departments are to continue to share policy planning and administration of services, that a common philosophical approach be articulated and used, perhaps overseen by an effective inter-ministerial, inter-provincial/territorial committee. This would break down the current "silo" approach that has developed as a function of funding mechanisms and overall mandates such as "education", "mental health", "hospital services", and so on. In the full report, we describe several pilot or new initiatives that address this need for a more comprehensive, integrated approach to children's services. Some key informants believe these are steps in the right direction but others believe that until fundamental changes at the broader system level take place, service integration and coordination will not improve.

Moving Forward. From our key informant interviews and the integration of past research and other literature, we have been able to highlight current issues and trends in health services for children with special needs and their families across Canada and described some of the relationships and gaps among children's health, social, justice, and educational services. Our findings depict a service sector which, in its complexity, has not been comprehensively researched or analyzed in the past. In the light of Canada's international leadership roles in health care, service sector reform, and the rights of the child, it is critical that governments and policy makers recognize that services for children and families are an essential, growing, but threatened element of community based service delivery across the nation. There are increasing numbers of children with long term health concerns of an increasing complex, highly technical, and acute

nature, now living in their communities rather than in institutions as they once did. This poses important challenges for policy-makers who must address a range of complicated issues around the funding, allocation and delivery of home and community care not only for children, but for children in relation to other needs groups such as acute care patients discharged earlier from hospitals and adults with disabilities. Our key informants stressed the urgent need for policy to "catch up" with reality, so that children and families in all Canadian communities, including rural and isolated areas, can access minimum levels of integrated, well-coordinated services that meet their needs, and in turn, enjoy reasonable standards of living and quality of life.

ACKNOWLEDGEMENTS

The authors wish to acknowledge the financial support for the project from Health Canada. We also wish to thank all the many individuals across the country who consented to, and participated in, study interviews and focus groups. Thanks are extended to the Federal/Provincial/Territorial Working Group on Continuing Care for helpful suggestions for key contacts in each jurisdiction and for their feedback on earlier drafts of this report.

Funding for this study was provided by Health Canada. The views expressed herein do not necessarily represent the official policy of Health Canada.

TABLE OF CONTENTS

Executive Summary i

Acknowledgements vi

Table of Contents vii

1. Background 1
   - 1.1 Two Key Questions to Address Policy Development 1
   - 1.2 Purposes 1
   - 1.3 Definitions 2

2. Methods 3
   - 2.1 Key Informants 3
   - 2.2 Key Informant Interviews 3
   - 2.3 Input from Families 4
   - 2.4 Analysis 5
   - 2.5 Strengths and Limitations of Methods 5

3. Systems of Services for Children and Families 7
   - 3.1 Key Questions 7
   - 3.2 Common Themes and Issues 7
     - 3.2.1 System or Not? 7
     - 3.2.2 Service Availability 7
     - 3.2.3 Geographic Disparities 8
     - 3.2.4 Entering the System 9
     - 3.2.5 Service Coordination and Integration 9
     - 3.2.6 Issues of Categorization and Labeling 10
     - 3.2.7 Early Intervention 11

4. Financing and Resource Allocation 12
   - 4.1 Key Questions 12
   - 4.2 Common Themes and Issues 12
     - 4.2.1 Inadequate Funding 12
     - 4.2.2 Inflexible Funding 13
     - 4.2.3 Financial Burden for Families 14

5. Adequacy of Services: Strengths and Gaps 16
   - 5.1 Key Questions 16
   - 5.2 Common Themes and Issues 16
     - 5.2.1 Human Resources Shortages 16
     - 5.2.2 Gaps in Research 17
     - 5.2.3 Gaps at Key Transition Points 17
     - 5.2.4 Gaps in Service Coordination 18

5.2.5 Lack of Information 19
5.2.6 Lack of Respite Options 19
5.2.7 Balancing System Gaps 20
5.3 Differences by Province and Region 20
5.3.1 Urban/Rural Differences 20
5.3.2 Regional Differences 21
5.4 Differences by Group (Government Officials, Service Providers, and Consumers) ...22

6. Blockages and Barriers in Effective Coordination Among Services 24
6.1 Key Questions 24
6.2 Common Themes and Issues 24
6.2.1 Funding 24
6.2.2 Organization of Services 25
6.2.3 Bureaucracies 25
6.2.4 Lack of Flexibility in Policy 26
6.2.5 Shortage of Trained Personnel 27

7. Linkages Among Service Components in Community Based Care and with Other Health and Social Services 28
7.1 Key Questions 28
7.2 Major Themes and Issues 28
7.2.1 Building Strong Linkages 28
7.2.2 Formal and Informal Caregiving 30

8. Improving Integrated Services for Children and Families 32
8.1 Key Questions 32
8.2 "Big Picture" Issues, Solutions and Approaches 32

9. Discussion 35
9.1 Overview 35
9.2 Children with Special Needs 35
9.3 Children's Needs on the Policy Agenda 37
9.4 Policy Objectives 39
9.5 Honouring a Commitment to Healthy Children and Families 40

Appendix A: Key Informants' Affiliations

Appendix B: Table of Service Components and Definitions used in the Survey

Appendix C: Interview Guides

1. BACKGROUND

1.1 Two Key Questions to Address Policy Development

This report focuses on care for children with special needs and their families. It is one element of a larger study, funded by Health Canada's Advisory Committee on Health Services, and initiated by the Working Group on Continuing Care, which examines the interfaces along the continuum of care for four populations: seniors, adults with disabilities, adults requiring mental health services, and children with special needs.

> "The F/P/T (Federal/Provincial/Territorial) Ministers and Deputy Ministers of Health have, since 1998, identified continuing care and home care as priorities for collaborative action in strengthening Canada's health care system. On behalf of the ACHS (Advisory Committee on Health Services), the WGCC (Working Group on Continuing Care) [of Health Canada] has been exploring the pressures and challenges which all jurisdictions are facing, and has identified two key questions which must be addressed to support policy development."[1] "Thus, the policy relevance of the analysis is a priority for FPT officials as is the potential for practical application and usefulness of the information/analysis in the context of each jurisdiction."[2]

The two key questions from Health Canada's Request for Proposals (RFP) that address the support of progressive policy development are:

- How can we promote a continuum of integrated home and community care, with adequate links to hospitals and primary health care?
- What supports in other sectors are essential to the success of home/community care and what are the policy options to strengthen the interface with these other sectors?

1.2 Purposes

Our aims, consistent with the RFP, were to contribute to a better understanding of the interfaces among the various parts of the health care system and between health care and other sectors for children and families.

In addressing these aims, we consider:

- Current explicit and implicit barriers to client flow across sectors of care and to the provision of the most appropriate care in the most appropriate cost-effective setting by the most appropriate provider(s)

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[1] Home Care and Pharmaceuticals Division, Health Policy and Communications Branch, Health Canada. (2000, September 15). *Request for Proposals: Analyses of Interfaces along the Continuum of Care* (p. 2). Ottawa: Author. Contract Reference H1011-00-002.

[2] Ibid, p. 2

- Whether and how funding follows services and/or individuals and if/how it flows from one sector to the other (level of fluidity between sectors)
- Inefficiencies and gaps in service availability and utilization
- Ways to maximize the optimal use of available resources to achieve better client health outcomes.

1.3 Definitions

To ensure consistency in data collection and analysis, the following definitions are used.

The *children* of interest to us are those who require a network of health, education, social, and other services in order to live with long-term health concerns in their homes and communities. The children in this population have a wide range of physical, developmental, or mental health issues, congenital or acquired. This includes: children who are chronically ill, disabled (mental and/or physical), or developmentally delayed; children with a psycho-social problem, complex care needs; those who are medically fragile, technology dependent, physically or mentally challenged. Conditions may vary from mild to severe, occur in multiples or singly, and include asthma, blindness, cancer, cerebral palsy, diabetes, head injury, heart, kidney, or liver disease, deafness, rare syndromes, seizure disorders, spina bifida, etc. In this report, we use the inclusive phrase "children with special needs" as a short-form way to refer to this population of children.

Children's conditions and their care invariably affect the child's family—its members and the family as a unit. We endorse a definition of family as a self-identified group of two or more individuals whose association may or may not be through blood lines or law, but who function in a way that they consider themselves to be a family[3]

A parent may be a natural or foster parent, another member of the family (a primary caregiver for the child with the health condition[s]), or a legal guardian.

Core services are those commonly required to meet the specific needs of children with special needs and their families.

Integration refers to the combining of several services into a set or system; the interaction among health services and services outside the health system. This implies that there are definable links and interdependencies.

Interface refers to the ways and means that components of the health and non-health related services come together or interact with one another; sharing, softening or touching the boundaries or limits of service components.

[3] Whall, A. L. (1986). The family as the unit of care in nursing: A historical review. *Public Health Nursing, 3*, 240-249.

2. METHODS

2.1 Key Informants

University of Toronto researchers conducted a total of 34 interviews with "key informants" in Ontario, Nova Scotia, New Brunswick, Prince Edward Island, and Newfoundland. In parallel, 24 key informant interviews were conducted by a University of Victoria researcher and her research assistant in Manitoba, Saskatchewan, Alberta, British Columbia, Yukon, the Northwest Territories, and Nunavut. An additional three interviews were conducted in French with key informants in Québec by a Québec-based biligual interviewer and submitted to the analytic team as verbatim transcriptions, and one additional Québec interview was conducted in English by one of the University of Toronto researchers.

"Key informants" in each province were *identified* by:

- Health Canada;
- contact individuals known to Hollander Analytical Services;
- members of the research team;
- government and regional health board websites; and
- “snowball" referrals from key informants interviewed.

Key informants included:

- representatives of community organizations/agencies providing services to children and families;
- senior government officials representing provincial programs and in departments funding or providing services to children and families;
- administrators of services for children located in a wide range of community agencies and hospitals;
- health planners in local health councils with expertise in children's health
- individuals representing advocacy organizations;
- academics with specialized knowledge of health and social services for children;
- health care professionals (physicians, nurses, occupational therapists, physical therapists) with extensive experience providing or managing services for children with special needs at the local level;
- leaders of organizations representing parents of children with special needs; and
- parents with children with special needs.

A list of key informants’ departments and jurisdictions, etc., by province or territory can be found in Appendix A.

2.2 Key Informant Interviews

Initial contacts were made by one of the researchers with potential key informants by telephone or by e-mail. In this initial contact, potential key informants were told that:

- they had been identified as "expert" in the field of services for children and families;
- the study was being funded by Health Canada;
- the study aimed to build a better understanding of the continuum of care for children; and
- participation was voluntary and all responses would be treated in a confidential manner.

In cases where a potential key informant indicated that he or she would like to participate in the study, a letter providing further information (including contact information for all members of the research team) was sent by e-mail or fax, along with a list of service definitions, a table of commonly used services for children (Appendix B), and potential interview dates.

Interviews were conducted either face-to-face or by telephone, using a standard, semi-structured interview guide (Appendix C). An initial draft of the interview guide was developed based on the requirements of the Health Canada Request for Proposals (RFP). It was then reviewed by members of the "children's team" to ensure that the specific characteristics and needs of children were taken into account and subsequently revised to produce a more open ended, qualitative protocol. Similarly, a table of potential barriers to the integration of services was designed by the overall planning group; this table was used for our key informant interviews more as a guide to prompts and requests for clarification than as an interview protocol per se. (Appendix C presents the data collection instruments used in this study.)

Key informant interviews ranged in length from 1 to 2 hours but averaged about 70 minutes. With the explicit permission of the interviewee, some interviews were audio tape recorded and later erased, solely for the purpose of verifying the interviewer's notes. Generally, interest in the study was high, and most informants asked for a copy of the final report.

2.3 Input from Families

To ensure that the concerns and perspectives of parents (in addition to organizations representing parents) were heard in this report, results from a focus group of parents conducted specifically for this research, and from interviews with parents conducted by local organizations are integrated into this report. They are supplemented by the results of focus groups conducted by one author (VEH) in BC and across Canada.

- A focus group of parent consumers and advocates was conducted in Vancouver specifically for the purposes of this report. It was attended by 7 parents of children with special needs and two family advocates. This group was audio-taped with permission, and extensive notes were taken. The tapes were reviewed, but not transcribed. They will be erased after the Final Report is tabled to Health Canada in August, 2001.
- In the Yukon, the Whitehorse Association for Community Living and an independent researcher had just completed a relevant study (funded by Human Resources Development Canada). Although the formal findings of this study could not be

released, preliminary findings were reported verbally and in writing to our team, and are integrated in the summaries that follow.

- The results of two reports originating from Ontario further elaborate families' views.[4,5] These reports were based on in-depth interviews with families about the financial costs associated with caring for children with special needs and focus groups with these families about home and community services for their children.
- As part of our key informant interviews, representatives of patient advocacy groups were interviewed in each province.

2.4 Analysis

The method for analyzing our textual data was modified content analysis[6], using Silverman's[7] notion of interpretation of "processes that turn talk into text". Our copious notes were reviewed, coded, categorized, and examined for themes of content. After initial coding and analysis, two team members drafted interpretations of alternate concepts that were to appear in the report, then exchanged these interpretations, each modifying the other's so that all concepts were incorporated.

2.5 Strengths and Limitations of Methods

It is important to highlight the strengths and limitations of this project to enable readers to judge the generalizability of the findings.

Strengths include the ability to develop a broad understanding not just of current issues and trends in health services for children and their families across Canada and by province, but of the relationship between health services and a range of associated social services which are likely to affect the development, health, and well-being of both children and their families. The key informants were chosen because of their in-depth knowledge of children's services within their jurisdictions, and because of their ability to describe existing services as well as identify those needed to establish a full continuum of care. Our findings, therefore, paint an initial picture of a service sector which has not been well researched in the past. This sector is becoming increasingly important as the population of children with special needs grows (as a result of demographic and technological changes), and as the primary location of care shifts from hospital to the home and community. In spite of the limitations discussed below, we believe that our

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[4] Toronto District Health Council (2000, February). *Advancing the agenda for families of children with complex care needs in Toronto*. Toronto: Author.

[5] Toronto District Health Council (1997, June). *A strategic plan for children with long term care needs: Final Report*. Toronto: Author.

[6] Ryan, G. W., & Bernard, H. R. (2000). Data management and analysis methods. In N. K. Denzin & Y. S. Lincoln, *Handbook of qualitative research* (pp. 769-802). Thousand Oaks, CA: Sage.

[7] Silverman, D. (2000). Analyzing talk and text. In N. K. Denzin & Y. S. Lincoln, *Handbook of qualitative research* (pp. 821-834). Thousand Oaks, CA: Sage.

results and analyses make an important contribution to understanding service delivery and integration for children and families across Canada, and in identifying where changes are needed.

Our data are *limited* by the fact that they consist of informants' perceptions rather than documentary evidence; by the finite number of interviews conducted; and by our interpretations of what we observed and heard. For instance, while some key informants represented organizations interested in children with a broad range of needs, others focused more on issues and trends related to the needs of specific sub-groups (e.g. children with autism). While reflecting the characteristics of a field which tends to be organized within "silos" linked to diagnoses, this means that we cannot claim that the findings accurately represent every aspect of children's services in every jurisdiction across Canada, particularly since the total number of interviews was restricted by the project's budget limitations and time constraints. What we are documenting, therefore, are the opinions, impressions and evaluations of individuals who have first-hand knowledge and experience in the field of pediatric care in home and community, rather than the field itself. We also note, that while we refer to the needs and preferences of children and families, we have not asked children themselves.

In spite of these qualifications, our findings do cast important light on the state of home and community services for children and families across Canada, on the strengths and weaknesses of these services, and on disparities which exist not only between provinces but in regions within them. Also, this project's findings emphasize the need to begin to build a more comprehensive, integrated continuum of care, one which serves diverse needs on a continuing basis of both children and the people who care for them in home and community: families, extended families, and lay and professional caregivers. Our findings should thus be seen as establishing an agenda for further research and analysis, rather than as providing definitive answers to such questions.

3. SYSTEMS OF SERVICES FOR CHILDREN AND FAMILIES

3.1 Key Questions

In the interviews, key informants were asked a series of questions about commonly required services for children and families in their jurisdictions (See Appendix C).

"We sent you a list of commonly required (or core) community, residential, hospital and educational services that may be used by children and their families. To us, these constitute the potential 'system' of children's services."

- From your point of view, are there any that don't belong or are missing in your jurisdiction?
- Are there any services that you would add to this list?
- In your opinion, is there adequate capacity for these services in your area?
- Please tell me about any efficiencies or inefficiencies in service provision.
- How do children typically access these services, or enter the system?
- To what extent are these services coordinated or integrated with each other?

3.2 Common Themes and Issues

3.2.1 System or Not?

If we hold that a system, as Hall and Fagan[8] defined it, is "a set of objects together with relationships between the objects, and between their attributes", then data from this survey indicate that services for children with special needs and their families across Canada are not a fully developed system (or set of systems). Particularly in urban areas, a variety of services are available for children and families. But across jurisdictions, we heard how the inter-relationships, the coordination, or the links are underdeveloped. In every jurisdiction, respondents told of places where coordination among services could be improved, of "dreams" for services that would minimize hassles and time-expenditures for parents, bureaucratic rigidities and inefficiencies, and optimize service spending. One informant said, "No, it's not a system—but we'd like it to be." Another expanded, "A system is inter-linked caring and sharing; what we have currently is a band-aid".

3.2.2 Service Availability

Key informants generally perceived that a wide range of services for children are available across Canada. Services range from basic support to highly specialized services including programs for children with autism or rare syndromes. However, as noted above, services are often not well coordinated or integrated. Moreover, they are frequently not available to everyone in all areas,

[8] Hall, A. D., & Fagan, R. E. (1956). Definition of systems, *General Systems, 1*, 18-28 (reprinted from *Systems engineering*. New York: Bell Telephone Laboratories).

particularly where there is not seen to be a “critical mass” sufficient to justify delivery of specialized services. In some areas with low population densities (especially Nunavut, the Northwest Territories, Northern Québec and Ontario, and many rural areas), fewer services are available. This applies to both community based care (including education and social services), and health care (primary care, physician services, hospital-based health care and social services). Across Canada, available publicly-funded formal supports and services are liberally supplemented by informal, volunteer services, which all informants agreed were essential for families living with a child with any kind of chronic condition, disability, or special need.

It was generally perceived that an awareness by service providers of children’s and families’ needs has not been matched by data to guide policy, the establishment of actual services to meet needs, or the training of health professionals with specialized expertise in pediatric care. While there has been some research into the needs (and unmet needs) of groups of children with specific diagnoses in particular regions or localities, there is very little documentation or systematic analysis. Therefore, there is insufficient evidence and documentation to guide resource allocation decisions between groups, across regions and localities, or between health services and social services. Key informants report a significant lack of systematic assessment of the success of interventions and programs in the community, or links between hospitals with community based services. A particular concern raised by some is the tendency to shift towards popular models of service delivery (such as single point of entry, case management, or even increased funding) without first assessing the children and families’ needs, determining outcome criteria and then fully evaluating the outcomes for children, families, service providers and funders.

Interestingly, one advantage of living in a region or community where services may be fewer is better coordination among those services that *are* available. In smaller communities, and health districts such as the territories, departments of health and social services are combined, making communication easier. For example, in the Yukon, where two-thirds of the population live in and around Whitehorse, families, service provider representatives and government personnel may know each other and see each other in grocery stores, at the rink, or in parks, so that formal lines of communication are supplemented by informal contacts. This is reported by parents to be the case in some rural areas as well.

3.2.3 Geographic Disparities

Regional and local disparities in service availability may transfer significant costs to families. In many areas in Canada, especially in the North and rural areas, both families and service providers may have to travel substantial distances, forcing up the costs, limiting the number and variety of contacts and limiting continuity and integration. Key informants stressed that there are too few trained personnel for the positions available, and that there are too few positions available for rehabilitation providers such as Occupational Therapists (OTs), Physiotherapists (PTs) or Speech and Language Therapists (SLTs). Nurses and nurse practitioners fill the gaps but are “overworked and understaffed”. Physician services are inadequate and medical specialists are in short supply.

A related issue was the persistence of rural/urban disparities. Some education respondents, parents, and service providers noted that federal funding is linked to population. Hence, where the population is sparse, services are sparse. But the families and children in these areas are no less needy. Frequently, families feel forced to leave their homes in rural or northern areas or small communities and relocate in more expensive urban centres close to the services their children require. It was pointed out by several key informants, and families in the researchers' past projects, that this is discriminatory, and a quality-of-life issue for them. When families are forced to relocate in order to have access to services, personal costs are high, and communities also suffer by losing contributing citizens. Employment may not be available in the urban centres to which families move, necessitating social assistance.

Frequently, rural/urban differences in service provision are complicated by a lack of appropriately trained service providers. We will say more about this later in the report.

3.2.4 Entering the System

Many children enter the service "system" directly from hospital, such as after birth and diagnosis, later childhood diagnosis and acute treatment, or clinic testing. The next most frequent entry point is via physician referrals. Otherwise, parents frequently have a long period of seeking assistance before a child's needs are acknowledged and acted upon. This starts with the parents being suspicious that something is wrong, their suspicions sometimes being minimized or contradicted at first, followed by a slow process of obtaining a diagnosis, and finally appropriate referrals to services. Frequently this is compounded by long wait lists for assessments.

Informants noted very few jurisdictions where there is a single point of entry, though in some areas, a community health nurse serves as an effective liaison between a tertiary level children's hospital and community based services. The Children's Home Care Teams in Alberta are considered central points of entry for Calgary and Edmonton, and in some jurisdictions assessment units have been set up as central entry points for children to the "system", but they may fall short of their objectives for various reasons. In some jurisdictions, such as Québec, parents can self refer, although eventually all access to home care is managed through the Centres Locales de Sante Communitaire (CLSCs). All too frequently, we were told, entry depends on parents identifying particular needs and searching for ways to meet them. In this way, many parents become the "care coordinator". Several jurisdictions are undertaking single point trials or pilot projects, such as Nova Scotia, BC, and Saskatchewan. In addition, we were told of several specific examples of funded pilot projects designed to improve integration of services both within health care and between health care and social services. Most are at early stages, and evaluation is not finalized. However, we also detected perceptions of a lack of political will to provide stable funding for such projects beyond the pilot stage.

3.2.5 Service Coordination and Integration

All key informants, including parents, were aware of the term case management, but this model of service coordination is not available for children and families in most jurisdictions. Where it is not available, it is acknowledged that some form of this type of service coordination would be

desirable. In jurisdictions where there is a form of “case management” the services vary widely as application policies and procedures are not standardized.

In a few jurisdictions, a case manager assists when the child enters the system, but disengages when the initial services are established and underway. The difficulty with this is that children’s conditions change over time (for the better and worse in unpredictable sequences). If professional care coordination has been discontinued, this translates to parents having to actively seek new and/or different services when they are under stress from the need to adapt to their child’s changing condition. In many jurisdictions, if there is a “coordinator” for the child’s care, this person often works for a specific agency, department or ministry and does not have the authority to cross service sectors or agencies that would allow him/her to fully coordinate all aspects of the child’s broad spectrum of care needs. In many instances the burden is left to the parents, who must coordinate a series of “case coordinators” or “case managers” who each represent one area of their children’s care needs.

As a footnote, many parents who participated in this study (and some service providers) reiterated what the project team members have consistently heard before, and is supported in the literature[9]; many dislike the term “case management”. Parents say that being thought of as a “case” is demeaning and dehumanizing. They do not like to think of their child or family as something being “managed”. One agency director called the term case management “offensive”. For the same reason, parents generally do not like to hear their child referred to as “a diabetic child” or a “CP child”, or even a special-needs child. Parent informants reminded us that their children are children first and have a health, learning, developmental, or mental health condition only after that (i.e., a child *with* diabetes).

3.2.6 Issues of Categorization and Labeling

Similarly, “children with special needs” are not a homogeneous group. “Children” includes a range of diagnostic groups including children with mental health and developmental issues, a range of acute and chronic care conditions (e.g., cystic fibrosis, cancer, inflammatory bowel disease). Moreover, many children have multiple conditions and needs (e.g., children with chronic illnesses who have long-term mental and physical needs). However, services are often delivered in “silos”, often by medical specialty or diagnostic category. The need for a child to separately visit speech and/or hearing, developmental, growth, and GI clinics, all staffed by different support staff, nurses, and physicians, rehabilitation therapists (OT, PT, SLT), perhaps located at different sites, and possibly even in different cities or communities, requires inconvenient, high-order coordination. As mentioned earlier, this time consuming activity of coordination of the many professionals and health care services required most frequently falls upon the parents. Conversely, sometimes being categorized as a child with one specific diagnosis, need, or problem causes other needs to be overlooked or downplayed as service needs

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[9] Hobbs, N. (date unknown). “No one wants to be a *case*, and no one wants to be *managed”*, quoted by Angela Kwok, Vancouver Neurological Centre, personal communication (a workshop: Shifting from case management to service coordination), November 6, 1998, and Bayard, J. M., Calianno, C., Mee, C. L. (1997). Care coordinator: Blending roles to improve patient outcomes, *Nursing Management (Chicago), 28*(8), 49-52.

are being considered, For example, in identifying a child as having a developmental delay, related needs for speech, hearing, or social services may receive insufficient attention. These are areas where the “interfaces” among service elements require strengthening.

When addressing issues of *children's* health, development, and well-being, the policies and subsequent delivery of the health care services only focus on the unit of care as the individual child and do not take into account the *family as a unit of care*. Parents report that family-level perspectives are only intermittently considered in funding, assessing and assigning services. One good example is qualification criteria for respite services, which frequently only focus on *some* characteristics of the child and do not take into consideration family needs or the complexity of the care-giving situation. Parents continue to take primary responsibility for the care and mental and physical development of their children, and more and more children now require care in home and community where service strategies must take into account the capacity of parents, extended family, and other care providers in order for them to remain healthy and able to sustain their community based caregiving.[10]

3.2.7 Early Intervention

Many key informants spoke positively of early intervention services. Often the first to come to a community, they are well developed, and as a general rule, have good networks and a strong track record of consistency in service delivery and working well across disciplines and service components. Even remote and rural communities have some form of early intervention, and some programs are offered by telehealth. These programs teach parents and interested others to work with babies and toddlers with developmental delays and other needs for stimulation as they grow and develop. This may be a reflection of greater awareness among policy-makers and the public of the importance of early identification of children's needs[11], and is supported by a child health focus at the federal level, and through local initiatives aimed at putting children's needs and children's issues (e.g., child poverty) on the policy agenda. In this, national and local associations show solid cooperation that could serve as a model for *other* children’s and families’ needs, such as the needs of children with long-term health conditions or illnesses, disabilities, mental health concerns, or developmental delays. Although, many key informants were supportive of early intervention programs there was great concern expressed because in several regions, once a child is identified as having a need for specific care or services they are not receiving them within an appropriate time frame. One reason cited for this backlog of cases was related to the human resource issue (which is discussed in more detail later in the report), regarding lack of availability of pediatric nurses, rehabilitation therapists, psychologists and psychiatrists in the community.

[10] Hayes, V. E., & McElheran. P. E. (2001). Family health promotion within the demands of pediatric home care and nursing respite. In L. Young and V. E. Hayes (Eds.), *Transforming health promotion practice: Concepts, issues, and applications*. Philadelphia: FA Davis.

[11] First Ministers’ Meeting Communiqué On Early Childhood Development (2000, Sept 11). Press release. Ottawa.

4. FINANCING AND RESOURCE ALLOCATION

4.1 Key Questions

Key informants were asked to respond to a number of questions related to the financing and allocation of resources for children and families:

- Is current funding adequate to meet the needs of children and families in your jurisdiction?
- To what extent does money follow the client from one service/program to another?
- To what extent is affordability of a service related to availability?
- What discretion do families have to determine how available funds are best used?
- Within the health, social services, and education sectors broadly (the overall "system"), is it possible to move funds between the identified sets of services and components of the system (e.g. *between* hospitals, physicians, social services, education, etc.)?
- To what extent are these associated services for children and their families currently provided in the most cost-effective way (that is, in the most appropriate setting by the most appropriate provider)?

In responses to these questions, a number of common themes and issues emerged.

4.2 Common Themes and Issues

4.2.1 Inadequate Funding

All informants emphasized that inadequate funding is a major barrier to a fully integrated, smoothly functioning system of services for children with special needs. Additional funding was seen to have potential to improve integrative functions by providing more staff to deal with issues, meet with colleagues to plan, avoid, and alleviate problems (such as inter-departmental or inter-ministerial committees), and provide for better service coordinators/case managers.

Funding shortfalls are particularly pressing in the community sector. Wait-lists for home and community services are a major problem in most jurisdictions, so funding improvements were seen to be a major way to improve community based care for children and families. Some key informants believed that the critical health human resource shortages are related to differences in salary between hospital and community sectors. In the current national nursing shortage, hospitals are attracting both new graduates and taking experienced nurses from the community. Key informants from Newfoundland, New Brunswick, BC, and Nova Scotia cited shortages of OTs, PTs, SLTs, and physicians as major issues in their provinces. Also, in all jurisdictions there were concerns raised regarding the "graying" of the workforce. The human resource issue is an area that requires immediate attention as there is a need to provide sustained funding to support the development and retention of health care professionals specializing in the care of children across the country. Largely, additional funding was seen to be important to increasing the quantity and quality of services, and improving access; however, several service providers and

parents remarked that children appear to be at the lower end of funding priorities for governments.

Inadequate funding for services was judged to be particularly acute in Nunavut and the Northwest Territories, where key informants reported that the funding-by-population system is not sufficient. In these jurisdictions, isolation and travel distances raise the costs of service delivery inordinately, and the level of frustration among all sectors (government officials, service providers, consumers, and advocates) is high. It was pointed out that approaches and policies appropriate in the South do not necessarily apply in the North. In many instances cultural differences make service delivery significantly more complex. Funded home care for children is non-existent for the most part and pediatric trained health care personnel are scarce due to the high cost of living and low salaries.

4.2.2 Inflexible Funding

In most jurisdictions, it is virtually impossible to move funding and/or resources across different, services, programs, ministries and/or departments or locations of care. The key informants talked about "turf wars" between government agencies, and between providers (e.g., hospitals, home care), within sectors (e.g., health care), and between sectors (e.g., health care, social care and education). These are seen as major impediments to integration of funding which could ultimately lead to the integration of the delivery of services.

For example, when children with tracheostomies (breathing tubes) "graduate" from ICU and hospital care and are discharged home, the huge amount of resources (and the associated dollars) necessary to sustain them in hospital do not follow to the community. Once the child is discharged home, the parent is expected to provide the bulk of care and the home and community services are provided to fill in any gaps in care. In many cases, to receive the care, the parents have had to go through numerous application processes and interviews with multiple ministries and agencies to determine eligibility for receiving the needed services for their child. In most cases, available funding is inflexible and, therefore, it is not possible to tailor the services to the needs of the child and family as a whole unit. In some areas (e.g., in Manitoba), funding moves with the child within "sub-systems" such as within Health, but not between systems, such as between Health and Education, from acute care services to community services, or even from child education services to adult education services.

Many parents would like control over some elements of funding and most service providers and governments were supportive of this model as they have seen successes with this in other populations. "Self managed care" for children and their families is in pilot testing in 2-3 communities, but to date is only minimally available across the country. Funding and services are often based on diagnostic categories or designated, narrowly defined eligibility criteria and are very rigid regarding types and amounts of services provided. A further burden for families is that, in order to care for a child with special needs at home, at least one parent is often needed in the home full-time. Funding is not available to compensate for lost wages and reduced quality of life resulting from lost salary for the parent who must stay at home. Also, funding in most

jurisdictions does not permit parents any relief from their caregiving responsibilities for their own health-sustaining/health promoting activities such as recreation, socialization, or exercise.

In many jurisdictions, funding of services is provided on a short-term basis (e.g., services and programs are funded yearly), even for services dedicated to the needs of children with long-term, continuing conditions. In addition, *eligibility* for services (e.g., for in-school support services) is often determined on a year-to-year basis, leaving families without any means of predicting what services will be available over the longer term. They constantly worry that competing demands for services may "push" them lower on priority lists even while they remain eligible for services. This is seen to lead to uncertainty for families, as well as instability and lack of continuity in service provision. Program personnel may sense a lack of permanency as well, which affects job satisfaction and the degree of confidence about service provision that they are able to project to families, in turn contributing to parents' and children's sense of tenuousness. This cycle compounds parental stress and anxiety.

Physicians' fee schedules in most provinces include significant disincentives for high-quality care management of children with special needs. Insured fee schedules do not pay for many of the services required by a family with a child for special needs. For example, these children and families often require: extra long visits due to the child's complex medical conditions; additional counseling and teaching; care coordination; participation in multi-disciplinary case conferences to develop a plan of care; and completion of application forms for special funding (an example of costs that must be borne by families). Short physician visits are seen to contribute to inadequate child assessment and parents' (and older children's) lack of confidence in, and frustration with, service delivery and coordination.

4.2.3 Financial Burden for Families

Many key informants expressed concerns over the financial burdens faced by families with children with special needs. This burden is two-fold:

- First, parents often face increased costs due to a lack of publicly financed services; they are forced to purchase drugs, services, and devices out-of-pocket, and incur many hidden costs related to hospital, doctor, or therapy visits, such as automobile expenses, eating out, etc.; and
- Second, even as out-of-pocket costs are increasing, the demands of caregiving may mean a loss of income if one or both parents are forced to stay at home.

Such burdens may be complicated by a range of factors including:

- Government programs require families to pay for travel expenses, service providers, or equipment first, and then submit receipts for reimbursement;
- Public drug plans in some provinces are inadequate to cover children's needs, such as common non-prescription (and even some prescription) pediatric drugs and formulae. Formulae and special creams can cost up to $1000-2000 a month;

- Inadequate public coverage for essential extraordinary equipment (e.g. braces, lifts, wheelchairs). This is an increasingly important issue as children are surviving longer and as they age and grow, they frequently require new equipment to keep pace with their changing bodies and needs;
- In some provinces, there is inflexibility regarding the funding of equipment that facilitates caregiving and prevents injuries (e.g., bath and toilet aids). There is also a lack of flexibility in funding adjunct equipment that promotes healthy physical and social development and independence, such a special tricycles for children with physical disabilities, special wheelchairs for athletic adolescents, adaptations of houses to accommodate special needs. Such expenses are frequently borne by those families who can afford them, and for those who cannot, children do without; and
- Financial burdens may be higher for families living in rural/remote areas because they have to travel to tertiary care centres and/or treatment centres to access required specialized services.

5. ADEQUACY OF SERVICES: STRENGTHS AND GAPS

5.1 Key Questions

Key informants were asked to respond to a number of questions related to "a list of commonly required (or core) community, residential, hospital and educational services that may be used by children and their families." The questions were:

- Is there adequate capacity for these services in your area?
- What are the gaps in current services for children and families?

5.2 Common Themes and Issues

As in the areas discussed above, key informants identified a number of common themes and issues.

5.2.1 Human Resources Shortages

Shortages of health and social care professionals specializing in pediatrics were identified as a major issue by key informants in every province. For example, key informants reported that there were insufficient numbers of speech-language pathologists, developmental pediatricians, psychologists and psychiatrists, nurses, occupational therapists and physical therapists to provide services to children and families. Such shortages exacerbate waiting lists for services and often compromise the quality of care since overburdened providers have insufficient time or visits to follow established treatment protocols. Moreover, a lack of pediatric specialists means that even when care is available, it cannot be tailored to the specific social, psychological, developmental and physiological needs of children and their families.

For example, in every province key informants spoke of a shortage of speech and language therapists leading to waits up to or exceeding a year in the publicly funded system. Also, mentioned frequently was the lack of access to publicly funded child psychologists and psychiatrists. Therefore, in order to access services of psychologists and psychiatrists in a timely manner, families who can afford it must pay out of pocket as there are long waiting lists for both assessments and treatment through publicly funded system. Also, there is a lack of pediatric nurses in the home and community sector, which in some jurisdictions can contribute to prolonged, expensive, stressful hospital stays. Furthermore, when families are already caring for their child in their home, and nurses' services become unavailable (which is currently happening on a regular basis), the families may have no alternative but to provide the care themselves. Key informants in Ontario identified a shortage of nurses in the community such that when children require almost continuous monitoring, some parents may consistently go without anything near adequate sleep, sometimes over years, in order to care for their child at home.

Particularly troublesome for key informants are waits for initial assessment for conditions that are not apparent at birth (e.g., cerebral palsy, some syndromes, learning difficulties, developmental delays). A child can wait literally years without getting appropriate services.

Diagnosis and entry to the system is often highly dependent on physician knowledge (about conditions and appropriate referral services) and willingness to listen to the parents' views about their children. Even when it is recognized that the child has a delay, there are lengthy waits to see specialists for definitive diagnosis and development of treatment programs. In some areas there is a three year wait list for Augmentative Communication Assessment at the appropriate treatment center; thus children are not receiving the communication equipment required to enhance school programs and learning.

5.2.2 Gaps in Research

A consistent theme for our key informants across all categories and across all provinces and regions, concerned the pressing need to begin to gather systematic data and evidence regarding the funding, allocation and delivery of services to children with special needs and their families. In particular, there is seen to be an urgent need to:

- Promote research related to outcomes of home and community care for children and families; and
- Develop and evaluate protocols for care for children with special needs.

It was generally perceived that a growing awareness of children's and families' needs has not been matched by data to guide policy, the establishment of actual services to meet needs, or the training of health professionals with specialized expertise in pediatric care. While some research exists into the needs (and unmet needs) of groups of children with specific diagnosis in particular regions or localities, there are very little documentation or systematic analyses. Therefore, there is insufficient evidence and documentation to guide resource allocation decisions between groups, across regions and localities, or between health services and social services. Key informants report a significant lack of systematic assessment of the success of interventions and programs in the community, or links between hospitals with community based services. A particular concern raised by some is the tendency to shift towards popular models of service delivery (such as single point of entry, case management, or even increased funding) without first assessing the children and families' needs, determining outcome criteria and then fully evaluating the outcomes for children, families, service providers and funders.

5.2.3 Gaps at Key Transition Points

Almost all key informants identified major issues and gaps in services connected with the transition from childhood to adulthood. Most services in all provinces and territories are divided arbitrarily into services for children and services for adults. The transition from childhood to adulthood, therefore, almost invariably involves families navigating a rocky transition between two different systems. Often these systems are not aligned, with little continuity in programs and service providers. Funding and eligibility mechanisms are often completely different, and there are few planning or coordinating mechanisms to assist the child in the transition to adult services. Indeed, the age at which a "child" becomes an "adult" changes across various jurisdictions (16 years to 19 years of age) and in some instances varies across providers, regional authorities and ministries within the same jurisdiction.

Compounding this issue is the fact that such transitions are more frequent now that an increasing number of children are now surviving into adulthood with conditions that were previously terminal before adulthood. For example, where a child's medical care has been coordinated by a pediatrician, transition to adult services often means transition to a new physician, care coordinator, or set of providers who may or may not have full and timely access to case files, and who may or may not have expert knowledge of illnesses or diseases of childhood, and their impact on adults. This may precipitate a "crisis of confidence" as care providers and professionals, who the child/family has learned to trust over the years, are arbitrarily replaced by a new group of providers. Another related concern for parents is when their child finishes high school since existing day programs focus either on the needs of young children (preschool) or seniors. Access to job training programs is very limited for children and young adults with special needs. These individuals, reaching the chronologically defined age of adulthood (as determined by the specific program or provider), are nonetheless still affected by their conditions and there may still be substantial psychological and physiological needs as a result, however many young adults with special needs fall into a service vacuum.

Related examples concern children moving from pre-school to school, or from primary to secondary school. Frequently, funding and services are supplied by Ministries of Health prior to school entry, but shift to the jurisdiction of Education or Social Services thereafter. Services may change, be lost, decrease, or not fit as well. Smooth transition may not be well coordinated. While in primary school, children may receive additional instructional assistance in the classroom, nursing care for feeding and medication administration, and transportation; whereas the transition to high school is only infrequently accompanied by service planning or coordination, and in some jurisdictions comparable programs and services are not provided in high schools.

Such transitions may thus place a significant added burden on parents who, in addition to their role as caregivers, must also function as care coordinators, advocates, and facilitators during these difficult transition times. Moreover, there are few supports for families who have to manage the effects of such transitions not only on the child with special needs, but on the rest of the family. Several informants also emphasized that too often at the transition times of a child's life, there is not timely planning to ensure appropriate services are in place. Therefore, a child could regress developmentally and medically due to lapses in appropriate services during these key transition points.

5.2.4 Gaps in Service Coordination

As already noted, there is often a lack of care coordination across services and sectors. No one institution, agency, or case manager/care coordinator is responsible or accountable to assist families to access, or provide ongoing navigation through the "maze" of services for children and their families. Departments, ministries and agencies often plan and act independently of one another. Parents are required to act as coordinators and advocates for themselves and their children, which may have some positive benefits, but which can also result in gaps, overlaps, inefficiencies, frustrations, and inadequate care. There are major gaps in communication within

and between sectors on both a service-to-service level and a systemic level. There is very limited formal support built into the process that facilitates information exchange about the children and families, their needs, their care requirements. Most of the between sector communication exchange occurs on an informal or random basis and is, therefore, very dependent upon the individual efforts of the service provider, government representative or parent.

5.2.5 Lack of Information

From diagnosis onward, families report that they are not provided with enough relevant information about available services and how they are/are not connected with one another. Furthermore, there is rarely one individual designated to help them access the information they need. Parents and service providers have been consistent about this in this study, across studies, and in the literature. Therefore in most cases, the more resourceful (and educated) parents are, the more services they are likely to know about, access, and receive. Some parents become extremely savvy about filling out multiple forms from various ministries and/or departments to "justify" the need for services to which they should be entitled. However, others without the time or knowledge, simply fail to navigate successfully and as a result are unable to access required services. Parents often expend unnecessary energy on "managing the system" and advocating for their children.

5.2.6 Lack of Respite Options

The lack of adequate respite services was the single most frequently expressed service gap; it came up in every province and territory and was mentioned by all three classifications of key informants. Although most jurisdictions offer some form of respite for families of children with special needs, the majority of providers and families felt that there are not enough respite options available, both in-home and out-of-home.

A lack of respite care is the result of numerous factors:

- inadequate funding;
- lack of flexibility of funding;
- failure of funding to "follow the child" especially from acute care to the community;
- devaluing of women's or family work and assumptions that families can absorb the extra demands of home care;
- lack of qualified workers (e.g. the nursing shortage, lack of training options for un-licensed personnel); and
- the cost of real estate and renovations (for group facilities).

Key informants stressed that respite issues must be solved in order to prevent more parents from "burning out" their capacity to provide adequate care to their children, and in the process, reduce potential costs for the public system. That is, if families become too burdened, and perhaps in the process, more activist, costs of caring for children with special needs will increase significantly. There are many jurisdictions where this is already happening (e.g., BC, Québec), where children "must go to hospital for respite care". Furthermore, key informants who work as advocates for

families discussed the "alarming trend" of families of children with special needs reluctantly considering the option of giving up custody of their child in order for their child to get the care they believe the child requires on an ongoing basis.

5.2.7 Balancing System Gaps

In spite of a range of perceived gaps in services for children, key informants frequently commented that dedicated individuals in government, provider agencies, hospitals, community organizations, and families, working as caregivers, care coordinators, supporters, advisors, managers and "navigators," try to compensate for the "non-system" through the sheer force of personal commitment and extraordinary efforts. All too frequently the potentially positive effects of such efforts were seen to be minimized by the fact that individuals worked within their own "silos" on individual situations and often on a crisis basis. Rather than forcing change within the broader system, in some ways such efforts actually work against change to the extent that they avert crises that would force broader changes at the system level for the population of children and families as a whole.

5.3 Differences by Province and Region

While virtually all key informants perceived that there were substantial gaps in the range of services and programs available to children and families, there were considerable variations in the nature and extent of these perceived gaps between and within provinces.

5.3.1 Urban/Rural Differences

As already mentioned, differences in service availability, access, and quality are frequently tied to urban/rural disparities. In some provinces and regions, it is not seen as cost effective or "best practice" to provide a full range of services for children, especially those that require specialist care and technology. Due to sparse populations, and thus an insufficient critical mass of children with special needs in rural areas, children have to be moved to services rather than the other way around. In some cases where there is low population density, issues related to service provision are addressed by moving the services to children – expert professionals visit the child through traveling clinics. These traveling clinics have been successful in many jurisdictions; however, in some remote areas the frequency of visits is not adequate for the special needs of some children. For example, one northern government informant who is also the mother of a hearing impaired son, reported that he had seen a speech-language therapist three times in his 26 years of life. As discussed earlier, this relates, to the human resource issue and the need to attract health professionals with specific expertise in the care of children and families to practice in rural/remote areas of the country. Also, in such areas strategies are required to ensure that these individuals can maintain their expertise in caring for children and families.

Disparities were also identified in the supports available to children and families forced to travel to urban centres to receive needed care. The financial burden on families can be substantial as they may have to pay for the travel as well as lose pay from missing work. Some provinces pay for travel to tertiary centres but others do not. Children requiring surgery for congenital heart

disease and living in Newfoundland must be flown outside their province for care (to either Ontario, Québec or Nova Scotia), which is paid for by the province. However, the parents will typically have to pay their own way in order to accompany their child. In Ontario, the Northern Travel Allowance provided to families to travel from northern and remote areas to tertiary centres does not fully cover parents' travel costs. These costs may be higher than usual because travel arrangements have to be booked at short notice during peak periods, and have to be paid before any reimbursement is received from the province. Telehealth clinics have been used with success in many jurisdictions including Ontario, BC, the Yukon, Nova Scotia, and Newfoundland. In many instances these services are able to lessen the number of visits the child and family must make to the tertiary centres for follow-up visits.

5.3.2 Regional Differences

Regional initiatives in most provinces were also seen to pose challenges for children's services. For example, in Ontario, even though it is the one province which has not regionalized hospital services, many services for children have been effectively regionalized through the introduction of 43 geographically-based Community Care Access Centres (CCACs). Personnel at CCACs assess service needs, purchase home and community care services on behalf of eligible individuals within their catchment areas, provide case management/care coordination, and, where necessary, refer to providers outside of their auspices. Children discharged from a pediatric hospital, for instance, are generally referred to a CCAC in order to have access to continuing home care services. However, while there are provincial service guidelines which cap the number of service hours (currently at 43 hours of RN services per week, and 80 hours of homemaking services in the first 30 days), actual service levels vary as a function of budget constraints and the competing needs of other groups such as adult patients discharged early from hospital, adults with disabilities, and seniors. Moreover, CCACs across the province may choose to purchase care from pediatric care specialists, or children and families may receive services from generalists with no expertise in pediatric care.

In Québec, the CLSCs (Centres Locaux de Santé Communitaire) operate in a similar manner to CCACs to some extent. Informants noted that children often enter the system through referral to a CLSC, from primary physicians, other health care professionals, or families' self-referrals. The CLSCs were "supposed to coordinate the services for these kids, but they do not have enough money or resources to do what is needed.... Centres do not all have the same mandates, nor do they offer the same services." Consequently, it is difficult to figure out where to send children for the services they need. This is compounded by the fact that services are delivered separately to Anglophone and Francophone populations. This affects health services, where Anglophone families may face longer waitlists in outlying areas, for example. Another example is in the English school system, children with special needs tend to be integrated into regular programs, whereas in the French system, they tend to be in separate classes. Another unevenness in service provision for children is that CLSCs were said to be mandated to provide services for children with intellectual or developmental deficits but not motor ones; at present, care coordination for children with motor deficits is handled by the hospitals (in Montreal), with less "red tape" than at the CLSCs. There are initiatives in Québec that bring together working groups at the regional level to address specific issues for different patient groups, but our key informants pointed out

that these groups have only generated several reports, and any associated changes to services are not evident as yet.

Concerns around the impact of regionalized health care also surfaced among key informants in other provinces. Some informants were concerned that the push to regionalize services posed an increased risk of diluting the expertise of the few specialists working in the area of pediatrics and the care of children with special needs. Concerns were also expressed that there has not been sufficient planning and evaluation regarding the decisions about which children's services are regionalized. Key informants felt strongly that careful planning must be in place regarding regionalization decisions in order not to compromise the level and types of services the children and families receive. Careful evaluation is required to determine which specialized programs and services should be provided on a regionalized basis and which should be provided centrally. In order for thorough evaluations to succeed there needs to be clear standards, protocols or pathways and outcome measures in place regarding children's services.

5.4 Differences by Group (Government Officials, Service Providers, and Consumers)

There were important differences in perceptions of service gaps by group. Most notably parents and advocates identified a series of problems and issues which from their perspectives meant that there was no effective continuum of care, and that they had to take up, as best as they could, the organization of care for their children—in addition to the burden of the care itself. A key issue emphasized by families is a relative lack of available services in the community. While in hospital, children receive 24 hour nursing care, as well as personal care, food, medications, and rehabilitation; yet in the community, service levels are often capped, and respite services for family caregivers are not available, or limited. For example, Ontario provides up to $3500 per family per year for families deemed to be eligible for respite care as determined by local CCACs. Parents emphasized that this amount does not go very far if they need to hire a Registered Practical Nurse or a Registered Nurse at $24-31 per hour. Even those who do not need a licensed health professional often experience difficulties finding a capable person for $12-15/hr. Thus, a weekend holiday for a family can cost over $1000 in respite care alone which means that in most cases, a family can hope for only 3 weekends or 6 days "off" per year.

As noted above, current human resources shortages (e.g., the nursing shortage) compound problems for families wishing to hire a health care professional. It was reported across the country that the relative minority of nurses who are experienced in the provision of pediatric home care are often under contract to local hospitals and other agencies which provide better wages and working conditions than families can offer. Since nurses frequently work both in a hospital and for an agency providing respite care, when there are shortages (or, as in BC where mandatory overtime for nurses is the norm), nurses cancel working for families in their home in order to work in hospitals. Shortages of nursing and therapy personnel may also limit families' choices in the quality of care their child receives. However, even when families are fortunate enough to find qualified, affordable personnel, cancellations are frequent and the parents or extended family members must fill in the gaps of care.

Some provinces are taking initiatives in this area. For example, Nova Scotia is developing a program specifically to help families find caregivers they can hire for respite. All of the five health authorities in Prince Edward Island work with families to find both in-home respite and out-of-home respite. A family support worker in PEI will work with individual families to find a respite option that meets the needs of the child and family. This could include officials helping the family to either find suitable workers the family can hire directly (through funding provided by the government, "worker banks," etc.) to care for their child in their home, or alternatively, they find placement with families designated as "respite" families. However, this type of respite in PEI does not include children who are medically fragile and/or technologically dependent.

6. BLOCKAGES AND BARRIERS IN EFFECTIVE COORDINATION AMONG SERVICES

6.1 Key Questions

Our informants were asked the following questions about blockages and barriers related to the coordination of services for children and families:

- In your opinion, what are the top two or three barriers to service access and/or integration for children and families in your jurisdiction?
- In your opinion, and in your jurisdiction, what are the main barriers to service access, coordination, and integration among the primary *health* services for children and families that we've been talking about and *associated* services, such as those in social or education services?

6.2 Common Themes and Issues

Many of the issues related to barriers to well integrated care for children and families are discussed in above sections of the report. They are repeated here only briefly.

6.2.1 Funding

As noted, many key informants cited a lack of funding as a major barrier to both the quantity and quality of services for children with special needs in the home and community. While inadequate funding is seen to affect service access and quality in most jurisdictions, more sparsely populated areas are most negatively affected. It was suggested, as a result, that there may be thousands of parents in Canada whose quality of life is severely compromised by the burden of care for their children, who need to rest and sleep, and whose families are experiencing enough distress to threaten their cohesiveness. Funding to increase the capacity of some existing services, particularly in non-urban areas, was widely seen to be a pressing need.

This is not, as some informants suggested, a matter of "throwing more money at the problem"; rather, it is a matter of careful evaluation of what is available, what is needed, and how needed services can be most effectively and efficiently delivered. Our informants suggested that many parents and service providers would welcome opportunities to be more actively involved in policy making, planning, implementation and evaluation of services. Perhaps because our focus in this study was on community based care, few key informants cited shortfalls related to hospital acute care services, although coordination between hospital and community could be improved upon. However, it is when the child moves to the community that more gaps become evident to our informants. They recommend seeking ways to facilitate funding mechanisms that "follow the child", and are flexible and responsive to changing needs as the child grows, develops, and their condition(s) change(s).

6.2.2 Organization of Services

The “silo” or “stove pipe” organization of services by ministry, departments, and regions often sets up barriers to integration and communication. Each department’s local area of operation (accountability for funding) encourages it to focus on its own realm and not see where duplications might occur, or where gaps exist. It was pointed out by our informants that each individual may be doing his or her best for children and families, but the responsibilities for “seeing beyond” or “outside the box” fall outside the individuals’ specific duties. It is in these gaps where the coordination of services can get lost, or be overlooked. While some key informants suggested that there should be more inter-departmental, inter-agency, and inter-ministerial committees to work on communication and integration issues, it was noted by others that often these are set up with a narrow focus on a particular problem, program or sector, rather than on the needs of a population across programs or sectors. Cross-appointing personnel between departments might be one solution

Communication and transmission of information is a significant barrier to well coordinated care. Even in jurisdictions where some form of care coordination or a central entry mechanism exists, communication is hampered by paperwork, means of transmission, and technology. Ethical considerations (safety and confidentiality of information while it is in transmission) is an important consideration, but current means of dealing with this often result in information being either slow in transmission to others, or possibly not being shared at all. The result is duplicate methods of obtaining and storing information, and parents’ and children’s sense that they are always “telling their stories”, and that they have to be “on top of things” all the time or some critical piece of information will be lost. This in turn undermines the confidence consumers have in the system, and contributes to their feeling devalued.

6.2.3 Bureaucracies

Government, service provider, and consumer informants all cited bureaucratic practices as hindrances to well coordinated care for children and families. Reports of “turf wars” or territorialism among ministries or departments as they compete for monies and reputation were cited. Long or short histories of doing things in particular ways hinder the visioning of more creative, efficient, effective ways to provide and coordinate services, use funds, and so forth. Lack of trust among professionals and workers of various kinds (including parents) exist, as do power issues ranging from the individual level to the ministerial level (including federal-provincial/territorial wranglings over responsibilities, priorities, and funding). One government participant cited self-interests and another “entrenched perspectives” that are putting the system “under siege” because there is a general absence of goodwill, and the idea that others are not doing their best, that is, a “siege mentality”. Care for the child or family is affected by conflicts between individuals or agencies, and in different interpretations of policy. Frequently, personnel in different components of the system do not know what the resources are in other components (i.e., social services or education personnel do not know what is available or what services a child is receiving from health or vice versa). Philosophies and beliefs can be vary substantially between different levels of government, within levels of government, between policy-makers and administrators, and among those on the “front line”—care providers and families. Therefore, not

only are children and families faced with countless numbers of guidelines and eligibility criteria arising from all the various ministries and providers involved in the care of their child, they are also faced with individuals in decision making positions who may interpret these policies and guidelines and rules differently.

Several informants cited the need for *policy* that specifically targets integration of services. The various organizations, departments and ministries must have integration or coordination of services explicitly stated in their mandates so that the individual decision makers have direction in program planning and service delivery to children and families. It was suggested that because of commonalties among services (e. g., those for children with motor disabilities, and those for children with intellectual or developmental delays), there was potential for far better integration of services and cost savings, while still having individualized plans of care. Policy could assist in re-conceptualizing the delivery of services to children and families using a more non-categorical perspective[12], thus reducing duplication, releasing resources that could be used in other ways to improve care, and eliminating some of the "seams" that are the hallmark of the aimed-for "seamless" delivery system.

6.2.4 Lack of Flexibility in Policy

As mentioned earlier, there is a lack of flexibility in making and enforcing policy related to services for children with special needs, and the failure to individualize care decisions for children and families. Policies, rules, and criteria for various programs are often too stringent to take into account the wide range of variations there are in children's conditions, care, management, and development. Our informants cited many surprising examples. In one area of Saskatchewan, respite cannot be provided unless a parent leaves the premises where the child is; so parents who are anxious about a new caregiver and would like to be around in case there are questions, or rest or sleep in their own bed, or do laundry, or have a friend in for tea, are barred from these activities. In Nunavut, there may be health money to have a child and parent travel South, but not to bring a specific service (e.g., PT, SLT, MD) *to* the child. Categorizing children by a single diagnosis in terms of assessment for services is another example.

It sometimes takes an emergency situation, or a family being in "dire straits" to initiate flexibility in interpretation of rules and regulations. In some cases, such interpretations may lead to innovative alternatives to traditional care delivery. In others, they are kept "under the table", even though a new, uncharacteristic, rule-breaking solution may have worked. Thus, the system's rigidity and hierarchical structures may cover up the realization of ways to overcome its own inflexibilities.

Unions were mentioned by some participants as adding additional complexities to providing care. For example, unionized workers may be assigned to provide services for children in order of seniority rather than by match of skills, training, or knowledge that is directly applicable to a specific child and family's situation, or child or parent preference. It was noted that unionized

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[12] Stein, R. E. K., & Jessop, D. J. (1989). What diagnosis does not tell: The case for a noncategorical approach to chronic illness in childhood. *Social Science in Medicine, 29*, 769-778.

workers who are assigned in this way may lack commitment to a specific child and family, resulting in poor communication and continuity of care problems.

6.2.5 Shortage of Trained Personnel

Not only are there shortages of all kinds of care providers from the highly trained and specialized to informal, volunteer caregivers, but the education and training of workers was frequently cited as a barrier to good services and coordination of services, especially for respite care and care in group homes. Whether an agency or the family does the hiring and training, families are frustrated by training a worker “from scratch” or orienting a new professional, only to have that individual move on to another job. This is especially discouraging when the worker is able to get a different job based on the training received from the parents.

As is well documented elsewhere, professional schools of medicine, nursing, rehabilitation, speech and language, and social work are not training enough professionals to replace those leaving the work force. Furthermore, the specialty of pediatric health care is not keeping pace with the needs of consumers, which are increasing as more children are living longer in their homes and communities. Vacant pediatric positions are acute in small communities and rural areas. This situation is exacerbated by the fact that some positions are only part-time, a deterrent to applicants reluctant to move to a new community without full-time work to sustain them. These vacancies, and the lack of funding for new positions, increases case loads, making those who do hold positions over-worked. Therefore, they do not have the time to provide the appropriate services to all who require them.

Several informants suggested that adjunct workers (unlicensed care providers) could assist the child or family in the “system”, but this would require appropriate training programs. For example, unlicensed providers could be utilized as companions for older children and teens; however, these workers would require systematic training and testing, perhaps on some standardized skills and knowledge. Other examples include the workers that are trained through non-credit courses on vocational training and rehabilitation practice offered at institutions such as Grant MacEwan College in Alberta.[13] Use of adjunct paraprofessionals was acknowledged to be controversial; however, their use was seen by some key informants to be required as a result of increasing shortages of other trained personnel. Thus, establishing training programs for adjunct workers was presented as an alternative to the haphazard growth of variously semi/untrained workers seen to be occurring in response to the human resource crisis.

[13] Grant MacEwan College website: www.gmcc.ab.ca

7. LINKAGES AMONG SERVICE COMPONENTS IN COMMUNITY BASED CARE AND WITH OTHER HEALTH AND SOCIAL SERVICES

7.1 Key Questions

Key informants were asked about the relationship between "health" care services and "associated" services.

- To what extent do you feel that the commonly required/core community health services for children and families are integrated with those in the associated services sector?
- What are the strengths and weaknesses in the linkages with these associated services?
- To what extent are formal services for children and their families integrated with informal services that may be provided by individuals such as family caregivers, including extended family members and volunteers?
- To what extent can children move between types of services and locations of services (i.e., moving from hospital based to community based to school based services)?

As our interviews unfolded, we found that participants provided information about service delivery from both within-sector (community based) and between-sector perspectives concurrently; they did not always make the distinction between sectors. Many findings in this section of the interviews thus repeat or elaborate those from earlier sections.

7.2 Major Themes and Issues

7.2.1 Building Strong Linkages

As stressed earlier, our key informants emphasized that services for children rarely constitute a complete "system;" lack of well-functioning coordination links that contribute most to the prevalent view that services for children do not constitute an integrated system. Lack of adequate funding and a "silo" approach common among ministries, health authorities, social services (or children and family services), education, justice, and service providers often undermined continuity and integration. Agencies in one sector are frequently not aware of the services available in the others, and it takes a while for the parents or other primary caregiver to learn to manage the system.[14]

Nevertheless, almost all informants were also able to point to examples of successful coordination between sectors, e.g., a child leaving hospital for home is assisted by good discharge planning; a physician makes an accurate, early diagnosis and refers a child for assessment and appropriate services; a child makes a "good" transition from private preschool to school even though the requirements for child aides are different in the education system. It was noted that most provinces and territories have inter-ministerial committees or other service

[14] Valkenier, B., McElheran, P. E., & Hayes, V. E. (2000, July). *Mothers' perspectives of an in-home nursing respite service: Coping and control*. Paper presented at the 5th International Family Nursing Conference, Chicago.

delivery coordinating committees struck to enhance knowledge transfer and plan policy or programs.

Additional examples of linkages that are being tried in various jurisdictions which show promise for future improvements in integration of services for children and families include the following:

7.2.1.1 Formal Mechanisms

- Single point of access assists with coordination, even if this is a partial method, (e.g., single access to the school system, to social services, or to respite services). It is an ideal model for the whole system of services for children with special needs, but not one informant thought that total single- or central-entry-point is practical. There are just too many human factors and too much complexity in children's long-term conditions.
- Care coordination (case management). "This can be anyone", and of course includes the possibility of being a neighbour or a parent, if the parent is amenable and able. The best candidate is one who is continuous over time, and is responsive to changes in the child and the family. Key informants described several models, including some pilot projects that are working but in need of refinement.
- Ministerial "Tables", inter-ministerial committees and task forces, intra-health district, inter-departmental committees (e.g., home care/long term care/community study groups) are working well. Such groups need strong, non-hierarchical ("transitional") leadership, clear objectives, established structures, and explicit frameworks in order to function well.
- Care/case conferences (that include families and/or other caregivers) are effective. Everyone needs to prepare, everyone hears what everyone else hears, options for services are expanded, and the objective is typically a change in plan or approach.
- Self managed care, where parents are responsible for the allocation of funding for, and organization of, their children's care is an option that is increasing, and is generally thought to be effective.
- The education system got high marks in many jurisdictions for positive attempts to communicate with other elements of the service delivery system, including health, social services, and justice, and to actively encourage coordinated services, (e.g., allowing rehabilitation or SLT at the school, teaching the affected child's peers about the condition(s) and care in order to enhance socialization). Teachers are actively assisted to modify their teaching around the special child in the classroom. Formal mechanisms in education may serve as good models for other inter-sectorial integration efforts. Where schooling breaks down, however, and more cross-over is needed between school and home is when the child who was previously in school needs to have a prolonged period away. If admitted to a tertiary-level hospital, special teachers can usually keep the child up with his/her peers, but if the child is at home, community based home schooling is in a "sad state". Unless parents are willing to home-school, the child's progress will drop off.

7.2.1.2 Informal Mechanisms

- Key informants reported the effectiveness of physician-to-physician communication, especially when one of these is a specialist (e.g., associated with a hospital or clinic) and the other a community based family practitioner or pediatrician. Perhaps a well established formal consultation mechanism and availability of support staff (office secretaries, dictation services) assists in this.
- Electronic communications are seen to be important to improved communications and coordination of services. Components of the “system” are becoming more computer savvy, software is improving, and hardware is ramping up across jurisdictions. Some informants noted that if this does *not* happen, consumers will overtake providers and government workers, as they are increasingly using the Internet to obtain information and for communication, and so are the children!
- As noted, in smaller communities and rural areas, communication and integration works better even though there are fewer services and many unmet needs. The informal networks and personal knowledge of one another assist professionals, non-professional workers, and families to maintain better linkages than in complex situations where players are distant and invisible from one another. There is a lesson here for formal integration functions.
- Parent-to-parent links are invaluable for the most part. Support groups and one-to-one consultations among families who share similar issues greatly assist parents to “learn the ropes” and begin and maintain coordination in their children’s care. Where these are not possible locally, Internet or long distance telephone contact works well, though they are not as effective for the tangible, practical aspects of care such as equipment demonstrations, and exchanges.
- In the same vein, advocacy groups were reported to be effective at making and maintaining links and information flow, as were consumer associations.

The most effective links, remarked one informant, are where “natural links” already exist (e.g., hospital to home care when both are in the same health authority). When children and families are well supported, have good advocates, and where parents are well informed and resilient, care is fairly well coordinated. Unfortunately, the current nature of the “system” undermines the very attributes of family-centred care coordination[15], and much work remains to be done to fully integrate services for children.

7.2.2 Formal and Informal Caregiving

Not much has been said in this report about informal caregiving. Key informants concentrated, in their restricted interview time, on formal service delivery. It was as if informal caregiving was taken for granted, an assumption, for it is widely held that with the restrictions in resources,

[15] Dunst, C. J. (1997). Conceptual and empirical foundations of family-centered practice. In R. Illback, C. Cobb, & H. Joseph, Jr. (Eds.). *Integrated services for children and families: Opportunities for psychological practice*. Washington, DC: American Psychological Association.

families who can depend on their informal systems or friends, extended family, neighbours, parents of school mates, and other community members (some sometimes unknown to them) are better off. When this was mentioned in a focus group, the members remarked that they could not exist without these informal helpers, who are subsidizing the formal (i.e., funded) service delivery system just as families are. At present, there is not much linkage between the formal and informal caregiving systems, except that the one could not exist without the other. Parents remarked that there would be increasing demand for payment for what are currently informal caregivers.

8. IMPROVING INTEGRATED SERVICES FOR CHILDREN AND FAMILIES

8.1 Key Questions

We asked our key informants to tell us about their ideal solutions or “dreams” for children’s services across the continuum of care.

- Do you see important trends and issues in your jurisdiction with respect to coordination and integration?
- Within the range of services we have discussed, what are your thoughts about what would be needed to achieve optimal integration (i.e., develop a *system* which would maximize the available use of resources to achieve better care and better health outcomes)?
- What supports across service sectors are essential to achieving the best possible health, social, and education services for children and families?
- What policy initiatives (if any) would strengthen the interface and level of integration or coordination between the set of commonly required/core health services and associated services for children with special needs and their families?
- What recent initiatives have been implemented or considered in your jurisdiction to promote the integration of services between sectors of services?
- Considering these associated services, what are your thoughts on what would need to be done (if anything) to achieve an integrated continuum, or system, of care which maximizes the available use of resources to achieve better care and better health outcomes for children and families?

8.2 “Big Picture” Issues, Solutions and Approaches

While key informants in each province agreed that there is no integrated system of care for children and families and that a key step toward improving the services for children with special needs would be to improve the coordination and integration of services both between and across sectors, they had differing views on what should be done.

Some individuals suggested that in order to build a true “system,” there needs to be an overall policy framework for children that gives one ministry or department the mandate, authority and funding to oversee children’s services. This could lead to the key ministries or departments being accountable to develop policies and services to meet the needs of children across various sites of care and throughout childhood, including effective, humane transitions to adult services. It was pointed out that in most provinces, each ministry or department has fundamentally different philosophies regarding care provision which often preclude or make common “big picture” thinking difficult.

However, other individuals (at all levels) were of the opinion that having one ministry or department for children was not necessarily the answer and improvements could be made as long as the ministries or departments were mandated or accountable to ensure there is cross sectoral collaboration and planning for children with special needs and their families in each jurisdiction.

They believed that too much time would be spent "battling" over who would control the services and there should not have to be a "winner" as long as the individual departments or ministries are committed to communication and joint planning for children. Several individuals who did not see one ministry or department for children as a feasible option suggested the need to have access to information across the system, flexibility in funding, and coordination along with the need to establish common ground rules/terminology as steps toward integration. Some provinces are looking into a "smart card" on which there is common information so once a child is identified in one program, services can be accessed and information shared by other ministries or programs. This is seen as a method of decreasing the burden of families who often have to constantly repeat their child's history over and over again and fill out new forms for each program and service.

Key informants suggested that there needs to be more meaningful integration of funding and planning for children between the community and "associated" service institutions such as hospitals and education. Currently in many jurisdictions the funding is in "silos" so each organization or ministry can try to "off load" patients to save dollars rather than determine the type and location of care based on what is best for the child and family. Although many were not sure of how to accomplish this, they said it was imperative that the "silos" be broken down and efforts be re-focused on common themes throughout the sectors as they relate to children's needs, starting at a regional level and moving to the local level. Some suggested that leadership could be provided by an inter-ministerial committee with active service provider and consumer participation. This committee would need to have both the mandate and authority to develop integrative planning for children. It could address funding, service delivery and recipient service levels, and look at service development, sustainability and integration, both within the home and community sector and across sectors. Another identified need is to streamline processes for accessing multiple services among agencies, programs, and ministries. For example, it would be helpful to have integrated forms and/or access across departments or ministries, and a central repository of information with solid checks and considerations of privacy and confidentiality.

Several provinces have set up committee structures or pilot projects in which the ministries or departments related to children's services are working collaboratively on joint initiatives to improve services. For example, in Nova Scotia they have cross departmental representation on what is called the Child and Youth Action Committee (CAYAC). A sub-committee of CAYAC developed a model for enhancing service delivery focusing on children with Autism Spectrum Disorders and they hope that this model can be used as a framework for a wide variety of children with special needs. Another example is in BC, where there is a Health Advisory Committee within the Ministry for Children and Families (MCF). MCF has also worked with consultants, across ministries and across disciplines, to develop a Policy Framework for Services for Children and Youth with Special Needs. This aims for "a new approach to service delivery within available budgets.... This system emphasizes promotion, prevention and early support for children and youth regardless of whether their needs are short-term, long-term or lifelong.... [It] presents a plan for implementing a new service delivery model in consultation with families and other community partners ...[and] results in a more flexible system that can offer short-term, long-term, lifelong, periodic and/or one time service, depending on the unique needs of a diverse

range of children and youth and their families."[16] Implementation is planned over approximately four years, though may have been delayed due to the recent change in government and reorganization of pertinent ministries.

In Ontario, four pilot projects are in progress for children with medically fragile and/or technology dependent conditions. The Integrated Services for Children Division (formerly known as the Office of Integrated Services for Children), in collaboration with the Ministries of Health and Long Term Care, Education, Community and Social Services and the Children's Secretariat chose four communities for the pilot projects. These community projects were designed to provide a better understanding of care coordination/case management practices and the mix of services and supports available for these children and their families in each community. The Ministries of Health and Long Term Care and Community and Social Services and the local sponsors (CCACs) committed to the creation of a low rules environment for the purposes of this project. Services and supports were to be individualized to meet the needs of the child/youth and family. Funding for each child could be clustered into a unified source for flexible redistribution tailored to meet the needs of individual children and their families. A community planning team made up of key service providers, the voluntary sector and parents would be encouraged to examine existing rules, establish new linkages, identify gaps in services and areas of duplication. Project sites were to identify best practices to contribute to the broader redesign of services and supports for children with multiple special needs. Final reports from each project were to be submitted to government officials in May 2001, thus evaluation findings are not available at this time.

It must be noted that many of these new initiatives and attempts at integration are in the early phases and some key informants believe they are steps in the right direction but others believe that until fundamental changes at the broader system level take place, service integration and coordination will not improve. However, most informants emphasized the pressing need to begin to gather data and evidence regarding this population in order that any new initiatives or changes can be evidence based. Another a key component that is lacking is tools to assess and measure the outcomes (such as effectiveness, cost differences) of any new initiatives or changes to care delivery or policy. Thus, there is a critical need to foster and support more research in the area of care for children in the home and community, especially related to outcome studies and evaluations. Also, there is a need to develop and evaluate protocols for care as well as examine and foster evidence-based practice.

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[16] British Columbia Ministry for Children and Families (2000, Oct. 5). *Draft Policy Framework for Services for Children and Youth with Special Needs*. (p.1). Victoria: Author.

9. DISCUSSION

9.1 Overview

This report examines the extent to which there is an integrated continuum of care for children with special needs in Canada. It is one element of a larger study, funded by Health Canada's Advisory Committee on Health Services and initiated by the Working Group on Continuing Care, which examines the interfaces along the continuum of care for four populations: children with special needs, seniors, adults with disabilities, and adults with mental health needs.

In this report, as in the larger study, we address two key questions:

- How can we promote a continuum of integrated home and community care for children and their families, with adequate links to hospitals and primary health care?
- What supports in other sectors are essential to the success of home/community care?

In addressing these questions, we consider:

- Explicit and implicit barriers to integrated service delivery for children and families
- How services are currently funded and how funding flows with the child as (s)he moves from sector to sector
- Efficiencies and inefficiencies and gaps in services
- Ways to optimize available resources to achieve better outcomes for children and families.

In the foregoing sections, we have presented an analysis and discussion based on the results of interviews with 62 key informants in government, service provider organizations, groups representing consumers and consumer advocates across Canada, and we have integrated insights from focus groups of parents conducted by us and by local planning councils.

In this section, we review and elaborate key findings.

9.2 Children with Special Needs

We considered "children with special needs" inclusively as a broad group with a wide range of diagnoses and needs. In doing so, we also considered the needs of the parents and family members on whom children depend for much of their care. As key informants emphasized, when addressing the needs of children, the unit of analysis is not the individual, but the family as a whole. Thus, throughout this report, we examine services for children and families together. Consistent with this approach, we did not ask children about their individual experiences and preferences; rather, we gathered information from experts who could provide a broad, system-level perspective on services for children and families.

In taking this approach, we acknowledge that it is not possible to address every aspect of service delivery in all provinces and territories across such a broad scope of health and related services:

acute and primary care; community based health and social services; educational and judicial services; and across children's age-spans and families' developmental stages. Our sample of informants, though made up of key people including articulate parents who are "in the trenches", is finite. Hence, our findings are not generalizable in the sense that they represent all perspectives and interests in this policy sector or document every program and service currently available. However, they do provide an important "snapshot" of the state of children's services, they identify many salient characteristics of current programs and services, and they raise important issues and considerations for planning, funding, and delivering services across Canada into the future.

One important observation can be made at this point. Although we were attempting to look at children and families with a broad range of diagnoses and needs, many of our key informants themselves had experience dealing with a particular diagnostic category or a more narrowly defined population of children. Some were, therefore, not able to look beyond their own immediate knowledge and experiences, to reflect on the "big picture" for the whole sector (i.e. across different ministries or provinces/territories) or the entire population of children. In an obvious way, therefore, our key informants both reflected and reproduced the characteristics of a system based on service "silos" or "stove pipes." While new initiatives and pilot projects are now emerging in some jurisdictions to address the needs of children and families, it is widely perceived that much work remains to be done as there is a strong recognition that with respect to children's services, the health care needs of children cross many different ministries, departments and programs. Therefore, it will be critical to address issues pertaining to children's services from a broader system level perspective. The current "system" or "non-system" of services for children and families *has* seams; the goal of a seamless system remains to be achieved[17].

Most importantly, our findings emphasize that programs and services for children and families, if not unique, have characteristics which distinguish them from programs and services for other groups such as seniors or persons with disabilities. As noted above, the unit of care is not the individual but the family. Children require specialized care linked not only to diagnoses but to their progression through developmental stages. Thus, a common theme throughout our interviews was that the particular care issues and needs of children and families require particular attention from policy-makers, planners, funders, and service providers. From our various key informant interviews we have been able to highlight current issues and trends in health services for children and their families across Canada and described some of the relationships and gaps among children's health, social, and educational services and their impact on community based services for this population. Our findings, therefore, paint an initial picture of a service sector which has not been well researched or understood in the past. These same concerns and issues were also emphasized in the Canadian Institute of Child Health's (CICH) recent profile entitled "The Health of Canada's Children".[18] The CICH's profile was the result of many years of work

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[17] Perrin, J. M., Shayne, M. W., & Bloom, S. R. (1993). *Home and community care for chronically ill children*. New York: Oxford University Press. American Academy of Pediatrics Committee on Children with Disabilities. (1995). Guidelines for home care of infants, children, and adolescents with chronic disease. *Pediatrics, 66*, 161-164.

[18] Canadian Institute of Child Health. (2000). The Health of Canada's Children: A CICH Profile, 3rd Edition. Ottawa, Canada.

and represents the opinions and knowledge of a diverse group of individuals from many sectors all across Canada. This CICH report stressed that there was an urgent need for more studies and methods to more accurately describe the health of children so that "we make sound recommendations and decisions" and that closer links need to be forged among and between various sectors such as health, education and justice.[19] In addition, it emphasizes the need to improve documentation and analyses of children's health and social issues.

9.3 Children's Needs on the Policy Agenda

Our key informants pointed to multiple factors which now converge to push care for children and families higher on the policy agenda for Canadian governments at all levels.

These factors include an internationally established philosophical and political commitment to the well-being of children. More than a decade after the UN Convention on the Rights of the Child (1989) and the subsequent declaration arising from the World Summit for Children in 1990, the UN General Assembly will convene a Special Session in September 2001 to examine the state of the world's children, and to review progress toward achieving the goals of the 1990 Summit. A signatory of the 1989 Convention, Canada has repeatedly restated its commitment to improve the state of children in this country and worldwide. Federal, provincial, and territorial governments have been working together to develop the National Children's Agenda founded on the belief that children's well-being is a priority for all Canadians, and in September 2000, the Prime Minister announced that $23.4 billion of new federal investments would be implemented over five years to support agreements by First Ministers on Health Renewal and Early Childhood Development (ECD). However, our key informants did not perceive that these commitments had yet resulted in service improvements at regional and local levels for children with special needs. Currently, there are substantial inter-provincial and intra-provincial differences in how home and community services are funded, allocated and delivered to children and other needs groups.

In addition, key informants stressed that the need for services for children and families, and the policy priority such services should receive, will increase due to continuing growth in the population of children with special needs. Reasons for such growth include: advances in technology which increase life expectancy for individuals, including children, with chronic conditions; the persistence of rates of low birth weight babies which have been linked to problems such as learning disabilities, increased risk of cerebral palsy and other disabilities and chronic illnesses; increases in multiple births due to improved reproductive technology and its associated higher incidences of morbidity and disability; increases in the survival rates of children with cancer, many of whom are now requiring long-term support for chronic conditions associated with the outcomes of treatment.

A third factor emphasizing the need for policy pertaining specifically to home and community care for children and families is related to the ongoing shift in the site of care. Driven by major health system restructuring initiatives, technological advances, and changing social values, an increasing proportion of Canadian health care has shifted outside of hospitals and institutions to

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[19] p.IV - Canadian Institute of Child Health. (2000). The Health of Canada's Children: A CICH Profile, 3rd Edition. Ottawa, Canada

home and community. As a result, a growing number of children, including children with special needs who formerly might have spent much or all of their lives in hospitals or long-term care institutions, now require care in non-institutional settings. The ongoing shift to home and community thus has major implications for families, who bear most of the responsibility for the care, development, and protection of children, and for providers, who are called upon to supply high quality and increasingly complex services in diverse settings on a cost-effective basis. It also poses important challenges for policy-makers who must address a range of complicated issues around the funding, allocation and delivery of home and community care not only to children, but to children in relation to other needs groups such as acute care patients discharged earlier from hospitals and adults with disabilities.

While in hospitals, care for children is provided as an universal entitlement under the terms and conditions of the Canada Health Act. In home and community, however, provinces and territories may choose to cover the costs of some or all services but there is no *obligation* for them to do so. On the one hand this provides provinces and territories greater freedom to restructure services in new and innovative ways along the lines suggested by some of our key informants; on the other hand, it also means that there is no minimum "basket of services" for children and families in most jurisdictions, and there is considerable variation in what services are available as well as the terms and conditions under which they may be accessed and obtained, across different jurisdictions. Without the protection and assurances of legislation and related policy, access for children and families to needed services could erode, particularly as service demands from other groups (e.g., seniors and persons with disabilities) also continue to increase intensifying political debate around the "sustainability" of the health care system as a whole.

The ongoing shift to home and community based care poses additional dilemmas related to human resources in the health, education and social service sectors. Health professionals working in the home and community are often not covered by the same collective agreements that cover hospitals; they are paid less, and working conditions vary considerably, even though the children they care for require the same specially trained professionals as they would in hospitals. This contributes to what our key informants discussed as the growing human resources crisis in home care which may translate into children with special needs and their families experiencing more problems in accessing the pediatric specialty services children require for adequate habilitation, rehabilitation, and palliation. Currently in Canada, we have dedicated children's hospitals to meet children's unique needs, but the equivalent specialized pediatric services in home and community care are minimal. This applies to OT, PT, SLT, nursing, rehabilitation, pharmacy, dentistry, specialist pediatricians, and paraprofessionals. How to attract and retain and qualified individuals to work with children in the community is a significant human resource issue, and one that requires the leadership of strong policy to effect change.

Our key informants stressed that such factors should motivate governments at all levels to assign higher priority to developing coherent policies for care for children and families, particularly in the home and community.

9.4 Policy Objectives

As for what policy *should* do, two common themes emerged. First, policy should ensure that a broad range of services tailored to the specific needs of children and families, are available in all jurisdictions. Virtually all of the services on the list (Appendix B) we provided to key informants were considered by them to be needed "core services," that is, services commonly required by families and children on a day-to-day basis.

Second, policy should ensure that services are coordinated or integrated both within the health care sector, and between health and other related sectors such as social services, education and housing. While some key informants felt that sufficient services were already available in their jurisdictions (many others felt that more services and funding were needed), virtually none felt that there was sufficient coordination or integration between available services, between or within sectors or across jurisdictions. There was a broad consensus among key informants that what makes a system a system is the coordinating, integrative functions that link services together. While individual services and ideas about integration are a start, what is needed to create a *system* is "out of the box" thinking; creative problem solving; thorough assessment, evaluation and research; and significant buy-in and commitment to change.

Our informants provided us with many examples of where coordination was missing, and where, as a result, children and families experienced difficulties in accessing needed services. However, they also pointed to some of the unresolved dilemmas in attempting to coordinate services for children and families with widely varying needs. For example, should children with mental illness be cared for differently than children with physical disabilities? Are there service components or approaches that could apply to both groups, or to both children and adults who have mental handicaps? If we try to organize a system of care with interfaces between sectors and locations of care, do we need to divide the population of children along categorical lines? And if so, how—by diagnosis, age, level of needs, category of needs? However, rather than suggesting that such issues are intractable, key informants stressed that *we must start somewhere* to address these issues in a coherent, systematic way in order to insure better integration and coordination across sectors, programs, ministries and/or departments for "all children"

These problems are being addressed differently in different jurisdictions. One example concerns children with autism. In Nova Scotia and New Brunswick, there are initiatives to build a framework for care for this diagnostic group of children, and a plan to apply the model to other children with special needs. A key question is how to evaluate or determine if a model of care developed for one group of children will be satisfactory for another group as needs among children in general, and their home care situations, vary so much. What about children with multiple diagnoses or needs that cross diagnostic groups or service sectors (e.g., Ministry of Children and Families/Social Services funded versus Ministry of Health funded)?

As noted at many points above, the current state of services for children and families was frequently characterized as a "stovepipe" or "silo" approach to service organization; families must navigate their way from silo to silo in order to access appropriate care. Families follow

services around to the extent that they can, but mobility is limited due to human, family realities and the costs of travel.

This situation is further complicated by the fact that services and funding found within hospitals often do not move with the child to the community when the child moves home. As one informant put it, “We need to have tertiary care services expanded in the community.” Each provincial and territorial government establishes its own priorities for funding and managing community based services, and the result is huge variation among the provinces and even regions of the availability of home and community care services. For example, in Québec, schools are assigned a global budget to offer rehabilitation services to students, but each individual school principal decides how that money is spent. So, for example, a principal may hire two psycho-educators rather than one speech therapist, thinking that she/he is getting more for the same amount, but the skills needed to work effectively with children at that school may not be appropriate.

Families may also face inflexible rules even when they are able to access services. For example, in Ontario where Community Care Access Centres act as “brokers” for delivering home care services, if the child is approved for nursing services, the nurse *must* provide the care to that child, even though a family may prefer to have a nurse’s aide to care for a well sibling while the parents spend their time feeding or bathing their child with special needs. This may mean that not only are the child’s needs not met, but that the needs of the family are also not addressed.

Again, key informants stressed that an important organizing principle for policy must be that the needs of the family, not just the child, must be taken into account. Parents have critical knowledge about their children’s conditions, management, and therapy. And in the final analysis, much of the burden of care, particularly as more care shifts to home and community, will rest on families.

9.5 Honouring a Commitment to Healthy Children and Families

It has been pointed out that most services available in home and community are modeled after the long term care needs of the elderly, since 50 years ago, seniors were the primary people requiring care. This is changing rapidly with shifting survival rates and increasing technology, so that currently, many more need-groups are requiring community based care. Significantly larger numbers of adults, seniors, those with mental health problems, and children who need “acute care substitutions” (that is, services in home and community that until now have been provided in hospitals) as well as long term care, are all competing for limited resources. The question remains: Will increasing pressures on available funding and services lead to a deterioration in access to and the quality of available services, or can such pressures become a catalyst for action which stimulates new and innovative solutions which more flexibly meet the needs of children and families?

Given that services for children with special care needs and their families fall under provincial jurisdiction, and given that there is currently extensive variation in the funding, delivery and availability of health and social services between and within provinces, territories and regions,

are there principles which can be used as the basis for a national consensus on care for children and families? For instance, can a basic "minimum" level of service be identified for children and families across Canada?

While our key informants generally did not discuss jurisdictional issues, they did emphasize that policy must begin with the basics by explicitly considering the unique characteristics of children and families including:

- Physical state (e.g., illness or disability progression and changes) which changes over time, often more rapidly than adults, and far less predictably.
- The fact that children grow and develop, and change size and abilities, capacity to self-care, to learn and adapt.
- The "well-being" of children is intricately linked with the "well-being" of the family which can include parents, siblings, grandparents, extended family members. This shifts the focus of care from the individual to the family, a focus which few health care practitioners and policy makers were educationally prepared to address.

They also stressed the need to do a better job of documenting services and programs currently available, and evaluating their strengths and weakness in terms of their ability to address the unique needs of children and families. Although it is widely held that more funding is a panacea, some thoughtful key informants noted that the place to start with effective reform for improved home and community care for children and families is with a thorough assessment of what we currently *do* have, followed by a systematic assessment of alternative models for crossing the multiple ministries, departments and programs currently in place.

Services for children and families are an essential and growing element of health and social care delivery for all Canadians. There are increasing numbers of children with long term health concerns of an increasing complex, highly technical, and acute nature, now living in their communities rather than in hospitals, institutions, and "homes" as they once did. Our key informants stressed the urgent need for policy to "catch up" with this reality, so that children and families in all parts of Canada, including rural and isolated areas, can access minimum levels of services that meet their needs, and in turn, enjoy reasonable standards of living and quality of life.

With the federal government's announcement regarding its commitment to the development of a National Children's Agenda in 2000 and as a signatory of the 1989 UN Convention on the Rights of the Child, it appears that from a philosophical and political perspective, the federal government is committed to improving the state of children's health in Canada. However, as informants pointed out in this project, and which was also emphasized in the CICH report,[20] there is a pressing need for governments and policy makers at all levels and within all provinces and territories to take actions to honour these previous commitments to the well-being of children and families across the country. As part of the UN Convention on the Rights of the Child, Article

[20] Canadian Institute of Child Health. (2000). The Health of Canada's Children: A CICH Profile, 3rd Edition. Ottawa, Canada

23 recognizes that children with disabilities have the right to enjoy full and decent lives. They are entitled to special care, assistance and effective services, including education, training, health care, rehabilitation, preparation for employment and recreation activities. This assistance is to be provided free of charge, whenever possible, considering the financial resources of the parents or others caring for the child.[21] However, those we interviewed felt strongly that as it currently stands in most Canadian jurisdictions, children's and families' needs are too often not being met, families and other care providers are burning out as a result, and the citizens and communities of tomorrow will pay the cost. Although we appear to be committed to improving children's health in Canada, "children" are not truly on the political agenda.

In conclusion, there is much work to be done to enhance the integration and coordination of services for children and families. Our interviews emphasized that there are many compassionate, skilled, and knowledgeable people in governments, agencies, families, and communities who are committed to making improvements. We believe that our results and analyses make an important contribution to understanding service delivery and integration for children and families across Canada, and in highlighting where changes are required and identifying priority areas where actions can be taken toward improving services for children and families.

[21] *The UN Convention on the Rights of the Child: How Does Canada Measure Up*? by; Canadian Coalition for the Rights of Children (1999), Ottawa, Canada.

APPENDICES

APPENDIX A:

Services for Children with Special Needs and their Families

Respondents' Affiliations
(Government Officials and Service Agency Personnel)

Province/Territory	Government Sector or Service	Position
Newfoundland	General Hospital, St. John's Janeway Children's Health Centre Newfoundland and Labrador Association for Community Living School of Nursing Memorial University of Newfoundland and Labrador	Cardiology Coordinator Coordinator, Home Care Diabetes Coordinator Executive Director Home Care Referral Nurse Professor
Nova Scotia	Acute and Chronic Care Program Children with Autism Program Children with Special Needs Progr Community Outreach Services, Dept of Community Services Dalhousie University Department of Health In-home Support for Children Dept of Community Services IWK Grace Health Centre	Assistant Director Chair of Pediatrics Chief of Pediatrics Coordinator of Services (2) Director of Child and Health Services Pediatric Neurologist Program Director Psychologist
PEI	Acute and Continuing Care Association for Community Living Child, Family and Comm Services Child Youth and Family Program East Prince Health Authority Department of Health and Social Services Disability and Support Services Program	Coordinator Director (3) Executive Director Youth Services Consultant
New Brunswick	Association for Community Living Community Services Early Childhood Initiative, Dept. of Health and Wellness Extra Mural Program and Rehab Special Services for Children Support and Maintenance, Family and Community Social Services Division	Director (4) Executive Director Manager
Québec	Ambulatory Acute Care Program. Montreal Children's Hospital Children with Intellectual Handicaps Program, Centre Locale de Sante Communitaire, Montreal Developmental and Behavioural Pediatrics, Children's Hospital	Administrative Head Continuity of Care Coordinator Director Pediatrician Person serving Francophone population Person serving Anglophone population

Province/Territory	Government Sector or Service	Position
Ontario	Child and Family Services for Toronto area CCACs Child Health Systems, The Hospital for Sick Children Children's Treatment Centres of Ontario Ontario Association for CCACs Ministry of Community and Social Services Ministry of Health Peel Region Project for Children with Special Needs Special Needs Branch, LTC, Integrated Services for Children Division Special Needs Program, Integrated Services for Children Branch, MOH and LTC Toronto District Health Council	Client Advocate Contract Researcher Director (4) Executive Director Policy Director Senior Planner Senior Policy Analyst
Manitoba	Children with Special Needs and Families Home Care, Manitoba Health Special Education Review Initiative, Manitoba Education, Training & Youth	Care Coordinator Case Worker Director of Child Health Project Manager Resource Coordinator
Saskatchewan	Alvin Buckwold Child Develop't Program, Kinsmen Children's Centre Department of Health Home Care, Department of Health	Associate Director of Professional Services Client Care Coordinator (Case Manager) Manager
Alberta	Child Health, University of Alberta Hospital Children's Home Care Team, Calgary Regional Health Authority Children's Home Care Team, Edmonton Gateway Association for Community Living Handicapped Children's Services, Family and Social Services	Clinical Nurse Specialist Home Care Manager Nursing Consultant Program Coordinator Representative
British Columbia	Children's Services for Community Living, Ministry for Children and Families Nursing Support Services & At-Home Program, Ministry for Children and Families Services for Community Living, Ministry for Children and Families (Burnaby)	Nursing Consultant Program Manager Social Worker

Province/Territory	Government Sector or Service	Position
Yukon	Association for Community Living & People First Program Family and Children's Services, Dept of Social Services, Government of Yukon FPY Advisory Network on Mental Health Inclusion Program, Association for Community Living	Chair Contract Researcher Director Representative
Northwest Territories	Community Wellness Programs, Health and Social Services	Manager
Nunavut	Arvite Hdq., Dept of Education Hospital & Mental Health & Family Services, Mental Health and Family Services, Baffin Regional Hospital Pangnirtun Health Centre, Baffin Region Qikiqtani School Operations	Regional Health Promotion Officer Student Support Consultant Student Support Coordinator

APPENDIX B

LIST OF SERVICES POTENTIALLY USED BY CHILDREN AND THEIR FAMILIES

Commonly Used Services	**Available (publicly funded or co-pay)**		**If yes, sufficient capacity**	**If no, should it be**	**Comments**
	Yes	**No**			
Community Based Services					
In-Home Nursing: Care services that are provided in the child's home by professional nurses (RNs, LPNs), to facilitate caring for the child within his/her natural or surrogate family. Developmentally appropriate comfort, diagnostic, treatment, rehabilitative, respite, palliative, or habilitative measures are provided by a nurse who visits for that purpose, occasionally or regularly, for a few minutes or several hours. The parent(s) or regular caregiver may be on-site or off-site when the nurse is providing care. Nurses may be publicly funded, or be provided by private (second party) agencies.					
Non-professional In-Home Care (aides, etc.): Care services provided in the child's home by non-professional but trained personnel who are paid for the services they provide. practical nurses, nurse's aides or care aides are examples. Developmentally appropriate comfort, diagnostic, treatment, rehabilitative, respite, palliative, or habilitative measures are provided by a nurse who visits for that purpose, occasionally or regularly, usually for two hours or more. The parent(s) or regular caregiver may or may not be on-site when the care is provided.					

Commonly Used Services	Available (publicly funded or co-pay)		If yes, sufficient capacity	If no, should it be	Comments
	Yes	No			
In-Home, Non-nursing Rehabilitation: Rehabilitative services provided in the child's home by personnel trained to maximize function related to the child's condition and promote growth and development, such as physio- and occupational therapists, speech and hearing therapists, infant development specialists, social and educative workers, etc. Visits may be occasional (say, for assessment) but are more often at regular intervals, though the intervals may be long and visits acutely time-limited. The parent(s) or regular caregiver may be on-site or off-site for these visits, but is more often present, working along with the therapist.					
Homemaker Services: Non-professional services provided to families who require assistance with housekeeping, meal preparation, grocery shopping, children's activities of daily living, etc. Personnel are usually provided by untrained or semi-trained individuals, who may be paid or volunteer. We include services such as Meals on Wheels in this definition.					
Group or Residential Home: Health care services are provided to the child in a home-like setting with other similarly affected children. Staff/caregivers are typically a mixture of professionals and trained semi-professionals and/or lay people. Group homes may offer short- or long-term placement, and the child may live in or attend in the daytime only.					

Commonly Used Services	Available (publicly funded or co-pay)		If yes, sufficient capacity	If no, should it be	Comments
	Yes	No			
Special Foster Care: Includes a wide range of alternative foster family care giving for the child with disabilities or chronic illnesses, such as: volunteer family, extend-a-family, co-parenting, auxiliary family, etc. Alternative families and children are "matched", and formal agreements are entered into. Caregiving may be temporary or permanent, regular or occasional, and natural families may or may not sustain relationships with their children and involvement in care. Foster parents usually receive public financing for this family care.					
Psychiatric/Mental Health Services for Children: Specific mental health services aimed at the community based care of children and adolescents and their families. These may include community based physicians (psychiatrists), counselors, Community Mental Health Teams with designated child/adolescent personnel and/or programs, autism workers, etc. Services encompass assessment, diagnosis, treatment, management, supervision, rehabilitation, or habilitation programs.					
Integrated Day Care: Care of children takes place on a daytime-only basis in a centre that provides paid care for "typical" children as well as those with disabilities or chronic illnesses. Usually, only a few children with disabilities or chronic illnesses are integrated with many "typical"/health children. Staff are trained (by education, the centre, and the families). Size (number of spaces for both affected and non-affected children), equipment and facilities, and training of staff vary. The age-range of the children accepted also varies.					

Commonly Used Services	Available (publicly funded or co-pay)		If yes, sufficient capacity	If no, should it be	Comments
	Yes	No			
Special Day Care: Care of children takes place on a daytime-only basis in a centre that specializes in providing for the needs of children with on-going disabilities or chronic illnesses. Staff are trained (by education, the centre, and the families) and provide services for pay. Size (number of spaces), equipment and facilities, and training of staff vary. The age-range of the children accepted also varies.					
Integrated Preschool Program: Educationally-focused activities for "typical" preschoolers integrate children with disabilities or chronic illnesses. Staff are trained to assist children's growth and development, with a concentration on cognitive and psycho-social needs. They are normally trained by families in the particular, special physical and health needs of the children, or affected children may attend with special care aides. Size (number of spaces), equipment and facilities, and training of staff vary.					
Special Preschool Program: Services to preschool aged children, primarily educative, take place on a daytime basis in a setting that specializes in providing for the needs of children with on-going disabilities or chronic illnesses. Staff are trained to assist children's growth and development, with a concentration on cognitive and psycho-social needs. They are normally trained by families in the particular physical and health needs of the children, or children may attend with special care aides. Size (number of spaces), equipment and facilities, and training of staff vary.					

Commonly Used Services	Available (publicly funded or co-pay)		If yes, sufficient capacity	If no, should it be	Comments
	Yes	No			
Support Groups (Parent/Sibling/Child): Support groups may be professionally led, or family/parent/adolescent initiated. They may be aimed to support parents, siblings, or children/adolescents, and normally cater to the informational and social needs of particular groups, such as adolescents with cystic fibrosis, parents whose children have cardiac anomalies, etc. Membership is voluntary, and attendance may be regular or intermittent. Frequently, those with more experience offer assistance to those with less (that is, peer support and mutual aid).					
Direct Financial Assistance for Families to Purchase Services, Equipment and/or Supplies: A program that on application and assessment, provides funds directly to families for parents' purchase of respite services (in or out of home), out-of-home carers (for example, day care for their special children), and special equipment and supplies necessary for their children's home care. This may include syringes, catheters, special diapers, wheelchairs, custom tri/bicycles, and so forth.					
Financial Assistance to Improve Physical Access: A program to recompense families or out-of-home carers for improvements that permit access to homes or service locations for children with disabilities and chronic conditions.					
Specialty Transportation Services: Publicly or privately owned transportation services that provide special services to accommodate children's special needs and equipment. An example is a commercial bus company with lift-equipped entry, or individualized, door-to-door taxi service with wheel-chair accessible vehicles, such as Wheel-Trans, Handi-Dart, etc.					

Commonly Used Services	Available (publicly funded or co-pay)		If yes, sufficient capacity	If no, should it be	Comments
	Yes	No			
Crisis Support: Services, based either in the community or out of agencies (for example, hospitals) that provide emergency assistance when a family's usual supports break down, when a primary caregiver becomes ill or is injured, or when the child's condition worsens unexpectedly.					
Buddy Program: Usually a volunteer program where trained personnel provide companionship to individual children for activities such as walks, sports, crafts, shopping, recreation (movies, videos, parties, etc.)					
Summer Camps: Summer camping experiences may be offered for children with disabilities or chronic illnesses, with or without their parents and siblings or other, "typical" children. That is, the camp may be integrated or not. Often such camps are run by societies, foundations, and other community agencies such as the Cancer Society, Lung Association, Arthritis Association, local recreation boards, etc. Camp periods are usually for 1-2 weeks, during which time children can experience special modifications of outdoor and other activities typical of other summer camps. Day camps may also be available in some municipalities.					
Case Coordination/Case Management: An organized system of health care delivery, care coordination centres all important, pertinent information about a child with a disability or chronic illness and his/her family with a single individual, or possibly two individuals. Care coordinators can be parents, professionals, or paid or unpaid lay advocates who initiate, facilitate, orchestrate and organize access to and use of community services and resources. Case management permits enhanced coordination and supervision of care that may be carried out by a variety of service providers in several different locations.					

Commonly Used Services	Available (publicly funded or co-pay)		If yes, sufficient capacity	If no, should it be	Comments
	Yes	No			
Institutional Services					
Family Practitioners, Pediatricians, Pediatric Medical Specialists, Nurse Practitioners: Primary care providers who diagnose, initiate treatment and management plans, refer, and monitor/follow the child and/or family. Services may be provided from private offices or hospital-based offices and clinics.					
Children's Hospital: Most provinces have designated tertiary or secondary institutions in which children with acute and long-term health problems receive treatment and care. Service delivery is restricted to those under a specific age (normally 17-19 years). These hospitals provide a wide range of intensive care, medical, surgical, neonatal intensive care, diagnostic, and rehabilitative services. These services are normally organized into care management specialties such as oncology, communicable diseases, etc. A full range of health care professionals and support personnel are available. Care may be delivered through in-patient, day care, out-patient, or out-reach services. Some staff physicians may see children who are not currently hospital patients at offices or clinics located in a hospital.					
Pediatric Unit, General Hospital: Where a separate pediatric hospital is not feasible, beds within a general hospital are designated for children who are admitted for acute or longer-term care, either in a pediatric unit or mixed on wards with adults. A full or partial range of services and trained personnel may be available to care for children in this setting. Services available for adults in such centres may be adapted or abbreviated for children. Not tertiary.					

Commonly Used Services	Available (publicly funded or co-pay)		If yes, sufficient capacity	If no, should it be	Comments
	Yes	No			
Outpatient/Ambulatory Clinics: Clinics may be associated with a variety of institutions, be held in a variety of settings, and offer a variety of special and generalized diagnostic, treatment, support, or monitoring services. Direct care may be provided by health care professionals from a number of disciplines, either individually or in a team. The child may be seen for a few minutes or a whole day, on one or several (consecutive) days, but attends from the community rather than being admitted to the institution.					
Extended, Chronic, or Rehabilitation In-Patient Services: A generalized or specialized institution for the care of children (or children and adults) with long-term health concerns. Length of stay is normally longer than one month, and begins when the patient is no longer in an acute phase and has a condition and management regiment that is stabilized. The aim of care is maintenance of the best possible health for the child, and may or may not involve active rehabilitation. Occasionally, a very limited number of respite beds may be available.					
Palliative Care or Hospice Services: When a child's condition is deemed terminal, care on a permanent or part-time basis may be provided in a palliative or hospice situation. In palliative care, the aim is to sustain optimal health and comfort rather than active treatment of the medical conditions(s). Some institutions offer some palliation for children in acute care or extended care settings.					

Commonly Used Services	Available (publicly funded or co-pay)		If yes, sufficient capacity	If no, should it be	Comments
	Yes	No			
Educational and Vocational Services					
Integrated School Program: Generally offered within the regular school system, educational institutions permit or encourage the integration of children with disabilities or chronic illnesses in classrooms with healthy, able children. In this case, teachers and other school personnel adapt regular classroom and school activities to accommodate any special requirements of the child's disability or chronic illness. Parents and children must often become active in interpreting characteristics of the condition and its management to peers, teachers, and school administrative personnel.					
In-home Teachers/Tutors: Teachers may be employed by school boards or other jurisdictions to provide home schooling or tutoring of children unable to attend regular classes, either on a short-term or long-term basis. This should be differentiated from those parents who choose to home-school their own children, and from privately hired individual tutors who supplement the child's learning in specific subjects.					

Commonly Used Services	Available (publicly funded or co-pay)		If yes, sufficient capacity	If no, should it be	Comments
	Yes	No			
Vocational Training: Special programs that prepare older children and adolescents with disabilities or chronic illnesses for jobs and careers are occasionally available from a variety of sources. Alternatively, individual courses may assist such children in developing skills adapted to their disabilities or illnesses to assist them to become contributing members of society once formal schooling is complete. Examples are adapted computer skills, job-searching skills, etc. Such training may be offered on a one-to-one basis, in small groups, or larger groups, integrated with able learners or not.					
Judicial Services					
Judicial Services: Services that focus on children and families who, because of the child's condition, bring the child in contact with the police and/or judicial systems. This may include apprehension of children, making and monitoring court orders, child protection activities, focussed programs (such as those for children with FAE/FAS/NAS or mental, emotional, or development challenges), and so forth.					

LISTE DES SERVICES QUI PEUVENT ÊTRE UTILISÉS PAR LES ENFANTS ET LEUR FAMILLE

Services les plus utilisés	Accessibilité (financé par l'État ou participation aux coûts)		Dans l'affirmative, capacité suffisante	Sinon, devrait l'être	Commentaires
	Oui	**Non**			
Services axés sur la collectivité					
Soins infirmiers à domicile : Services de santé fournis chez l'enfant par des infirmières professionnelles (infirmières licenciées, infirmières auxiliaires licenciées) et qui permettent de prendre soin de l'enfant dans sa famille naturelle ou adoptive. Une infirmière, qui vient chez l'enfant à cette fin, de façon occasionnelle ou régulière, pendant quelques minutes ou plusieurs heures, fournit des services en matière de confort, de diagnostic, de traitement, de réadaptation, de relève, de soins palliatifs ou d'habilitation qui favorisent le développement. Le parent (ou les parents) ou le soignant habituel peut être présent ou non au moment où l'infirmière dispense des soins de santé. L'infirmière peut être rémunérée par l'État ou par des organismes privés (autre partie).					
Soins non professionnels à domicile (auxiliaires, etc.) : Services de santé fournis chez l'enfant par du personnel non professionnel, mais qui a reçu une formation et qui est rémunéré pour ses services. Il s'agit, par exemple, d'infirmières auxiliaires, d'aides-infirmières ou d'aides-soignants. Une infirmière qui rend visite à l'enfant à cette fin, de façon occasionnelle ou régulière, habituellement pour une période d'au moins deux heures, fournit des services en matière de confort, de diagnostic, de traitement, de réadaptation, de relève, de soins palliatifs ou d'habilitation qui favorisent le développement. Le parent (ou les parents) ou le soignant habituel peut être présent ou non au moment où l'infirmière dispense les soins.					

Services les plus utilisés	Accessibilité (financé par l'État ou participation aux coûts)		Dans l'affirmative, capacité suffisante	Sinon, devrait l'être	Commentaires
	Oui	Non			
Soins non infirmiers de réadaptation à domicile : Services de réadaptation offerts chez l'enfant par des personnes formées dans le but de maximiser les fonctions liées à l'état de l'enfant et de favoriser sa croissance et son développement, comme des physiothérapeutes et des ergothérapeutes, des orthophonistes et des audiothérapeutes, des spécialistes du développement du jeune enfant, des travailleurs sociaux et des éducateurs, etc. Les visites peuvent avoir lieu de façon occasionnelle (par exemple, pour une évaluation). Toutefois, elles ont habituellement lieu de façon régulière et sont, le plus souvent, de courtes durée. Le parent (ou les parents) ou le soignant habituel, peut être présent ou non au moment de ces visites. Il est souvent présent afin d'aider le thérapeute.					
Services d'aide familiale : Services non professionnels offerts aux familles qui ont besoin d'aide pour l'entretien ménager, la préparation des repas, les courses, les activités quotidiennes des enfants, etc. Les personnes qui fournissent les services n'ont habituellement aucune formation, ou une formation limitée; elles peuvent être rémunérées ou bénévoles. Cette catégorie comprend des services comme la livraison de repas à domicile (popotte roulante).					
Foyer de groupe ou résidence : Services de soins de santé offerts aux enfants qui vivent dans un établissement semblable à une maison, avec d'autres enfants atteints de la même maladie. Le personnel (les soignants) est constitué d'un mélange de professionnels, de semi-professionnels formés et de non-professionnels. L'enfant peut être placé dans un foyer de groupe à court ou à long terme, il peut y vivre ou y passer seulement ses journées.					

Commonly Used Services	Available (publicly funded or co-pay)		If yes, sufficient capacity	If no, should it be	Comments
	Yes	No			
Placement spécial en famille d'accueil : Cette catégorie inclut une large gamme de soins offerts en famille d'accueil à un enfant handicapé ou atteint d'une maladie chronique. Il peut s'agir d'une famille bénévole, d'une famille étendue, de partage du rôle parental, d'une famille auxiliaire, etc. On jumelle les familles d'accueil et les enfants, et des ententes officielles sont conclues. La prestation de soins peut être temporaire ou permanente et peut avoir lieu de façon régulière ou occasionnelle. Les familles naturelles peuvent entretenir ou non une relation avec leur enfant et participer ou non à la prestation des soins. Les parents de la famille d'accueil reçoivent habituellement du financement de l'État pour pouvoir dispenser ces soins familiaux.					
Services psychiatriques/de santé mentale destinés aux enfants : Il s'agit de services particuliers de santé mentale qui visent à fournir des soins axés sur la collectivité aux enfants, aux adolescents et à leur famille. Il peut s'agir de médecins de la collectivité (psychiatres), de conseillers, d'équipes communautaires en santé mentale offrant des programmes destinés aux enfants ou aux adolescents et disposant d'employés à cette fin, de spécialistes de l'autisme, etc. Les services offerts englobent des programmes d'évaluation, de diagnostic, de traitement, de gestion, de surveillance, de réadaptation ou d'habilitation.					

Services les plus utilisés	Accessibilité (financé par l'État ou participation aux coûts)		Dans l'affirmative, capacité suffisante	Sinon, devrait l'être	Commentaires
	Oui	Non			
Services de garde intégrés : Des personnes rémunérées fournissent, dans un centre, des soins à des enfants « ordinaires » et à des enfants handicapés ou atteints d'une maladie chronique, et ce, pendant le jour seulement. Habituellement, seuls quelques enfants handicapés ou atteints d'une maladie chronique sont intégrés aux enfants « ordinaires » en bonne santé. Le centre, la famille et les établissements d'enseignement collaborent à la formation du personnel. La taille du centre (nombre de places pour des enfants malades et pour des enfants en santé), l'équipement et les installations, ainsi que la formation du personnel peuvent varier. La tranche d'âge des enfants acceptés varie aussi.					
Services de garde spéciaux : Il s'agit de soins offerts aux enfants le jour seulement dans un centre spécialement conçu pour répondre aux besoins des enfants atteints d'une maladie chronique ou d'un handicap permanent. Le centre, la famille et les établissements d'enseignement participent à la formation des employés, qui sont rémunérés pour leurs services. La taille du centre (nombre de places), l'équipement et les installations, ainsi que la formation du personnel, peuvent varier. La tranche d'âge des enfants acceptés varie aussi.					

Services les plus utilisés	Accessibilité (financé par l'État ou participation aux coûts)		Dans l'affirmative, capacité suffisante	Sinon, devrait l'être	Commentaires
	Oui	**Non**			
Programme préscolaire intégré : Des enfants handicapés ou atteints d'une maladie chronique participent, avec des enfants « ordinaires » d'âge préscolaire, à des activités éducatives. La formation des employés leur permet de contribuer à la croissance et au développement des enfants et de répondre plus particulièrement à leurs besoins psychosociaux et cognitifs. La famille de l'enfant les informe habituellement des besoins physiques et sanitaires particuliers de l'enfant. L'enfant malade peut aussi être accompagné d'un préposé aux soins. La taille de l'établissement (nombre de places), l'équipement et les installations, ainsi que la formation du personnel, peuvent varier.					
Programme préscolaire spécial : Dans un établissement qui a pour spécialité de répondre aux besoins des enfants atteints d'une maladie chronique ou d'un handicap continu, des enfants d'âge préscolaire reçoivent des services, principalement éducatifs, le jour seulement. La formation des employés leur permet de contribuer à la croissance et au développement des enfants et de répondre plus particulièrement à leurs besoins psychosociaux et cognitifs. La famille de l'enfant les informe habituellement des besoins physiques et sanitaires particuliers de l'enfant. L'enfant peut aussi être accompagné d'un préposé aux soins. La taille de l'établissement (nombre de places), l'équipement et les installations, ainsi que la formation du personnel, peuvent varier.					

Services les plus utilisés	**Accessibilité (financé par l'État ou participation aux coûts)**		**Dans l'affirmative, capacité suffisante**	**Sinon, devrait l'être**	**Commentaires**
	Oui	**Non**			
Groupes de soutien (parents/frères et soeurs/enfants : Les groupes de soutien peuvent être dirigés par un professionnel ou créés par une famille, un parent ou un adolescent. Ils peuvent viser à soutenir les parents, les frères et soeurs ou l'enfant/l'adolescent, et visent habituellement à répondre aux besoins sociaux et aux besoins en matière d'information de groupes particuliers, comme les adolescents atteints d'une fibrose kystique, les parents d'enfants ayant des problèmes cardiaques, etc. L'adhésion à ces groupes est volontaire, et la participation peut se faire de façon régulière ou occasionnelle. Souvent, les membres du groupe ayant le plus d'expérience offrent de l'aide à ceux qui en ont moins (il s'agit de soutien par les pairs et d'entraide).					
Aide financière directe aux familles destinée à l'achat de services, d'équipement et (ou) de fournitures : Il s'agit d'un programme qui, à la suite de la présentation d'une demande et d'une évaluation, offre du financement direct aux familles afin que les parents puissent avoir accès à des services de relève (à la maison ou non), à des soignants à l'extérieur de la maison (par exemple, un service de garde pour leur enfant malade), ainsi qu'à de l'équipement spécial et des fournitures requises pour les soins à domicile de l'enfant. Il peut s'agir de seringues, de cathéters, de couches spéciales, de chaises roulantes, de bicyclettes ou de tricycles faits sur mesure, etc.					

Services les plus utilisés	Accessibilité (financé par l'État ou participation aux coûts)		Dans l'affirmative, capacité suffisante	Sinon, devrait l'être	Commentaires
	Oui	**Non**			
Aide financière visant à améliorer l'accès physique : Il s'agit d'un programme qui dédommage les familles ou les soignants à l'extérieur de la maison qui apportent des améliorations permettant aux enfants handicapés ou atteints d'une maladie chronique d'avoir accès aux foyers et aux établissements qui offrent des services.					
Services de transport adapté : Il s'agit de services publics ou privés de transport qui fournissent des services spéciaux permettant de répondre aux besoins particuliers que constituent les enfants malades et leur équipement. Il s'agit, par exemple, d'une entreprise commerciale d'autobus dont les véhicules sont équipés d'un monte-charge, ou d'un service porte à porte personnalisé de taxis accessibles par fauteuil roulant (comme les services Wheel-Trans, Handi-Dart, etc.)					
Soutien en cas d'urgence : Il s'agit de services d'aide en cas d'urgence, offerts par la collectivité et par des organismes (comme des hôpitaux) si l'aide habituelle à la famille ne fonctionne plus, si le soignant principal tombe malade ou est blessé, ou si l'état de l'enfant se détériore de façon inattendue.					
Programme de compagnonnage : Il s'agit habituellement d'un programme bénévole dans le cadre duquel des personnes formées servent de compagnon personnel à un enfant et font avec lui des activités comme se promener, faire du sport, bricoler, magasiner, se divertir (aller au cinéma, louer des films, organiser des fêtes, etc.)					

Services les plus utilisés	Accessibilité (financé par l'État ou participation aux coûts)		Dans l'affirmative, capacité suffisante	Sinon, devrait l'être	Commentaires
	Oui	Non			
Camps d'été : Les enfants handicapés ou atteints d'une maladie chronique peuvent vivre des expériences en camps d'été, qu'ils soient accompagnés ou non de leurs parents et de leurs frères et soeurs. Il peut s'agir d'un camp intégré ou non, c'est-à-dire que l'enfant peut se trouver en compagnie d'enfants « ordinaires » ou non. Ce type de camps est habituellement dirigé par des sociétés, des fondations et d'autres organismes communautaires comme la Société canadienne du cancer, l'Association pulmonaire, la Société d'arthrite, des conseils récréatifs locaux, etc. Au cours du camp, qui dure habituellement d'une à deux semaines, les enfants peuvent effectuer des activités extérieures spécialement adaptées et d'autres types d'activités qui se déroulent habituellement au cours d'un camp d'été. Certaines municipalités offrent aussi le service de camps de jour.					
Prise en charge et coordination : Il s'agit d'un système organisé de prestation de soins de santé et de centres de coordination dans le cadre duquel une seule personne, ou parfois deux personnes, possèdent tous les renseignements importants et pertinents au sujet d'un enfant handicapé ou atteint d'une maladie chronique et de sa famille. Les coordonnateurs des soins peuvent être les parents, des professionnels, ou des intervenants non professionnels, rémunérés ou non, qui mettent en oeuvre, facilitent, orchestrent et organisent l'accès aux ressources et services de la collectivité, ainsi que leur utilisation. La prise en charge permet une meilleure supervision et coordination des soins qui peuvent être offerts par différents fournisseurs de services à différents endroits.					

Services les plus utilisés	Accessibilité (financé par l'État ou participation aux coûts)		Dans l'affirmative, capacité suffisante	Sinon, devrait l'être	Commentaires
	Oui	**Non**			
Services en établissement					
Médecins de famille, pédiatres, spécialistes en pédiatrie, infirmières practiciennes : Il s'agit des principaux fournisseurs de soins de santé qui posent un diagnostic, lancent le traitement et conçoivent les plans de gestion, effectuent des recommandations, surveillent et font le suivi de l'enfant et (ou) de la famille. Leurs services peuvent être offerts par des cliniques privées ou des cliniques en milieu hospitalier.					
Hôpital pour enfant : On trouve, dans la plupart des provinces, des établissements tertiaires ou secondaires désignés dans lesquels les enfants qui ont des problèmes de santé graves et continus reçoivent des traitements et des soins. On y offre uniquement des services aux personnes qui ont moins qu'un certain âge (habituellement 17, 18 ou 19 ans). Ces hôpitaux offrent différents soins intensifs, comme des soins intensifs néonataux, chirurgicaux et médicaux, posent des diagnostics, et offrent des services de réadaptation. Ces services sont habituellement regroupés en fonction des différents types de soins, comme l'oncologie, les maladies transmissibles, etc. Les patients ont accès à une équipe complète de professionnels de la santé et d'employés de soutien. Les hôpitaux offrent des soins sous forme de services aux patients hospitalisés, de services de garde, de services en clinique externe ou de services d'approche. Certains médecins peuvent rencontrer, à leur cabinet ou à une clinique qui se trouve dans l'hôpital, des enfants qui ne sont pas des patients de l'hôpital.					

Services les plus utilisés	Accessibilité (financé par l'État ou participation aux coûts)		Dans l'affirmative, capacité suffisante	Sinon, devrait l'être	Commentaires
	Oui	**Non**			
Service de pédiatrie, hôpital général : S'il est impossible d'établir un hôpital pour enfants en bonne et due forme, on réserve des lits dans un hôpital général aux enfants qui doivent recevoir des soins actifs ou prolongés, que ce soit dans un service de pédiatrie ou dans une salle commune avec des adultes. Dans ce type de service, les enfants peuvent avoir accès à une gamme complète ou partielle de services et à du personnel formé. On y adapte ou modifie les services offerts aux adultes afin de pouvoir les offrir aux enfants. Il ne s'agit pas d'un établissement tertiaire.					
Cliniques ambulatoires/externes : Les cliniques peuvent être associées à différents établissements, peuvent se trouver dans différents types d'installations, et peuvent offrir différents services spéciaux et généraux de diagnostic, de traitement, de soutien ou de surveillance. Les soins directs peuvent être dispensés par des professionnels de la santé issus d'un certain nombre de disciplines, qui peuvent travailler seuls ou en équipe. L'enfant peut être examiné pendant quelques minutes ou pendant une journée entière, et au cours d'une seule journée ou de plusieurs jours (consécutifs), mais il demeure dans la collectivité et n'est pas admis à l'établissement.					

Services les plus utilisés	Accessibilité (financé par l'État ou participation aux coûts)		Dans l'affirmative, capacité suffisante	Sinon, devrait l'être	Commentaires
	Oui	Non			
Services prolongés, continus ou de réadaptation offerts aux malades hospitalisés : Ces services sont offerts par un établissement général ou spécialisé qui offre des soins de santé prolongés aux enfants (ou aux enfants et aux adultes). Le séjour du patient dure habituellement plus d'un mois et commence au moment où l'état du patient n'est plus grave et où il y a eu stabilisation de son état et de son programme de traitement. Les soins visent à procurer le meilleur état de santé possible à l'enfant et peuvent inclure ou non un programme de réadaptation active. Parfois, l'enfant et sa famille peuvent avoir accès à un nombre très réduit de lits réservés au service de relève.					
Soins palliatifs dans la collectivité ou dans les hôpitaux : Si l'on juge qu'un enfant est en phase terminale, il est possible de lui offrir des soins à temps plein ou à temps partiel sous la forme de soins palliatifs dans la collectivité ou à l'hôpital. Les soins palliatifs visent à garder l'enfant le plus en santé possible et à lui offrir du confort; il ne s'agit pas d'un traitement actif de sa maladie. Certains établissements offrent une certaine forme de soins palliatifs aux enfants qui reçoivent de soins actifs ou des soins prolongés.					

Services les plus utilisés	Accessibilité (financé par l'État ou participation aux coûts)		Dans l'affirmative, capacité suffisante	Sinon, devrait l'être	Commentaires
	Oui	**Non**			
Services en matière d'éducation et de formation professionnelle					
Programme scolaire intégré : Dans le cadre du système scolaire habituel, les établissements d'enseignement permettent ou encouragent généralement l'intégration des enfants handicapés ou atteints d'une maladie chronique aux classes d'enfants en bonne santé. Dans ce cas, les professeurs et les autres employés de l'école adaptent les classes habituelles et les activités scolaires afin de pouvoir répondre à tout besoin particulier de l'enfant handicapé ou atteint d'une maladie chronique. Les parents et les enfants doivent souvent participer et expliquer les caractéristiques de l'état de l'enfant et de ses traitements aux autres enfants, aux professeurs et aux employés administratifs de l'école.					
Programme scolaire intégré, avec aides aux études : Dans le cadre du système scolaire habituel, des établissements d'enseignement permettent ou encouragent généralement l'intégration d'enfants handicapés ou atteints d'une maladie chronique dans les classe d'enfants « ordinaires », en bonne santé, à condition que l'enfant malade soit accompagné d'une personne qui l'aide dans ses études ou dans ses soins. Cette personne reçoit une formation lui permettant de répondre aux besoins de l'enfant au chapitre des soins de santé, alors que les professeurs et les autres employés de l'école s'occupent de ses besoins en matière d'éducation. Il faut parfois modifier l'accès à l'école, les installations et les programmes afin de répondre aux besoins de l'enfant handicapé ou atteint d'une maladie chronique.					

Commonly Used Services	Available (publicly funded or co-pay)		If yes, sufficient capacity	If no, should it be	Comments
	Yes	No			
Écoles et (ou) programmes spéciaux : Certains programmes d'enseignement, offerts dans le cadre du système scolaire habituel ou par une école privée, peuvent être élaborés afin de répondre particulièrement aux besoins des enfants handicapés ou atteints d'une maladie chronique. Le personnel a alors reçu une formation lui permettant de contribuer à la croissance et au développement de l'enfant d'une façon appropriée, en répondant plus particulièrement à des besoins psychosociaux et cognitifs. Les employés reçoivent une formation officielle (à laquelle s'ajoute souvent une formation offerte par la famille) concernant les besoins physiques et sanitaires particuliers de l'enfant. L'enfant peut être accompagné ou non d'un aide-soignant particulier. La taille de l'établissement (le nombre de places), l'équipement et les installations, ainsi que la formation du personnel, peuvent varier.					
Professeurs ou tuteurs à domicile : Les conseils scolaires ou d'autres instances peuvent embaucher des professeurs qui offriront de l'enseignement ou du tutorat à domicile aux enfants qui ne peuvent assister aux cours habituels, que ce soit à court ou à long terme. Il faut distinguer cette situation de celles où des parents choisissent d'enseigner à domicile à leurs propres enfants, ou de celle où les parents embauchent personnellement des tuteurs pour améliorer les connaissances d'un enfant dans une matière particulière.					

Services les plus utilisés	Accessibilité (financé par l'État ou participation aux coûts)		Dans l'affirmative, capacité suffisante	Sinon, devrait l'être	Commentaires
	Oui	Non			
Formation professionnelle : Certains programmes spéciaux, offerts occasionnellement par différentes sources, préparent les enfants plus âgés ainsi que les adolescents handicapés ou atteints d'une maladie chronique à des emplois et des carrières. De plus, une fois que les enfants ont terminé leur scolarité officielle, ils ont accès à des cours personnels qui peuvent les aider à perfectionner leurs compétences en fonction de leur handicap ou de leur maladie, ce qui leur permet de devenir des membres à part entière de la société. Ils peuvent, par exemple, acquérir des compétences en matière d'informatique adaptée, en matière de recherche d'emploi, etc. Ce type de formation peut être offert sur une base individuelle, en petits groupes ou en plus grands groupes, et des jeunes enfants en santé peuvent aussi y assister.					
Services judiciaires					
Services judiciaires : Il s'agit de services axés sur les enfants et les familles qui, en raison de l'état de l'enfant, vivent une situation qui les pousse à entrer en contact avec la police et (ou) le système judiciaire. Cette situation peut être l'arrestation de l'enfant, l'établissement et la surveillance d'une ordonnance de la Cour, les mesures prises afin de protéger l'enfant, les programmes ciblés (comme ceux qui sont destinés aux enfants qui souffrent des EAF, du SAF, du syndrome d'alcoolisme néonatal, ou de problèmes mentaux, émotifs ou d'apprentissage), etc.					

APPENDIX C

Analysis of Interfaces along the Continuum of Care Project
Children's Research Team

INTRO

Thank you for agreeing to participate in our survey which is part of an Analysis of Interfaces Along the Continuum of Care. The purpose of this project is to examine what makes for an integrated continuum, or system, of care delivery for four population groups, including families (and others) who are caring in the community for children who have a wide range of chronic physical, developmental, and/or mental health conditions or disabilities that require community based services. (As a short-form, I may use the term 'children with special needs' to refer collectively to this population of kids.)

We'll try to take approximately one hour to obtain your views about:

- what the most commonly used or needed (core) health services are for children and their families, and where the gaps and efficiencies are.
- how well these services are currently integrated into a system of care
- how well these services are linked to other parts of the health system (such as hospitals, physicians and community/public health)
- how well they are linked to services outside of the health system that also have an impact on children and their families (like social, education, or judicial services)

We will also ask for your views about what you think makes for an effective system of service delivery, what current barriers there are to effective, integrated service delivery, and what suggestions you may have for improving the system of service delivery for children and their families.

As you know from our letter/e-mail, your participation is totally voluntary. You may refuse to answer any question, and you may stop the interview at any time. Any responses you provide are confidential to the research team. Do you have any questions before we start?

A. Commonly Used Community Based, Health Related Services for Children and their Families

The first set of questions addresses commonly used health care services for children in home or residential care; later questions will address a range of associated services such as acute-care, social, educational, and judicial services used by the same children and families.

1. Commonly Required (Core) Health Services for Children

We sent you a list of commonly required (or core) community, residential, hospital and educational services that may be used by children and their families. To us, these constitute the potential "system" of children's services.

From your point of view, are there any there that don't belong or are missing in your jurisdiction?

- Are there any services that you would add to this list?
- In your opinion, is there adequate capacity for these services in your area?

2. Current Gaps in Commonly Required/Core Health Services

What are the gaps in current services for children and families?

- Please tell me about any efficiencies or inefficiencies in service provision

3. Access to Commonly Required/Core Health Services

How do children typically access these services, or enter the system?

- To what extent are these services coordinated or integrated with each other?
- Do you see important trends and issues in your jurisdiction with respect to coordination and integration?

4. Positive and Negative Factors Influencing Access and Integration to Commonly Required/Core Health Services

In your opinion, what are the top two or three barriers to service access and/or integration for children and families in your jurisdiction?
(Interviewer uses "barriers grid" to record and prompt for responses.)

- What recent initiatives have been implemented or considered in your jurisdiction to promote integration among services?
- Of those initiatives that ARE underway, how well have they worked/how are they doing?

5. Funding

Is current funding adequate to meet the needs of children and families in your jurisdiction?

- To what extent does money follow the client from one service/program to another?
- To what extent is affordability of a service related to availability?
- What discretion do families have to determine how available funds are best used?

6. Future Steps

Within the range of services we have discussed, what are your thoughts about what would be needed to achieve optimal integration? (i.e. develop a **system** which would maximize the available use of resources to achieve better care and better health outcomes).

B. Associated Services

This second set of questions addresses issues related to the integration or coordination between children's services in the home care/community health sector and other associated services (such as hospital and physician services, and social, educational, and judicial services) used by the same children and families. We're calling these "associated services".

7. Current Gaps in Associated Services

What are the gaps in service availability or utilization in associated services for children and families? (You may refer again to the chart of services and their definitions that we provided earlier— the end of section 1, all of 2 and 3)

- Are there efficiencies or inefficiencies in the provision of services in this sector of "associated services"?

  If so, please explain.

8. Positive and Negative Factors Influencing Access and Integration among Commonly Required (Core) Health-Related Services and Associated Services for Children and Families

In your opinion, and in your jurisdiction, what are the main barriers to service access, coordination, and integration among the primary **health** services for children and families that we've been talking about and **associated** services, such as those in social or education services? (Interviewer uses same "barriers grid" as in #4 to record and prompt responses.)

- What recent initiatives have been implemented or considered in your jurisdiction to promote the integration of services between sectors of services?
- Of those initiatives that ARE underway, how well have they worked/how are they doing?

9. Strengths and Weaknesses of Integration between Sectors

9a) To what extent do you feel that the commonly required/core community health services for children and families are integrated with those in the associated services sector?

9b) What are the strengths and weaknesses in the linkages with these associated services?

9c) To what extent are formal services for children and their families integrated with informal services that may be provided by individuals such as family caregivers, including extended family members and volunteers?

9d) To what extent can children move between types of services and locations of services? (i.e. moving from hospital based to community based to school based services)

9e) To what extent are these associated services for children and their families currently provided in the most cost-effective way (that is, in the most appropriate setting by the most appropriate provider)?

10. Funding/Financial Issues Between Sectors

Within the health, social services, and education sectors broadly (the overall "system"), is it possible to move funds between the identified sets of services and components of the system (e.g. **between** hospitals, physicians, social services, education, etc.)?

- How does funding follow the client between the commonly required/core health related services and the associated services such as education and social services?
- Are there cases where children meet criteria for one service but not for another? For example, different policy requirements among various Ministries and/or programs?

  Please explain

- To what extent are there funding incentives to provide particular services?

11. Future Steps related to associated services for children

Considering these associated services, what are your thoughts on what would need to be done (if anything) to achieve an integrated continuum, or system, of care which maximizes the available use of resources to achieve better care and better health outcomes for children and families?

C) Strengthening the Level of Coordination Between Services

12. What supports across service sectors are essential to achieving the best possible health, social, and education services for children and families?

- What policy initiatives (if any) would strengthen the interface and level of integration or coordination between the set of commonly required/core health services and associated services for children with special needs and their families?

Examples of Potential Positive and Negative Factors Related to Integration Barriers Grid for Interviewers use During Interviews

Category	Potential Factors Related to Integration	Comments
Clinical Practice	Single point of entry	
	Assessment instruments for each type of service	
	Consistent classification system across types of service	
	Care Coordination across service components	
	Other	
Communication Within and Between Services	Consumer access to relevant information at all service locations	
	Communication between types of services	
	Other	
Administration	Integrated planning across service components	
	Single administrative structure to coordinate care	
	Consistent human resources policy across service components	
	Other	
Finance	Funding incentives for quality care	
	Equitable funding models	
	Performance contracts	
	Other	
Evaluation and Outcome/Accountability	Accountability system	
	Evaluation and quality assurance	
	Integrated information system	
	Other	
Policy	Policy which reflects a coherent philosophy of care	
	Policy which allows front line workers to make decisions based on need rather than fiscal limitations	
	Other	
Regional Differences	Influence of the size/location of a region on the availability of a service	
	Other	

Plan d’entrevue

A. Soins de santé les plus utilisés par les enfants et leur famille

Les premières questions porteront sur les soins de santé les plus utilisés par les enfants; et les dernières questions porteront sur les services connexes qui servent à ces mêmes enfants et leur famille, notamment des services sociaux, scolaires et juridiques.

1. Soins de santé les plus utilisés (ou essentiels) par les enfants

Nous vous avons envoyé une liste des soins les plus utilisés (ou des soins essentiels) par les enfants et leur famille aux niveaux communautaire, résidentiel, hospitalier et scolaire. Selon nous, cette liste représente ce qui pourrait constituer un « système » de services pour les enfants.

1a) Selon vous, certains des soins sur la liste sont-ils de trop ou inaccessibles dans votre région?

1b) Ajouteriez-vous d’autres soins à cette liste?

1c) Selon vous, ces soins sont-ils adéquats dans votre région?

2. Lacunes courantes aux soins de santé les plus utilisés (ou essentiels)

2a) Quelles sont les lacunes actuelles des soins pour les enfants et leur famille?

2b) Pourriez-vous me décrire en quoi les soins sont efficaces ou inefficaces?

3. Accès aux soins de santé les plus utilisés (ou essentiels)

3a) En général, comment les enfants ont-ils accès à ces soins ou sont-ils inscrits dans le système?

3b) Dans quelle mesure ces soins sont-ils coordonnés ou intégrés les uns aux autres?

3c) Selon vous, votre région est-elle touchée par certains courants ou enjeux relatifs à la coordination et l’intégration des soins?

4. Facteurs, positifs et négatifs, qui ont une influence sur l’accès et l’intégration aux soins de santé les plus utilisés (ou essentiels)

4a) Selon vous, quels sont les deux ou trois principaux obstacles à l’accès et (ou) à l’intégration des soins pour les enfants et leur famille dans votre région?
(L’intervieweur utilise « la grille des obstacles » pour susciter des réponses et les inscrire.)

4b) Quelles initiatives gouvernementales ont été récemment mises en oeuvre ou envisagées dans votre région pour promouvoir l'intégration des services?

4c) Les initiatives **actuellement** en cours ont-elles été efficaces jusqu'ici?

5. Financement

5a) Le financement actuel répond-il adéquatement aux besoins des enfants et de leur famille dans votre région? Veuillez préciser.

5b) Dans quelle mesure les fonds sont-ils répartis en fonction des besoins du client d'un service, ou programme, à un autre?

5c) Dans quelle mesure le coût lié au service est-il lié à son accessibilité?

5d) Dans quelle mesure les familles peuvent-elles déterminer la meilleure manière d'utiliser les fonds alloués?

6. Étapes futures

Selon vous, comment devrions-nous nous y prendre pour intégrer aussi complètement que possible les soins dont nous avons discuté? (c.-à-d. pour élaborer un **système** qui puisse utiliser toutes les ressources à sa disposition pour assurer de meilleurs soins et résultats dans ce domaine?

<u>B. Services connexes</u>

Cette deuxième série de questions porte sur l'intégration ou la coordination des soins pour les enfants dans le secteur des soins à domicile et de la santé communautaire, et des services connexes (p. ex., soins fournis par les médecins et les hôpitaux, et services sociaux, scolaires et juridiques) qui servent aux mêmes enfants et à leur famille. Nous les désignons par « services connexes ».

7) Lacunes actuelles des services connexes

7a) Quelles sont les lacunes au chapitre de l'accessibilité ou de l'utilisation des services connexes pour les enfants et leur famille? (Vous pouvez consulter de nouveau la liste de soins et de définitions que nous vous avons fournie à la fin de la section 1, ainsi qu'aux sections 2 et 3.)

7b) Ces « services connexes » sont-ils fournis de manière efficace ou inefficace? Veuillez préciser.

8) Facteurs positifs et négatifs qui influencent l'accès et l'intégration des soins de santé les plus utilisés (essentiels) et des services connexes pour les enfants et leur famille

Selon vous, quels sont les principaux obstacles, dans votre région, à l'accès, la coordination et l'intégration des soins de **santé primaires** pour les enfants et leur famille, dont nous avons déjà discuté, et des services **connexes**, par exemple les services sociaux ou scolaires? (L'intervieweur se sert de la « grille des obstacles », comme il l'a fait à la question numéro 4, pour susciter des réponses et les inscrire.)

8a) Quelles initiatives gouvernementales ont été récemment mises en oeuvre ou envisagées dans votre région pour promouvoir l'intégration des services entre secteurs?

8b) Les initiatives **actuellement** en cours ont-elles été efficaces jusqu'ici?

9. Forces et faiblesses de l'intégration des services entre secteurs

9a) Selon vous, dans quelle mesure les soins de santé communautaire les plus utilisés (ou essentiels) pour les enfants et leur famille sont-ils intégrés avec ceux du secteur des services connexes?

9b) Que constituent les forces et les faiblesses de l'intégration à ces services connexes?

9c) Dans quelle mesure les soins officiels pour les enfants et leur famille sont-ils intégrés aux soins officieux que peuvent fournir des particuliers, notamment les soignants d'une famille, y compris les membres de la famille étendue et les bénévoles?

9d) Dans quelle mesure les enfants peuvent-ils facilement avoir accès à différents types de soins et se déplacer entre établissements (p. ex. entre soins hospitaliers, communautaires et scolaires)?

9e) Dans quelle mesure ces services connexes pour les enfants et leur famille sont-ils actuellement rentables (c.-à-d. l'établissement et le fournisseur qui conviennent le mieux)?

10) Questions de financement et de finances entre les secteurs

10a) Dans l'ensemble des secteurs de la santé, des services sociaux et de l'éducation (le « système » global), les fonds peuvent-ils être répartis différemment entre les services précisés et les composants du système (p. ex. **entre** les hôpitaux, les médecins, les services sociaux et l'éducation)?

10b) Dans quelle mesure les fonds sont-ils répartis en fonction des besoins du client entre les soins de santé les plus utilisés (ou essentiels) et les services connexes, comme l'éducation et les services sociaux?

10c) Arrive-t-il que des enfants soient admissibles à un service, mais pas à un autre? Par exemple, en raison d'exigences stratégiques différentes selon le ministère et (ou) les programmes? Veuillez préciser.

10d) Existe-t-il des mesures qui encouragent (ou découragent) la prestation de certains services?

11) Étapes futures relatives aux services connexes pour les enfants

Selon vous, compte tenu des services connexes, que faudrait-il faire (s'il y a lieu) pour établir un continuum, ou un système, intégré de soins de santé qui utilise toutes les ressources à sa disposition pour améliorer les soins et la santé des enfants et leur famille?

C) Renforcement de la coordination des services

12a) Quels appuis tous les secteurs de services doivent-ils obtenir pour assurer les meilleurs services sanitaires, sociaux et scolaires qui soient aux enfants et à leur famille?

12b) Quelles initiatives stratégiques (s'il en existe) renforceraient l'interface et le niveau d'intégration ou de coordination entre l'ensemble des soins de santé les plus utilisés (ou essentiels) et les services connexes pour les enfants ayant des besoins particuliers et leur famille?

Focus Group Questions
for the Coordination of Services
for Children with Special Needs and their Families

Introduce selves and roles

Sample Introduction:

As you know, we're interested in your views, as experts, about the “big picture” of service delivery for children with long-term or chronic conditions, disabilities, challenges, handicaps—the whole range of situations for children and families that are often termed “special needs” for short. [*Refer to printed handout of definitions and grid of services*] The project is funded by Health Canada, who are interested to know your views on two main things:

- How services are integrated with one another, both in the home care/community sector and also among **other** services, like hospital and primary care, social services (MCF), judicial services, education, and so on, and

- What supports are essential to the success of home/community care. That is, what needs to change and how (i. e., strategies), with a special emphasis on policy changes that are necessary.

- Mention who we’re working with (on kids’ part of the study):

  - 4 populations in all
  - Children’s Team: group from UofT and us
  - Marcus Hollander from Hollander Analytical, who’s the overall coordinator for the 4 teams

The government and agency people we’ve talked with across the country have identified some major issues related to the lack of integrated, coordinated systems of services for children and families, funding shortfalls, organization of services, “silo” or “stovepipe” approaches, problems of access, waitlists, rural/urban disparities, human resource issues, lack or respite options, and so forth. In all, we’ve found that they have a good grasp on the issues, but we really need **your** voices, “from the trenches” so to speak.

We have formulated some questions to get us and keep us going, but we’re interested in any of your views relevant to the integration of service delivery for children and families. Please try to think “big picture”, even though we know we’re all influenced by situations in BC.

Finally, we just need to agree that what's said here is private. The information we gather will not be associated to any one individual. Rather, it will be noted and analyzed as group information.

Questions

1. From the big table of all the services for kids and families on your handout [same as for gov't and agency interviews], can you think of any services that are missing?
   - What do you see as the strengths of service delivery?
   - Shortfalls (i. e., inefficiencies and gaps)?

2. Typically, how would a child enter the "system"?

3. Can children move around in the system easily?
   - What makes this movement possible, in your view? (i. e., the facilitators)
   - What do you think are the blockages or barriers to free movement?
   - So, once in the system, does the funding follow the child as service needs change?

4. What are the linkages with the community sector?
   - What about between home-based services and other services, like hospital and MD care, social services, etc.?

5. Can you tell me a bit more about any funding issues, say, related to resource allocation?

6. So in summary, would you say that services for kids are a **system** of care?

7. If you had your "dream scenario", what would you wish for children and their families?
   - In other words, what **could be** (rather than what is)?
   - **How** do you see this being accomplished?

8. Got a "last word" for Health Canada?

Thank you **so** much for participating. We'll be sure that your ideas are well represented in our report.