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DEPARTMENT OF HEALTH POLICY, MANAGEMENT  
and EVALUATION

***Prescriptions for Pediatric Home Care:  
Analyzing the Impact of the Shift from  
Hospital to Home and Community on  
Children and Families***

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## ***Executive Summary***

This report summarizes the findings of a multi-year research project, conducted at the University of Toronto, which analyzed key policy questions connected with the funding, allocation and delivery of pediatric home care in Ontario.

Ontario, like other jurisdictions, has experienced steadily increasing need for home care for children and families due to multiple converging factors. The first concerns a growing population of children with continuing care needs. More children who would previously have died at birth or before becoming adults, now live longer and fuller lives due to advances in medical technology, although they require ongoing care for most or all of their lives. A second factor is related to health system restructuring. During the past decade, Ontario, like other jurisdictions nationally and internationally, has seen a marked trend away from care in hospitals and institutions through a reduction of in-patient beds and decreased lengths of in-patient hospital stays. As a consequence more children with more complex needs require care in home and community.

In principle, a shift from hospitals to home and community should benefit children. A growing literature suggests that, other things being equal, health outcomes and quality of life for children may be better in non-institutional settings due to family support, nurturing, and the home environment. Care at home may also aid in healing through provision of a more normative environment where the psychological needs of children are better met. However, this assumes that children and families who require care in home and community are able to access care at a level which is at least comparable to that available in hospitals and institutional settings. Without such access, children and families may instead experience a variety of negative outcomes as they cope with the stress of providing care, often on a long-term basis.

This research examines the case study of Ontario. It utilizes qualitative and quantitative methods and multiple data sources to investigate the extent to which growing needs for pediatric home care were matched by access to publicly funded services provided by Community Care Access Centres (CCAC) between 1997 and 2002, a period of significant policy change. Specifically, it documents and analyzes:

- The organization of services for children and families in Ontario's publicly-funded home care agencies (CCACs);
- Trends in the demand for, and the supply of, such services;
- Patterns of allocation decisions determining the mix and volume of home care services provided to different groups of children (e.g. acute care in comparison to chronic care), and to children in comparison to other needs groups (e.g. seniors) across Ontario; and
- The impact of Ontario's managed competition model for purchasing services on the supply, costs and quality of pediatric home care services.

Our analysis leads us to a number of major conclusions.

First, pediatric home care in Ontario is not yet a cohesive policy field. Programs and services,

legislation and funding mechanisms, and approaches to care remain fragmented. While a lack of integration and coordination is common across Canadian jurisdictions, Ontario provides an excellent example of how, lacking a coherent policy framework, services for the growing number of children who require them may be influenced by a range of system level, organization level and provider level factors, leaving need as only one and possibly not even the most important factor determining access to services for children and families.

Second, the organization of pediatric home care varied substantially across the province. While study respondents stated that there was a growing awareness of the importance of pediatric home care, no CCAC had a dedicated or “protected” pediatric budget. Nor were there specific individuals at the management level who were solely responsible for children’s programs; these were combined with other responsibilities. While producing considerable degrees of freedom to move resources between service categories and client groups, there were few mechanisms to regulate or evaluate the outcomes of alternative organizational arrangements or resource allocation decisions.

Third, there was overwhelming agreement among our respondents that pediatric home care needs had grown substantially due to technological advances which meant that more children with higher levels of need lived longer and fuller lives, and health system restructuring which had shifted pediatric needs to home and community. Other factors impacting on demand for pediatric home care included shifts in proximate policy fields such as education, where cuts to classroom resources had made it increasingly difficult to provide individualized attention to children with special needs, and eroded opportunities for professionals sent by CCACs to develop care plans which could be implemented in the classroom.

Fourth, we found broad consensus that there was a growing gap between pediatric home care needs and access to services. Even though service utilization by children and families increased somewhat as a proportion of all CCAC services, it was widely perceived that needs grew at a faster pace. Particularly as CCACs experienced budget constraints, parents felt that they had moved from “care management,” focused on the needs of children and families, to “cost management,” focused on the need to reduce costs and balance budgets. Utilization management strategies employed by CCACs included the implementation and management of wait lists; changes in treatment goals and delivery modalities; systematic reviews of “active caseloads” often resulting in service reductions; and management of expectations.

Fifth, the introduction of managed competition was widely seen to have had a range of negative consequences for pediatric home care. Although the competitive bidding process had been justified as a way of achieving “highest quality, lowest cost,” it instead resulted in a decline in the number of providers willing to bid on CCAC contracts for specialized, low volume services in uncertain markets; in higher service and administrative costs; in downward pressures on service volume; and in structural impediments to service quality.

Sixth, filling a vacuum created by a lack of provincial policy, by few explicit CCAC guidelines

for the allocation of limited resources between and within needs groups, and by little collaboration between the major actors in the field, CCAC case managers took on increasingly important roles as resource allocation decision-makers. On the one hand, their discretion presented opportunities to individualize care to the needs of children and families. On the other hand, discretion with few decision-making supports also produced major inconsistencies both in approaches to determining needs and allocating resources.

Finally, as CCACs responded to resource constraints, higher priority was given to "medical" services such as nursing over "non-medical" services such as rehabilitation and homemaking. While paralleling trends in other parts of the health care system, this runs counter to one of the major justifications of the shift of pediatric care from hospitals to home and community, which was that care would be progressively "de-medicalized" within the context of the family home. However, because home care is not a universal Medicare entitlement, access even to medical care through the CCACs was no longer guaranteed.

In summary, we note that while our data have gaps, they paint the most comprehensive picture to date of home care developments in Ontario between 1997 and 2003 and their impact on children and families.

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## ***1.0 Introduction***

This report summarizes the findings of a multi-year research project, conducted at the University of Toronto, which analyzed key policy questions connected with the funding, allocation and delivery of pediatric home care in Ontario.

While growth in the need for such care is the result of many converging factors, two factors have played a pivotal role. The first concerns a growing population of children with complex continuing care needs. While it is often remarked that demands on the Canadian health care system are increasing because of an aging population, what has been less remarked, and not well documented, is the extent to which the care needs of children and families have also grown. Many children who would have died at birth or during their childhood, now live longer and fuller lives due to advances in medical technology. Moreover, the prevalence of low birth rate babies, and the acute and chronic complications that often accompany them, have proven remarkably persistent, while new immigration patterns have brought with them unfamiliar children's health problems requiring not only complex continuing care, but culturally-sensitive care within the family context.

A second factor is related to health system restructuring. During the past decade, Ontario, like other jurisdictions nationally and internationally, has seen a marked trend away from care in hospitals and institutions, through a reduction of in-patient beds, decreased lengths of in-patient hospital stays, and a concomitant emphasis on care in home and community (Havens, 1998; Health Canada, 1999a, 1999b, 1999c; Coyte & Young, 1997; CIHI, 2000; 2004). There have been three major justifications for this trend: evidence that many procedures done on an in-patient basis can be done just as effectively on an ambulatory basis; assumptions that care in home and community can achieve cost-efficiencies compared to care in institutional settings; (Coyte & Young, 1999; Chappell, 1994; Jackson, 1994; Hollander, 1994; 1999); and the belief that services provided "closer to home" can enhance consumer choice, independence and quality of life, positively affecting health and well-being (Shapiro, 1992). In this connection, a growing literature suggests that, all things being equal, health outcomes and quality of life for children may be better in non-institutional settings due to family support, nurturing, and the home environment (CACC, 1995; Fahrenfort, 1996; Jessop & Stein, 1991; Kohrman et al., 1997; McKeever, 1992; Stein & Jessop, 1984; 1991; Wright, 1995). Care in the home may also aid in healing through provision of a more normative environment where the psychological needs of children are better met (Jessop & Stein, 1991, 1994; Stein & Jessop, 1984, 1991). The report of the Kirby commission into health care in Canada estimated that children now account for up to 15% of home care clients in this country (Kirby, 2002).

However, such positive outcomes assume that children and families who require care in the home and community are able to access care at a level which is at least comparable to that available in hospitals and institutional settings. Without such access, children and families may instead experience a variety of negative outcomes as they cope with the stress of providing care, often on a long-term basis, thus jeopardizing not only the health and well-being of the child, but the integrity of the family unit (McKeever, 1992, 1996). Research shows that families with children with chronic conditions tend to have low levels of income from sources other than employment; thus inadequate access to services can produce the double jeopardy of disrupting

employment income, because of the need for family members to provide care themselves, even as they may have to purchase additional services out-of-pocket. In such circumstances, the health and well-being of the child and the family may suffer (CICH, 2000). An inability to access needed services is likely to have the most detrimental impact on children with long-term and chronic care needs who are disproportionately represented in the 20% of Canadian children living in poverty (National Council of Welfare, 1999; CICH, 2000).

From the perspective of the well-being of children and families, the matching of needs with services is crucial; as pediatric care needs grow and as they shift to home and community, access to home and community services must follow. However, from a health policy perspective, this matching is not automatic, particularly in a period when demands from multiple, often competing needs groups (e.g., seniors, persons with disabilities, and adults with acute care needs) for home care are also increasing, and when governments are called upon to fund a range of services beyond home care including housing and education, which also impact directly on children's health and well-being. Canadian governments have placed high priority on children's needs; in 2000 the federal government announced an infusion of an additional \$2.2 billion to the provinces over five years for children (Lawton, 2000). Nevertheless, there has been little evidence to show what proportion of these resources have actually been used to enhance home care services for children and families, how available pediatric home care resources are allocated, or the extent and impact of service gaps.

Issues of access to home care are complicated by the fact that the Canada Health Act, the legislative basis of government health care insurance (Medicare), requires that provincial plans provide universal, comprehensive coverage, but only for medically-necessary services delivered in hospitals and by doctors; when delivered in home and community or by other providers, even medically-necessary services may or may not be publicly funded. This applies to a range of common hospital services including nursing, rehabilitation, personal care, nutrition, and social work as well as pharmaceuticals. This means that provinces have considerable freedom to innovate and find more cost-effective ways to deliver services. However, it also means that provinces are free to limit the volume and mix of home care services they will fund in order to contain costs. As both the recent Romanow and Kirby commissions into the future of health care in Canada observed (Romanow, 2002; Kirby, 2002), as care has moved from hospitals to home and community, differences in coverage not only between provinces but within them have become more marked.

In Ontario, issues of access to home care for children and families, as well as for other needs groups, have been further complicated by a major policy shift which regionalized home care services. In 1996, Ontario's Progressive Conservative government established 43 Community Care Access Centres (CCACs) across the province, each with its own geographic catchment area. CCACs conduct client assessments, provide case coordination and case management and they purchase mostly professional services to meet client needs (e.g., nursing, physiotherapy, occupational therapy, speech-language pathology, social work, and homemaking). They also make referrals to community support services and arrange admissions to long-term care

institutions (Baranek, Deber and Williams, 2004).

There are important differences between the CCACs and the provincial home care programs they replaced. While the home care programs often delivered specialized, low volume services such as physiotherapy using their own staff, or contracted services mostly to not-for-profit providers such as the Victorian Order of Nurses (VON) on a collaborative basis, CCACs purchase services on a competitive basis from private for-profit and not-for-profit providers through a request for proposals (RFP) process similar to tendering. By introducing commercial market forces into home care, while “managing” competition to ensure that quality was not sacrificed, Ontario’s “managed competition” reform was supposed to achieve the goal of “highest quality, lowest cost;” the logic was that lower costs would allow for a greater volume of services to be purchased to meet growing needs. Further, while services provided by the previous home care programs had been covered as a Medicare entitlement under the Ontario Health Insurance Plan (OHIP), CCAC services are purchased within capped annual budget envelopes set by the province, and as such, they are not under universal Medicare coverage or the uniform terms and conditions of the Canada Health Act. The only entitlement clients have is to be assessed for home care services, not to receive them. While CCAC services are free of charge to the client when they are provided, access varies from CCAC to CCAC and from year to year due to variable eligibility requirements and budget constraints. Indeed, after successive years of budget overruns by many CCACs, in 2001 the province “capped” CCAC budgets at 2000/2001 levels. As some CCACs complained publicly that provincial funding was not sufficient to meet need, the province introduced legislation which in effect terminated all CCAC Executive Directors (EDs) and Board members; it then appointed EDs and Boards directly accountable to the government.

While these trends and developments are well documented, our research aimed to assess the implications for children and families. In the sections below, we provide details of our data and methods, and then present findings and conclusions.

## **2.0 Research Questions**

This research examined patterns of utilization of pediatric home care services, and factors impacting on these patterns, in Ontario between 1997 and 2002, a period of significant policy change.

Specifically, it aimed to document and analyze:

- The organization of services for children and families in Ontario's publicly-funded home care agencies (CCACs);
- Trends in the demand for, and the supply of, such services;
- Patterns of allocation decisions determining the mix and volume of home care services provided to different groups of children (e.g. acute care in comparison to chronic care), and to children in comparison to other needs groups (e.g. seniors) across Ontario; and
- The impact of Ontario's managed competition model for purchasing services on the supply, costs and quality of pediatric home care services.

### **2.1 Relevance**

While focused on Ontario, these questions are relevant to other jurisdictions.

First, paralleling a trend in most OECD (Organisation for Economic Co-operation and Development) countries during the past decade, all Canadian provinces have experienced a substantial decline in hospital beds and in-patient hospital stays, and a concomitant increase in demand for home and community care. However, there has been relatively little documentation of the extent to which access to home care services has matched needs, although there is a strong sense, reflected in the Kirby and Romanow reports, and more recently in the 10-Year Plan to Strengthen Health Care arising from the First Ministers' meeting in September 2003, that more publicly funded home care services are required.

Second, it appears that the shift out of hospitals, and thus out of universal Medicare coverage, has contributed to considerable variation in the mix and volume of publicly funded home care services available not only between provinces, but within them. While care in hospitals is covered by universal government health insurance, care in home and community is not. In this connection, Ontario provides an instructive case study since its 43 CCACs have each responded in different ways to needs within their geographic catchment areas.

Third, Ontario's home care reform raises the crucial question of what happens to relatively small needs groups like children as services are placed under capped budgets. Ontario's CCACs, like regional health authorities in other provinces, face tough allocation decisions, not only between service categories (e.g., nursing versus rehabilitation) but between needs groups (e.g., adults, seniors, children, persons with disabilities) and within them (e.g., children with post-acute short term vs. chronic care needs).

Finally, although Ontario's health care system is often seen as unrepresentative of other parts of the country, a national study conducted in 2001 (Spalding, Hayes, Williams and McKeever,

2001), found that with respect to children and families, all provinces and territories experienced similar problems. For instance, the study concluded that there was no real continuum of services for children and families in any province or territory and that there were only loosely linked services with multiple transitions between life stages, programs, agencies, providers, and funding sources. It found that little progress had been made in addressing previously identified home care policy issues for children and families. (Hayes, Hollander, Tan, & Cloutier, 1997; McKeever, 1996). Findings suggested that services to children were fragmented and unequally distributed in most Canadian communities. Further, ongoing fiscal pressures had reduced the basic skeletal home and community supports currently available to an unprecedented low. Up to 20 different supports and services in the home and community were needed; however, lack of access to appropriate pediatric health care services in home and community was a common issue across the country.

### ***3.0 Data and Methods***

Before describing our data and methods, we note a key challenge in conducting the research. While Ontario's CCAC reform was justified, in part, as a way of increasing public accountability, one result was to make it more difficult to obtain data on a province-wide basis. Each CCAC manages budgets and services within its geographic area using different eligibility and allocation criteria, and reports the results in different ways. While a common data system is being developed, to date there has been no common system or protocol for reporting other than basic administrative information such as total budgets and numbers of services provided in broad categories such as nursing, homemaking, physiotherapy, and so on. Lacking a consolidated data source, it was necessary for our team to gather CCAC data from 43 different organizations separately, adding considerable complexity to the data gathering process, and posing problems of comparability and missing data.

Moreover, in requiring home care to be treated as a business in a competitive marketplace, Ontario's managed competition reform also required CCACs, as purchasers of home care services, to be at arms length from providers who compete with one another for service contracts through the Request for Proposals (RFP) process. While justified as a means of ensuring the fairness of purchasing decisions, the result is that information concerning bids, the RFP adjudication process, or the terms and conditions of contracts awarded, is widely considered to be proprietary. Moreover, there is a clear incentive against providers sharing detailed information about their businesses for fear of losing a competitive edge. As we observed in an earlier article, this means that Ontario's reform makes access to information difficult (Williams et al., 1999).

Because of this, our research design employs multiple data sources and methods linked together by the principle of "triangulation." Triangulation is not merely a combination of different kinds of data but an attempt to relate them (Berg, 2004). The use of multiple sources of data allows for richer understanding and a means to verify insights. Thus, as detailed below, our conclusions are based on the triangulation of multiple qualitative and quantitative data sources.

### **3.1 Documents**

In the first stage of the research, public documents describing the characteristics and activities of Ontario's 43 CCACs were collected and reviewed. These included CCAC annual reports and other relevant information obtained from their web-sites; and provincial legislation, regulations, and guidelines related to the CCACs. Of particular interest was information describing:

- patterns of service need (e.g., numbers of children requiring services in home and school)
- the organization and volume of pediatric home care services
- wait times for children's services
- criteria utilized to award contracts to providers and allocate resources to consumers.

In addition, organization charts were requested from all CCACs. However, the majority of these charts did not clarify how children's services were organized, funded and managed, since they were seldom listed or designated as a separate program/division. We accordingly supplemented

this information through in-depth telephone interviews.

### **3.2 In-Depth Telephone Interviews**

Beginning in January of 2002, personalized letters were mailed to the Executive Directors (ED) of each of the 43 CCACs in the province, informing them about the study and asking for an interview with the director or manager most responsible for, or knowledgeable about, children's services. In response, some CCACs allowed us to interview both a director/manager and a case manager with responsibility for children's services, resulting in a total of 52 CCAC interview participants.

A semi-structured telephone interview guide was developed with input from the Ontario Association of Community Care Access Centres (OACCAC) and other experts in pediatric home care in Ontario. (See Appendix B for exact wording). The guide was field tested with 7 experts who worked in management or senior health care planning positions in the home care sector; revisions were made as a result.

As detailed in Appendix B, the telephone interview guide included questions asking about:

- the funding and organization of children's services
- the range and volume of services provided to different groups of children (in-home short stay, school support services, and complex/chronic in-home care)
- how allocation decisions were made between groups of children (e.g., acute care vs. chronic care) and between children and other needs groups (e.g., seniors and persons with disabilities).

All telephone interviews were conducted by one of the researchers. They typically lasted about 90 minutes and with the explicit permission of the respondent(s), they were audio-taped for the purpose of transcription. Verbatim transcriptions were converted to electronic text files and imported into the qualitative data analysis program NVivo. Field notes taken during the key informant interviews were treated in the same manner. After a review of approximately half (20) of the CCAC phone interviews, analytic categories were refined by means of what NVivo refers to as coding from the original "free" nodes and shifting them to "tree" nodes (Bazeley & Richards, 2000). This involves taking broader, more general codes ("free nodes") and splitting them into more specific codes ("tree nodes") that provide a narrower focus.

### **3.3 CCAC Utilization Statistics**

Because CCACs were not mandated by the government to report utilization statistics separately for children's services until 2003, a CCAC Utilization Data Collection Template was designed covering the period 1997 to 2002 and provided to respondents prior to their interviews. (See Appendix C). While all 43 CCACs participated in the telephone interviews, only 30 were able to provide any of the data requested; those that did not provide data typically indicated that they lacked either the technical or human resources needed to respond to our request. However, even those CCACs that did provide data often did not provide everything requested; the amount of information varied considerably by CCAC limiting our analysis. We note that during the data

collection phase, there were four different types of information systems used by Ontario's CCACs; in all cases, CCACs had to manually extract data related to children's services. Data received from the CCACs were entered into SPSS a powerful quantitative data analysis program.

### **3.3 Focus Groups**

Focus groups are useful in qualitative research to contribute to fundamental theory and knowledge; illuminate a societal concern; determine program effectiveness; and provide opinion on policy creation or revision (Beaudin & Pelletier, 1996; Slaughter et al., 1999). They can address specific issues in more depth from a perspective of the individuals' experiences and opinions. Focus groups are a style of group interview that profits from communication and shared interaction to generate data (Bartels-Desrosiers & Cavanaugh-Zellers, 1989; Nyamathi et al., 1990; Kitzinger, 1995; Beaudin & Pelletier, 1996; Morgan, 1998; Slaughter et al., 1999).

To elaborate and enrich our data sources, we conducted focus groups of 3 key stakeholder groups:

- parents of children with home care needs
- CCAC case managers for pediatric clients
- representatives of private for-profit and not-for-profit home care provider agencies with CCAC contracts for pediatric services.

A focus group protocol was developed based on the research questions; minor modifications were made to make it appropriate to participants in the different focus groups. (See Appendix D for the wording used for the focus group of providers). All focus groups lasted approximately 120 minutes. Each was facilitated by a member of the research team and, with the permission of all participants, audio-taped for transcription. As with the in-depth telephone interviews, the results were analyzed using the qualitative data program NVivo.

#### *3.3.1 Parents*

The parents' focus group was arranged with the assistance of a senior health planner at the Toronto District Health Council (TDHC). Parents who had participated in a previous study conducted by the TDHC were sent a letter by the TDHC (thus blinding their identities to the researchers) asking them to participate in a focus group, and providing them details about the research and the research team. Of 25 parents for whom current addresses could be confirmed, 12 responded positively and 8 were able to participate in the focus group. Parents were asked the following questions:

- Over the past 5 years, what changes, if any, have you seen in services to children and families from the CCACs?
- To what do you attribute these changes?
- Compared to 3 years ago, do you now purchase more/fewer services privately outside of the CCACs?
- Would you say that children and families are now doing better or worse than 3 years ago?

#### *3.3.2 CCAC Case Managers*

Two focus groups of CCAC case managers were conducted.



For the first, we invited case managers from 11 CCACs within driving distance of Toronto (Toronto (6), Peel, Durham, York Region, Halton and Simcoe). All 11 CCACs sent at least one case manager, with one CCAC sending 2 case managers for a total of 12 participants.

The second focus group took place in the eastern part of the province. It included case managers from 6 CCACs representing an urban area with a tertiary hospital; an urban area with a community general hospital; a rural area; and a semi-rural area. A total of 35 case managers participated. Since focus groups work best when there are 12 or less participants (thus giving all participants an opportunity to speak), 3 separate groups were conducted simultaneously in different rooms. However, a standard protocol was used, and each group was audio tape recorded for transcription. At the end of the separate groups, all case managers were brought together in one room and a plenary discussion was facilitated by a member of the research team.

For the case managers' focus groups the second question asked of parents was replaced with the following question:

- How do you, as a case manager, determine the types and amount of services children and families will receive through the CCAC?

### *3.3.3 Provider Agencies*

We also conducted a focus group with representatives of agencies contracted by CCACs to provide pediatric home care services in the Toronto area. Agencies were identified through information obtained from CCACs. A total of 23 provider agencies were contacted by phone and positive responses were received from all 23. However, because of space and scheduling limitations, only 12 (both not-for-profit and for-profit) were invited to participate. All participants consented to having the focus group audio tape-recorded.

For the provider focus group the second question in our protocol was replaced with:

- What impact has the change from the former home care program to CCACs had on your organization?

## **4.0 Findings**

### **4.1 Organization of Pediatric Home Care**

#### *4.1.1 Budgets*

CCACs are provided annual global budgets by the Ministry of Health and Long-Term Care (MOHLTC) based on historical utilization patterns with various enhancements and adjustments. Then the executive team in each CCAC develops its budget based on projected service units (e.g., nursing, physiotherapy, personal support workers, homemaking, and occupational therapy).

No CCAC reported a dedicated or “protected” budget for children’s services (with the exception of private schools, as noted below). The term “protected” refers to money that can only be used for a specific purpose (i.e., for one particular client group or type of service). Some advocates have argued for protected budgets for relatively small, but potentially high needs client groups such as children as a way of ensuring that resources are not used or “cannibalized” by other, more populous needs groups. While some CCACs did generate specific budget estimates for pediatric needs, and at least nominally allocated resources for this purpose, even these allocations were not “carved in stone” and could be folded back into other budget lines if the need arose.

The exception was that separate budget lines for private school health support services were protected. As a result of a policy introduced by the Progressive Conservative government in 2000, each CCAC was allotted a certain amount of funding directly from the MOHLTC to pay for school health-support services in private schools and/or for home schooling. MOHLTC directives make it clear that this funding could not be folded into the CCAC global budget or used for services to children in public schools.

The flexibility to re-align budgets when faced with increasing demands for services for children and families varied among CCACs. A key factor was whether the manager of children’s services had control over a broader area than pediatrics, which they generally did. For example, in instances where the manager oversaw both therapy and children’s services, the manager could move money from adult clients to children. Directors/managers from 4 CCACs stated that they had transferred dollars that were originally dedicated for adult clients to serve pediatric clients in this way. In only one instance did a director/manager report transferring money from children’s programs (due to a strike by school workers) to adult clients. There was little evidence, therefore, to suggest that budget resources for children’s services had been negatively impacted by the absence of a protected children’s budget.

#### *4.1.2 Services*

The organization of pediatric home care services varied substantially across CCACs. However, mirroring the fact that there were no specific budget lines for children, no CCAC had a manager solely responsible for children’s services. In most cases, children’s services were subsumed under generic service categories (e.g., nursing or physiotherapy). In 10 cases, CCAC respondents had the title of Director or Manager of Pediatric or Children’s Services, but all had additional responsibilities. In 8 cases, children’s managers also managed “therapy services”

including speech language pathology (SLP), occupational therapy (OT), and physiotherapy (PT) on the grounds that children utilize a disproportionate volume of these services compared to other needs groups such as seniors.

All CCACs reported that they had a “school program” and many said they had a “pediatric program” including both in-home and school services provided by pediatric specialists such as nurses; however, in only one case was a corresponding managerial position identified.

#### *4.1.3 Case Management*

Case managers constitute the interface between CCACs and clients; they assess needs and manage services for children and families. Whether or not there were dedicated budget lines for children, or specific pediatric programs, CCAC directors/managers emphasized the importance of having case managers experienced in children’s needs and services to manage pediatric home care.

Three main reasons were given:

- First, the assessment and understanding of children’s and families’ needs requires specialized knowledge of the unique requirements of children as they grow and mature, physically, socially, and intellectually.
- Second, accessing the services for pediatric clients is often a complex process involving several different ministries or programs which requires a great deal of experience. As an example, it is not uncommon for case managers to have to draw on services from up to 20 different programs, agencies and ministries for children with ongoing home health care needs
- Third, while the centrality of the individual “client” is often stressed in home care, the focus in pediatric home care is the family. This distinction is crucial. Respondents emphasized the need for specialized knowledge and skills to ensure a “family-centred approach” to case management; case managers work with the child and key family members, including parents, grandparents, foster parents, and/or siblings. Not only does the family play the key role in maintaining the health and well-being of the child, but the case manager must be sensitive to the needs of the family.

CCACs often divided caseloads among case managers by school clients or in-home clients, because each of these have different needs and combinations of services available to them. For example, the majority of children receiving services in the schools required rehabilitation services (SLP, OT, and/or PT); this necessitated working with school boards and individual school staff. However, clients receiving services in their homes often required some type of nursing care; this client group accessed different provider agencies and many used service maximums. In CCACs in urban centres with a tertiary children’s hospital there always were specialized case managers who specifically focused on children with complex and/or chronic care needs.

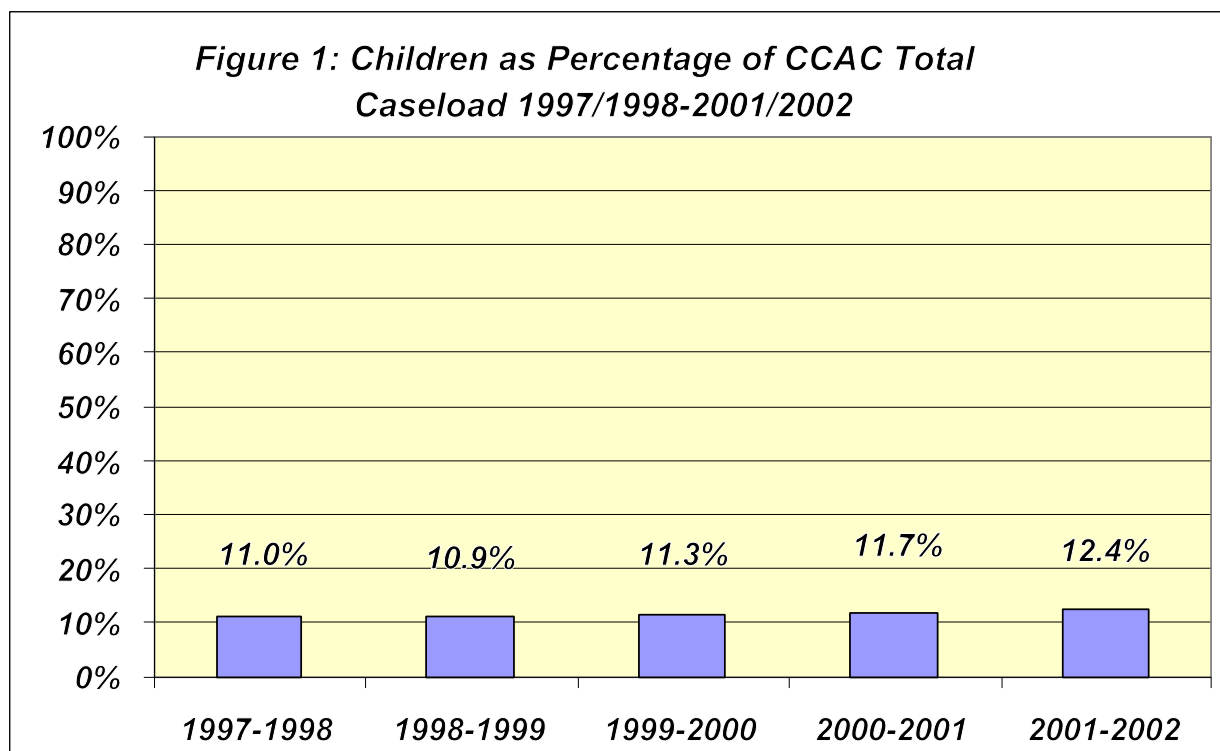
Directors/managers stressed the importance of ensuring that case managers for in-home pediatric

clients had smaller caseloads, since organizing and monitoring children's care is more complex and time consuming than care for other needs groups. However, they also commented that this was becoming more difficult as referrals were increasing and becoming more complex, even as available resources were constrained. Case manager's caseloads varied substantially among the CCACs, ranging from 48 to 340 clients. Case managers assigned only to clients receiving care in the schools had higher case loads compared to those who were managing children with more complex care needs in school and in home.

#### 4.2 Trends in Demand and Utilization: 1997-2002

If there were differences between CCACs in the organization of pediatric home care services, there was consensus that demand for children's home care services, and the supply of these services, had increased significantly between 1997 and 2002 both in terms of volume and complexity.

With respect to volume, Figure 1 presents CCAC utilization data which show that between 1997 and 2002, children's services increased as a percentage of CCAC overall caseloads from 11.0% to 12.4%. This suggests a ramping up of pediatric home care services in response to the growing needs of children; it also suggests a relative decline in the resources available to other needs groups such as seniors.



Several converging factors were identified as shaping this trend; three are highlighted below.

#### *4.2.1 Health System Restructuring*

All respondents noted that population related factors (e.g., more children with chronic conditions living longer due to improved medical technology) had significantly increased the need for pediatric care since there were more children with more needs. However, the need for pediatric home care had been as strongly impacted by health system restructuring, and particularly, by a continued decline in the number of in-patient beds and lengths of in-patient hospital stays, as well as by a de-emphasis on institutional care.

While the shift from hospital to home and community had affected all client groups including post-acute care adult patients, seniors, and persons with disabilities, its impact was particularly marked for children, who often required care for all or most of their lives. Once on CCAC caseloads, these children and their families tended to stay on for extended periods with little possibility of discharge. Not only did the number of children requiring home care increase, but the complexity and duration of their needs also increased. For CCACs near tertiary-level pediatric hospitals, the effects had been particularly obvious and direct since hospitals expected CCACs to provide services needed to discharge patients. However, CCACs in other parts of the province were also affected, since pediatric hospitals, which admit clients from across the province, also expect that a high level of care will be available upon discharge regardless of where children live.

Other changes within the health sector had also had an impact. For example, due to “early years initiatives” funding from the federal government which began in 1999, public health departments across Ontario began early identification programs. Public health departments conducted pre-school screening of children at risk of learning delays (such as in economically disadvantaged communities where a child’s nutrition, and thus brain development, might be compromised). They subsequently identified many children requiring the specialized services of a physiotherapist or occupational therapist in their pre-school years (0 to 5 years of age); these services would then be provided by public health departments. However, even though many of these children required therapy after the age of 5, there was no federal funding and public health departments would not provide services, instead referring them to CCACs. Thus, while the early years initiative did identify many children requiring care, it did not address the long-term needs it revealed. It also created additional worries for families as children were identified as having a health problem (i.e., not meeting their developmental milestones) without a guarantee of continuing access to publicly funded care.

#### *4.2.2 Shifts in Other Sectors*

Changes in other proximate policy sectors, particularly in education, also impacted on demand for pediatric home care. As school boards experienced budget strains as the province sought to reduce education funding, they sought to reduce costs through their own cuts. Forty of the 43 CCACs reported that they had experienced substantial increases in school referrals between 1997 and 2002. For example, as their budgets were constrained, school boards decreased the number of educational assistants (EAs) in their classrooms, as well as the number of psychologists and speech language pathologists available to assess and provide interventions. With fewer

psychologists and SLPs to assess and devise treatment plans, and fewer EAs to implement interventions for children with learning delays such as articulation (speech) and fine motor (writing) problems, the schools referred these children and families to the CCACs. This combination of factors contributed to the CCACs receiving referrals for a new group of children that had not previously been CCACs clients. As a result, only 3 CCACs reported that they did not have wait lists for in-school services. Although some directors/managers did not know the average wait list time for rehabilitation services or did not want to comment, those who did said that waits for speech language therapy ranged from 8 months to 2 years while wait lists for school PT and OT ranged from 3 months to 18 months.

Other agencies and ministries also downloaded assessment, co-ordination, and case-management responsibilities to the CCACs. For example, the Ministry of Community and Social Services (MCSS) required that CCAC case managers or their delegates also assess eligibility for MCSS respite funding. This reflects the complex, resource-intensive nature of continuously assessing needs as the child progresses through different physical and psychosocial developmental stages, and as they come under the aegis of different service programs. Moreover, children with chronic and/or complex care needs require services in multiple locations since they may attend nursery school, pre-school, day care (private or public), or public and private elementary and secondary schools while receiving care from tertiary-level and community hospitals and from rehabilitation centres, as well as receiving in-home services. As a result of shifts in other sectors, greater responsibility not only for serving needs, but for assessing needs and coordinating and case managing care across multiple programs and funding streams, was shifted to the CCACs, thus placing additional strains on their resources.

#### *4.2.3 Rising Expectations*

A related factor concerned rising expectations about the ability of CCACs to provide for the needs of children and families in home and community.

In the focus groups of case managers there was consensus that parents had become “more demanding.” For the most part, case managers were sympathetic because they realized the stress many parents were under, some for many years; they say saw parents running up against systemic barriers in accessing needed services and becoming increasingly frustrated and burnt out. Nevertheless, this translated into increasing pressure for CCACs to provide services or to find ways of accessing services from other parts of the system.

Additional, and sometimes unrealistic pressures came from elsewhere in the health care system. Case managers indicated that they often had to deal with hospital personnel who didn’t understand the different funding and delivery arrangements, and who had unrealistic expectations of what services were available to children and families after discharge. A common complaint was that hospital personnel, under pressure to discharge as quickly as possible, would not give CCACs adequate time to process referrals and make care arrangements. Led by hospital personnel to expect appropriate home care on a timely basis, parents would often blame CCACs when services were not available or adequate. Moreover, in some communities, hospital

personnel would take on the role of family advocates, generating increased pressure on CCACs to divert additional resources to pediatric home care.

### **4.3 Managing Utilization**

Against the backdrop of steadily increasing need for home care, Ontario's CCACs faced budget constraints which forced tough service allocation decisions. Not only would CCACs have to manage competing demands between different needs groups including children and families, adults with post-acute care needs, seniors, and persons with disabilities, they would have to decide which needs sub-groups (e.g., children with acute care, or children with chronic care needs) were given priority for available services.

As we noted earlier, prior to the introduction of the CCACs, home care services in Ontario had been covered under the provincial health insurance program (OHIP) as a universal Medicare entitlement. While home care programs also had budget constraints, the province would give additional dollars when demand exceeded supply. As governments attempted to contain health care costs during the 1990s, however, this open-ended budgeting became increasingly problematic and promised to become even more troublesome as the population aged.

With the CCACs, home care was effectively removed from OHIP coverage, and capped home care budgets were introduced, set by the province. However, particularly in their first years of operation, many CCACs ran significant budget deficits. By 2000, the Progressive Conservative government of Mike Harris warned that CCACs would no longer receive financial "bail outs" and that budget overruns would be considered a sign of poor management, since in the government's view, adequate funds had been made available to meet home care needs. When some CCACs continued to run deficits, the government warned that jobs would be in jeopardy. An example of this occurred at the Hamilton CCAC, where the government appointed a supervisor and dismissed the volunteer board of directors after a review found that the "CCAC had chronically suffered from staggering deficits" (Stepan, 2001). In June of 2001, the provincial government instituted a province-wide budget freeze, with no prospect of a bail out, forcing all CCACs to re-examine their services and many to institute service cuts. From a policy perspective, this freeze was controversial as some CCACs and consumers' groups contended it meant an erosion of services. From a research perspective, however, the freeze, which occurred during the period when the research was being conducted, provided a strong opportunity to analyze the impact of a budget freeze on allocation decisions pertaining to children's services.

#### *4.3.1 Re-Balancing Resources*

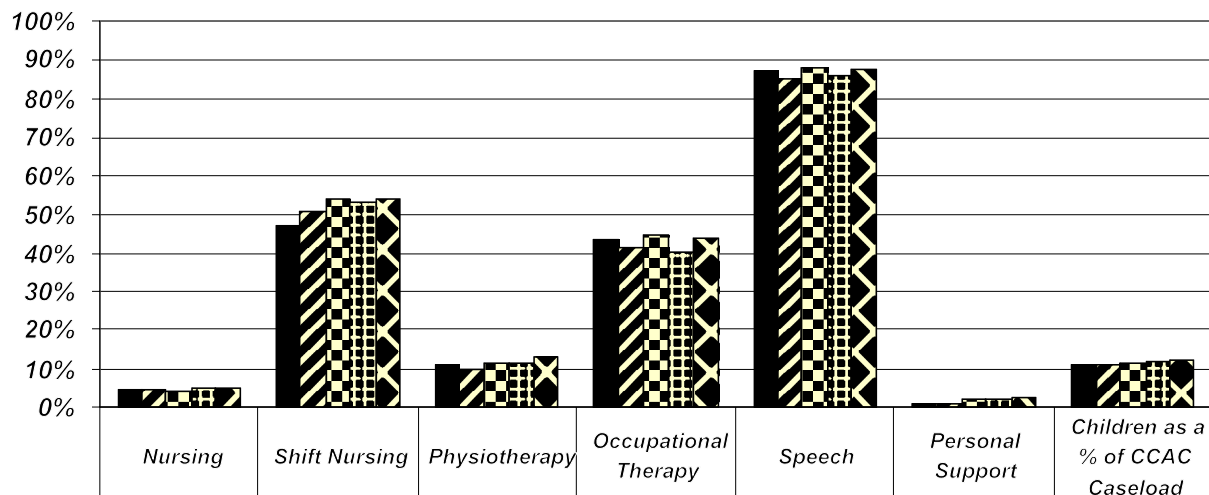
One response was to re-balance priorities within available budgets. Our findings suggest that CCACs as a group re-balanced priorities so that children and families received proportionately more available resources.

Utilization data collected from the CCACs are presented in Figure 2. Key findings can be summarized as follows:

- First, as noted earlier, over the 5 year period, children grew from 11.0% to 12.4% of overall CCAC caseloads. Although there was little sense among the respondents that this increase had matched growing need, it was clear that children had done better than other needs groups whose shares of CCAC services had correspondingly declined.
- Second, reflecting the nature of their needs, children were relatively under-represented in some service categories, but over-represented in others. For example, while constituting more than a tenth of CCAC caseloads, children used only about 5% of nursing visits. However they used 50% or more of shift nursing (where a nurse is required for 4 or more hours continuously); shift nursing is only provided to clients who require ongoing monitoring of their medical condition by either an RN or an RPN which will not be met through single home visits. Because of the complexity of their medical problems, a growing proportion of children fall into this category.
- Third, there was considerable variation within rehabilitation services. While children utilized a proportionate amount of physiotherapy, they consistently used over 40% of occupational therapy services, and over 80% of speech-language pathology. This reflects the nature of services provided to children in schools.
- Finally, children received only a marginal proportion of personal support services such as homemaking. As we discuss at greater length below, this should not be interpreted to mean that children do not have personal support needs; it has more to do with the view that such needs should be met by families.



**Figure 2 : Average Proportion of Caseload and Services Utilized by Children  
1997/1998 to 2001/2002**



■ 1997-1998	4.49%	46.90%	11.01%	43.77%	86.85%	1.28%	11.00%
▤ 1998-1999	4.68%	51.01%	9.86%	41.37%	84.81%	1.27%	10.94%
▥ 1999-2000	4.33%	53.89%	11.23%	44.49%	87.90%	2.03%	11.28%
▧ 2000-2001	5.01%	53.54%	11.22%	40.58%	86.21%	1.95%	11.73%
▨ 2001-2002	5.19%	53.80%	12.91%	43.94%	87.72%	2.56%	12.42%

### *4.3.2 The Role of Case Managers*

Even as children and families received greater proportions of available resources, needs grew, budgets were capped, and CCACs faced increasingly tough resource allocation decisions. Although there were provincial regulations to define service maximums, there were no service minimums, and few CCACs had explicit guidelines for the allocation of resources between client groups or for individual clients. In the absence of standard allocation principles and mechanisms, case managers had considerable decision-making discretion. The results of the qualitative analysis suggest that case managers brought widely varying perspectives and values to their decision-making.

For example, some case managers described their role in terms of “managing expectations.” They stated that in determining what levels and types of home care services to approve, they attempted to determine the “needs” of children and families, rather than their “demands” or “wants.” Indeed, particularly following the budget freeze of 2001, case managers felt that they should not only manage available resources in a responsible manner, but manage expectations and spread the word that parents should not expect the same level of service they might have enjoyed in previous years.

The process for determining the needs of pediatric clients varied considerably between CCACs and among case managers. In 31 CCACs, there were no standard assessment tools. Even in the 12 CCACs which indicated that they had developed tools for assessing the needs of pediatric clients, case managers appeared to retain considerable scope for interpretation. Indeed, there was disagreement among case managers even about the usefulness of standard assessment tools for children. Many believed strongly that subjective assessments were beneficial and claimed that a case manager who meets with the family and child face to face could take into consideration the child’s and/or family’s special needs which could not be captured in any standard assessment tool.

There was also variation around service allocation following assessment. During the key informant interviews and case manager focus groups respondents talked about their CCAC’s “guidelines” for service allocation. When asked, some used the term “guideline” to refer to unwritten rules that their managers had discussed regarding service levels for their clients. For others, guidelines referred to service limits. In some cases, CCACs had actually developed priority guidelines which were used by case managers to determine which clients should go on wait lists and which should receive services immediately. However, there appeared to be few guidelines for what services individual clients should actually receive.

As indicated earlier, the literature and respondents emphasized that in dealing with children, it is crucial to take the family context into account, since it is in this context that care is provided, and that the physical, psychological and social development of the child takes place. The unit is therefore the family rather than the individual. In the telephone interviews and focus groups, case managers confirmed the importance of addressing the family as a unit. However, their approaches to doing this again varied substantially. In some instances, case managers emphasized that they attempted to determine what services would be needed over a period of time

to support the child and the family. The logic was that by providing appropriate services, families with relatively fewer resources and greater risks (e.g., single-parent families) could be supported as a unit. By contrast, other case managers emphasized the need to assess family resources as a way of determining the minimum level of support that could be provided; for instance, if grandparents were available to provide care, fewer CCAC services would be allocated. In such cases, it was suggested that instead of using CCAC services, family members could be trained to provide services themselves. Thus, some case managers assessed service needs in terms of adding to family capacity while others first subtracted family capacity.

In this context views about the role of women as family caregivers were important. While some case managers recognized that women could have legitimate interests and career goals outside of the family, other case managers seemed to suggest that women's first responsibility was to care for their family. Such subjective views could produce very different assessments of service needs. Ironically, one parent reported that when she had terminated her paid employment in order to provide care to her child, CCAC services had been reduced since she was now more available and thus her child required fewer services.

Subjectivity surrounding assessment to determine needs and services was corroborated by parents who had experience working with CCACs as well as the home care programs which predated them. As one mother pointed out, the role of the case manager was crucial; they could make your life “hell” or “bearable.” Another parent stated, “If you have a good case manager, all of a sudden the rules are interpreted correctly, better for you—flexibly.” This parent also indicated that services received from the local CCAC often changed without any change in need; service cuts or enhancements instead coincided with the CCAC budget cycle, and with changes in case managers. Another parent reported that the family had actually moved from one area to another as they knew from other parents that case managers in the neighbouring CCAC were more understanding of families with children with complex, continuing care needs.

#### *4.3.3 Management Strategies*

Based on the analysis of the key informant interviews, only 13 out of the 43 CCACs indicated that there was a significant impact on children’s services following the budget freeze of June 2001. According to the directors/managers, the financial position of the CCAC prior to the freeze did not directly determine whether or not certain services or client populations would be targeted. However, it is important to note that many CCACs across the province said that they had anticipated the 2001 budget freeze and had already instituted tighter management of available services, often leading to reductions in service levels to individual pediatric clients, if not overall reductions to pediatric services.

Sparked by the 2001 freeze, the majority of CCACs undertook a systematic review of their programs and the outcomes. However, without any legislation and only service maxima provided by the provincial government, CCACs’ responses varied considerably at both the level of the organization, and the individual case manager. More aggressive strategies for managing services emerged.

**Wait lists.** These were a common response to budget constraints particularly for school rehabilitation services. Forty CCACs reported wait lists for at least one type of therapy (SLP, PT, and OT) offered through school health-support services, with SLP typically having the longest wait list. In some cases, children would go through an entire school year and still not be seen by an appropriate professional.

Case managers in the focus groups and key informant interviews indicated that they used wait lists to deal with the combined pressure of increased demands, budget constraints, and health human resource shortages. In this connection, some managers saw wait lists as a desirable alternative to more restrictive eligibility requirements. While more restrictive eligibility would mean that fewer children and families received services (more would receive none), wait lists meant that available services were distributed across more children and families. However, as a result, many children and families now waited weeks for the services they required (as long as 18 - 24 months for speech language pathology).

In most instances, wait lists were seen to be largely a function of budget constraints. However, health human resources shortages also contributed to wait lists, particularly outside of urban areas where it was difficult to find pediatric providers. One CCAC director/manager made the distinction between wait lists due to health human resources shortages, which she did not consider to be "an internal CCAC wait list," and those due to CCAC budget constraints which would, presumably, be "internal." For instance, her CCAC would not report a wait list for children's services if pediatric providers were not available. The logic was that since there was no service, there could not be a wait list.

Wait lists had also appeared for services which previously had had no wait, for instance, for children in the school setting with fine motor problems. Within these wait lists, case managers indicated that they did their best to "prioritize the cases of children who need therapy related to their physical condition where it is a safety issue, such as transfers from wheelchairs." For comparable in-home services, however, there might not be a wait list, or a much shorter wait list, reflecting the view that children at home, particularly with identifiable medical problems, should be given priority.

**Change in treatment goals and delivery modalities.** A related change involved a shift to "block therapy." Instead of providing continuous service once they had received assessment, children would receive a "block" of either 4 or 6 treatments and then would be put back on the wait list. This allowed more children to be treated within a school year, but reduced the number of treatments that an individual would receive.

While this delivery modality had not been formally evaluated from a clinical perspective, it was indicated that 15 CCACs had worked with practice experts to develop diagnosis-specific care pathways which specified numbers of treatments based on the child's condition. These pathways could be used by case managers and the direct health care provider. CCACs called these treatment pathways either "care maps", "decision trees", or "priority guidelines." Note that the

CCACs that developed these specific pathways had either case managers or directors who were also licensed rehabilitation therapists.

Paralleling this shift of delivery modality, was movement from an intervention model of care to a consultative or educational model, with a focus on providing consultation and support to the main caregiver about the child's care needs. Using this model, referred to by some respondents as "teach and discharge," the family members and/or teachers or educational assistants would be taught how to care for the child.

**Active caseload reviews.** Another management strategy involved active case review to ensure that there continued to be a demonstrated need for home care services and that clinical goals were being met. If it was judged that insufficient progress was being made, professional services could be increased, reduced or terminated.

In this connection, case managers indicated some ambivalence around the notion of appropriate "progress" toward clinical goals. While this notion of "progress" might be relatively straightforward for acute care patients who "recover" from an illness, it was seen to be more complicated with regard to chronically ill children who might never recover, or who might get progressively worse. When asked how this notion was applied to children who, due to complex conditions would never progress beyond their current status but for whom it was important to maintain their range of motion, swallowing, and so on, case managers said they "worked with the pediatric providers for the wording" or they would "fiddle with the goals."

One case manager in their focus group explained that through the review process she had "brought down" the numbers of hours of services for many children and families who had been long-standing CCAC clients. She suggested that relatively high historical levels of care had not been based on need, but on inflated expectations on the part of parents which had been fueled in large part by the willingness of the CCACs and previous home care programs to provide more services than necessary in the past. For instance, she indicated that in her CCAC, nursing services had been used as much a way of supporting parents, as a response to the health needs of the child. While she had no objective tool on which to base her judgements, she suggested that her CCAC was developing a tool which would "make things more fair between clients." This meant that service levels for longstanding clients would be reduced to the more realistic levels provided to newer clients. This case manager also stressed the shift from a model of direct service, to a model which involved "teaching them and then discharging them" from the CCAC caseload.

Another case manager also directly connected the process of case review to the imperative for cost containment. She noted that case managers in her CCAC had literally had to go through their entire case loads and "contact[ed] all the families and let them know that we were going to now give less hours of services at home and that was very difficult to do." In the past, case managers, sympathetic to the needs of the child and family, had often authorized the service maximum; now they would receive less. It had proved difficult to convince parents they were still getting sufficient services as service levels were cut.

**Cuts to school services.** Only 13 of 43 CCACs reported that they had to make overall cuts to children's services prior to or following the June 2001 budget freeze. Although most case managers said they did not target one particular group of children, responses indicate that the greatest impact was felt in the school programs.

This was again related to the fact that the majority of children requiring services in the school required therapy for developmental delays, articulation and/or fine motor problems. While crucial to functional capacity, learning and development, these services were often not considered to be medically necessary particularly in comparison to children requiring services in their homes following hospital discharge or with ongoing complex care needs.

As CCACs experienced budget constraints, in-school pediatric services came under close scrutiny. One director/manager noted that the biggest impact was on the wait list for SLP and OT in the school setting: "...we did huge caseload reviews, we actually...tightened up our criteria...we were never supposed to be in the school setting to monitor the ongoing health needs." Once immediate medical and physical needs had been met, CCACs now transferred responsibility back to the school boards, who during the same period, had also experienced budget cuts, leaving more children to "fall through the cracks." Of major concern were children receiving occupational therapy services. Because of cutbacks in the school system, CCACs were getting more children with behaviour problems, attention deficit disorders, handwriting problems, and fine motor problems, problems which many did not see as falling within the CCAC mandate. As a result, children were discharged, and at least in some CCACs, follow-ups consisted of workshops for school personnel as well as parents on strategies for addressing the needs of these children.

**Cuts to personal support/homemaking.** While children and families thus felt the weight of cuts to school services, mostly in rehabilitation, cuts to personal support/homemaking, implemented by CCACs across the province, had less direct impact. This is because children and families had never received a large proportion of these services on the grounds that "there are parents to do that" [quote from case manager focus group].

Directors/managers emphasized that they had discontinued household management that was not related to a client's safety and hygiene, and that if a family had been receiving help to do housecleaning, such help was usually terminated. However, while reductions in the personal care and homemaking had impacted on seniors, the impact on pediatric clients was marginal since they had rarely received homemaking services from home care programs or the CCACs in any case.

#### **4.4 Managed Competition**

There was consensus among respondents that managed competition had had a major independent impact on the provision of pediatric home care in Ontario. Particularly because of the low volume, specialized nature of services for children and families, this impact was seen to be particularly marked, and mostly negative. Although a few respondents noted some benefits (e.g., the pressures of managed competition had raised the profile of children's services) virtually all respondents, including CCAC director/managers and case managers, providers, and parents, indicated that managed competition had resulted in a range of perverse outcomes, that is, outcomes opposite to those desired. A number of these outcomes are discussed below.

##### *4.4.1 Limited Competition*

Underlying managed competition are two assumptions: the competitive forces of the marketplace will produce innovation and cost-efficiencies; and the potentially perverse effects of unfettered competition (e.g., erosion of access or quality) can be "managed" or minimized in the public interest.

Ontario's reform was based on these assumptions. As noted earlier, prior to the reform, home care programs across the province had often provided low volume professional services (e.g. rehabilitation) through their own staff, and contracted for high volume professional services (e.g. nursing) on a cooperative, and continuing basis with established mostly not-for-profit provider agencies such as the Victorian Order of Nurses and St. Elizabeth. With managed competition came the "purchaser-provider split" which meant that CCACs would tender service contracts to the competitive forces of the marketplace. The logic was that in their drive to win contracts, competing not-for-profit and for-profit providers would be forced to achieve innovation and cost-efficiencies. CCACs would "manage" the process at arms length to ensure that quality was not trumped by cost. Thus, CCACs were to divest service delivery over a period of three years; staff would be encouraged to establish their own businesses and compete for CCAC contracts. To ease the transition, the CCACs offered staff partial but declining protection of their historical service volumes; by the fourth year, they would have to compete with other providers without any advantage.

However, respondents emphasized that the assumption of competitive forces did not reflect reality in the field of pediatric home care. In this low volume, specialized field there were never more than a few providers. Indeed, particularly outside of urban areas, a lack of providers was the reason why home care programs had maintained their own staff to deliver rehabilitation services and some specialized nursing services. At their inception, only 6 of 43 CCACs had contracted out rehabilitation services; prior to 1996, there were only 13 provider agencies for rehabilitation home care in the whole province, located mostly in urban areas.

The process of divestment thus proved problematic. Instead of stimulating competition and cost-savings, in many cases it actually resulted in additional costs for CCACs, as reluctant staff and their unions resisted layoffs, and as some CCACs were forced to pay incentives (including the costs of employee benefits) to private providers to have them take on former staff.

#### *4.4.2 Health Human Resources Shortages and Erosion of the Provider Base*

As noted earlier, a key assumption of managed competition is that there is sufficient competition to drive down prices. An important corollary is that, particularly during periods of growing demand, new providers will enter markets and stimulate increased competition particularly where barriers to entry into the marketplace were low, as in the case of home care where extensive capital investments are not normally required, and where there are considerable degrees of freedom for the substitution of lower paid, less specialized and often unregulated caregivers in place of higher paid, more specialized and regulated professionals.

However, at least in the case of pediatric home care in Ontario, respondents indicated that managed competition had actually resulted in provider agencies and individual care providers leaving the marketplace, complicating existing health human resources shortfalls.

First, CCAC directors/managers and provider agencies indicated that upon learning about the RFP process, some agencies that had provided pediatric home care with specialty-trained paediatric nurses, decided not to respond. CCAC directors/managers described these agencies as small operations to begin with and mainly run as family or individually owned businesses. One contributing factor was that in smaller areas CCACs expected provider agencies to be able to supply both adult and pediatric services. While the owners were well known, they did not have the resources to develop a complex proposal and compete with larger home care agencies over a wider range of services.

As specialized providers pulled out of the market, the effects rippled down to individuals. For example, it was reported that nurses who had worked for pediatric provider agencies who had decided not to compete, also decided to stop working within the home care sector.

Moreover, those agencies which did put in bids, often attempted to reduce wages and employment benefits as a means of gaining a competitive advantage. For instance, while travel time had commonly been reimbursed prior to managed competition, nurses would now be expected to "start their clock" only as they reached their client. Other benefits were eroded as well as agencies sought to contract employees on a casual or part-time basis, thus reducing their costs, and giving them greater flexibility in the event that they received lower service volumes and needed to lay off workers. The most aggressive of these practices was "elect to work" which meant that agencies would employ nurses only on a casual basis as needed. While, because of their specialized expertise, most pediatric nurses had not been directly affected by such practices, a major outcome was that fewer were willing to continue to work in the field, either withdrawing from the labour force altogether, or seeking employment in other health care sectors such as hospitals where jobs were unionized, and they would receive better treatment.

One provider agency representative emphasized that the RFP process "has made it very, very tenuous for people who are working in the community. The job satisfaction in the community is less because they are frightened to death that with the next RFP that their agency is not going to get the contracts, and therefore 'why would I join [X home care agency] when I am getting a job



offer at [X hospital] for maybe the same or more money and I spend less time travelling in my own vehicle?"

Further, because individual specialist providers such as pediatric nurses were seen to be limited as to the client populations they could serve, they were no longer as cost-effective as generalists to agencies wishing to secure CCAC contracts. When faced with pressure to reduce costs in order to win contracts, pediatric specialists were sometimes let go. According to one director/manager, "the agencies started letting go [pediatric] staff...and a lot of the recruitment that had happened around children's services was specific to the RFP...since they were the staff that had just come on, they would be the most recent hires, so they're the first ones that were let go to be more cost effective and so the agency could win the contract."

These effects were compounded by the divestment process: as CCACs moved to divest employees, additional pediatric specialists left the home care field as they did not want to be employees of the provider agency in their area at what they considered to be unfavorable terms and conditions. In other cases, there continued to be no provider agencies to hire them. In fact, after a great deal of turmoil, and severe shortages of pediatric health care professionals particularly in rehabilitation home care (OTs, PTs, SLPs), the government relented and permitted some CCACs to employ in-house staff to provide these services. At the time of our survey, 7 CCACs had OTs, PTs, and SLPs on staff. CCAC key informants stated that they were annoyed that originally they had no choice about going ahead with the RFPs for pediatrics when many predicted that they would lose pediatric health professionals through the transition phase. They recognized that many would leave the field to be employed by organizations not serving home care clients (such as hospitals) since they were unhappy with employment instability in the sector. The directors/managers said they were frustrated that their original concerns were not heard by government and that by going forward with managed competition, it wasted CCAC resources, caused disruption and stress for health care professionals only to end up in worse shape than before the process was started.

#### *4.4.3 Rising Service Costs*

There was consensus among respondents that managed competition, instead of reducing costs, had actually resulted in higher costs.

According to respondents, growing shortages of specialized health care providers and agencies were compounded by declining service contract volumes following the 2001 budget caps; as volume dropped there was less incentive to employ specialists, resulting in a further hemorrhaging of expertise from the field. This meant that when CCACs required provider agencies to supply specialist services, agencies had to offer more favorable conditions to attract workers, and these costs resulted in higher CCAC contract bids. Given limited competition, providers had more leverage to push costs higher. According to one parent, "the one very important point is that in the last three years the [X agency] Registered Nurse rate has risen from \$22 to \$38 an hour, which is solely as a result of [X agency] having an absolute monopoly in this market. That is a 70% increase, of which, might I add, the nurses themselves don't get [very

much, of that increase]." CCAC representatives confirmed such increases. For example, "[X agency] and [Y agency] have only come on board in the past year and part of the major problem that we've had over this past year with service recovery is the cost of the providers. April 2001 is when we brought on a new nursing contract and personal support services contract in response to RFP. And the major problem there is the cost of nursing—and nursing personal support services almost doubled. And so we were dealing with the same budget, but it's stretching a lot thinner."

Increased costs affected families in multiple ways.

First, as service costs rose, the dollars available under capped CCAC budgets purchased fewer services for children and families.

Second, as CCACs rationed services, using some combination of the strategies described above, families had to "top up" services themselves. Families could pay for such services out-of-pocket; they might have third party insurance coverage (such as employee insurance); or they could have access to a yearly stipend (maximum of \$3,000 per year) provided through Special Services at Home (SSAH), a Ministry of Family and Community Services program.

Third, as service costs increased for CCACs, they also increased for private purchasers including parents. According to one parent, and confirmed by CCAC case managers, provider agencies that had been able to contract specialist nurses, had done so at premium prices. As a consequence, they often stipulated that their nurses could not work for families directly or they could face being fired. Thus, the options available to families for hiring privately also narrowed, as they had to work through provider agencies, and pay the same prices as the CCACs. However, during this period, insurance companies and SSAH did not increase the amount of money allotted for children's home care services so that available dollars purchased fewer hours of service. As a result, children and families now faced multiple jeopardies.

#### *4.4.4 Rising Administrative (Non-Service) Costs*

Rising administrative costs both for CCACs and for home care provider agencies were cited by virtually all respondents as an important additional factor driving up the overall costs of home care, and thus, driving down service volumes within constrained budgets. These costs related in large part to the costs of issuing RFPs, evaluating proposals from provider agencies, concluding contracts, and monitoring contract compliance.

The managed competition process itself was widely seen to be complex and resource intensive. During the focus groups with representatives of provider agencies, a common theme was the amount of "red tape" and "paper work" involved. The various RFP requirements and reporting structures were seen to be very time consuming and expensive. Moreover, agency managers were required to spend considerable amounts of time negotiating with CCACs around services to individuals even after contracts were awarded. According to one agency manager, "There is a lot of time doing that negotiation which costs us more money and costs the system more money. It

really isn't an efficient way of using people's time. Usually there is a solution, but it takes quite a number of hours. It takes time to get to one." Another agency manager described the example of a CCAC that requires the provider agencies to apply for authorization for visits every two weeks even for children whose needs are lifelong and unlikely to decrease (but more likely to increase as they grow) due to the nature of a chronic condition or disability.

Provider agency representatives suggested that instead of producing innovations and cost efficiencies, the managed competition process had produced a range of cumbersome bureaucratic requirements which drove up costs. A manager representing a not-for-profit agency that delivers care to high-needs children in school settings noted that her agency was funded through different government programs with only a proportion of total funds coming through the RFP process. Moreover, her agency was the only one in the CCAC catchment area that provided these services. Nevertheless, her agency was still required to produce a full-scale RFP proposal which required diverting resources from service delivery. This manager stated, "We could be putting all this money related to responding to the RFP into service for the client, but it is huge—and I'm sure all of you having done RFPs—it's a huge cost and we also go through accreditation and it's just as rigorous if not more so, so if you are already an accredited agency...it's [the RFP] a huge cost and it's redundant and it takes it out of the system for clients."

For agencies providing services in more than one CCAC catchment area, such challenges were multiplied by the fact that they had to respond to a separate RFP for each CCAC. However, RFP requirements varied considerably between CCACs as did compliance requirements. Thus, when provider agencies had contracts with more than one CCAC, they had to keep track of different requirements in order to win contracts and get paid. Representatives of private, for-profit companies stressed that these higher administrative costs were passed on to purchasers, so that service costs increased, not just for CCACs, but for other third-party payers (insurance companies, employee health programs), and for families requiring additional services to "top up" CCAC services.

An additional consideration, linked to worsening health human resources shortages, concerned the challenge of finding a pediatric nurse specialist for each child requiring home care. As noted earlier, Ontario's managed competition reform forced CCACs to divest staff, and it created economic disincentives against provider agencies retaining relatively costly specialists on contract, particularly outside of urban areas where service volumes were low. Thus, when CCACs required a pediatric nurse to provide shift care, individual agencies had to be asked to find nurses on a case-by-case basis. This was time consuming for CCAC case managers, and for provider agencies, creating added costs for both. Of course, when pediatric nurses were not available to do shifts, an additional burden of care, and the cost of that care, was shifted to families, who either had to find a nurse privately, or provide care themselves.

#### *4.4.5 Structural Impediments to Quality*

Under Ontario's reform of home care, competitive market forces were to be managed so that cost-efficiencies did not come at the expense of quality. However, particularly with respect to "soft"

services like home care defining, measuring and ensuring quality is inherently problematic (Williams et al., 1999a). This is because there are no standard, quantifiable methods of defining or measuring quality. Existing measures are focused on process rather than outcomes. Outcomes may also vary considerably particularly where conditions are chronic and individuals may decline regardless of the quality of care provided.

Although this research did not attempt to measure directly the quality of pediatric home care, key informants and focus groups participants made important observations about quality of care issues. While some noted that quality had never been adequately measured, and that it varied considerably even under old home care program, many voiced concerns that Ontario's reform had resulted in structural impediments to quality care.

For instance, provider agency representatives indicated that they no longer shared best practices, or information about approaches that did not work, for fear of losing a competitive advantage and CCAC contracts. Given the competitive market situation, provider agencies were increasingly concerned about protecting intellectual property and their competitive edge. They reported that when they used their own resources to develop new clinical pathways or delivery plans to improve quality of client care, CCACs would often share them with competing providers agencies. While the sharing of best practices was seen as optimal in terms of benefiting clients and raising standards of care, such information was proprietary; to win in the competitive process agencies had to keep their successes and failures "close to the chest." Particularly as the CCACs moved into new rounds of RFPs, agencies expressed reluctance to cooperate on approaches that would threaten their market share, or force them to raise their bids, since "quality costs money."

The issue of proprietary rights was highlighted in an example where different provider agencies delivered care to the same child. One agency had devoted significant resources to developing specialized guidelines for pediatric nursing (e.g., care of central venous lines, dressing changes, and tracheostomy changes). In principle, at least, once in place, such guidelines should be followed by all providers to ensure continuity of care; it is normal practice to record them in the nursing care plan in the client's home. However, the agency that had developed these guidelines was reluctant to do this, knowing that the other agencies providing care had not developed their own specialized expertise and would likely appropriate those of the first agency. Although raising ethical and moral issues, the first agency felt it was in their interest to discourage dissemination of their "best practices" since sole proprietorship would enhance their chances of winning the next RFP. Not only then was the dissemination of new knowledge discouraged, but in this case, the care of the child was potentially compromised since the different provider agencies used different care protocols.

Issues of monitoring and ensuring care quality were raised by CCAC case managers. Most voiced concerns related to their growing work loads due to increased numbers of pediatric cases complicated by the increasingly time-consuming activity of trying to find suitable pediatric home care providers. These factors limited the time they could devote to monitoring the quality of care to any individual client.

Two related quality issues were raised. The first concerned the impact of the combination of chronic shortages of pediatric health care providers and pressure on home care agencies to fulfill their volume quotas specified in RFPs. Usually, once a referral is accepted by the case manager in a CCAC, they contact one of the contracted provider agencies to deliver the type of service required based on the information received on the intake form. However, once the agency sends a health care professional into the home, he or she, in conjunction with the manager in their agency, provide an assessment of client need to the CCAC case manager. If the agency does not have a professional to deliver the required service, this is documented by the CCAC case manager, who then contacts the next contracted agency (if any). The documentation regarding inability to fulfill a request for service is kept in the provider agency's file and considered in any subsequent RFP. There is a clear incentive, therefore, for the provider agency to ensure that "someone" is sent, whether or not that individual has pediatric expertise.

Particularly in non-urban areas experiencing general nursing shortages, promises of pediatric specialists were not always kept. Families stated that because CCAC case managers did not have the capacity to monitor this routinely, it took a formal complaint from the families to alert them to the fact that the professional coming to their home did not have the expertise to care for their child. However, this required the families to have a fairly high level of knowledge about what care should be provided, and how it should be provided, placing an added burden on families.

A second issue concerned pressures to substitute less qualified, and less costly non-regulated workers for more qualified, more costly regulated professionals. Since few agencies across the province had more than a few Registered Nurses (RNs) with pediatric expertise prepared to take on shift work, there was increasing pressure to substitute Registered Practical Nurses (RPNs) particularly in situations where children with constant monitoring needs were medically stable. Although the effects of such substitution remain controversial, agencies argued for it as a way to meet their contacted service volumes. However, from the parents' perspective, this left them with a less qualified provider, whose scope of practice (controlled tasks which can be performed under provincial legislation) was relatively restricted. It also meant that care beyond the scope of the RPN would fall to the parents. Under conditions of budget constraints and health human resources shortages, pressures had also grown for families to accept the substitution not only of RNs by RPNs (both of which are regulated health professionals), but RPNs by PSWs (personal support workers who are not regulated and who may not perform controlled medical acts except under the direct authority of a regulated professional).

In this connection, concerns were voiced by parents about the extent of the influence contracted agencies had over the qualifications of individual providers sent into the home. Parents reported that it seemed that they were expected simply to accept whomever agencies sent whether or not they had any concerns, and whether or not they had the capacity (due to language or knowledge barriers) to judge appropriate care.

When asked how they determined who should be sent, provider agency representatives stated that it depended on the individual case manager assigned to the child and family, so that there was

variation. While some CCAC case managers worked very closely with the agency, child and family to determine the correct level of provider, in many cases, according to both provider agencies and parents, it was left up to the discretion of the provider agency. For their part, provider agencies emphasized that they were in the best position to assess needs, as their personnel worked face-to-face with the client.

Participants in the provider agency focus group stated that instead of originating from them, pressures to substitute RPNs and PSWs for RNs originated from CCACs which often pushed for such substitutions in order to reduce overall service plan costs while providing families with more hours of care. They indicated that a lot of their time was spent trying to find the "cheapest and best level of care provider" to help the CCAC keep costs low. In the current climate, they found that negotiations with CCAC case managers had becoming increasingly difficult, and that where there were choices between quality and costs, low cost won. This was supported by one CCAC case manager who stated that with respect to "quality versus costs - costs have won."

The following is typical of comments heard in the provider agency focus group:

"I'm seeing a decreased level of service compared to a few years ago. Where I know 5 years ago the type of child that we would bring home and the acuity of that child would be much less and there would be no question about requiring an RN level of care but now they [CCAC case managers] wonder about an RPN. Especially in school programs between a large school program, a lot of requests to withdraw from RN level of care to take care of 5 to 6 kids in a school program with huge needs down to RPN care. For one RPN to take care of that volume of kids...I don't think it's right. I think that is the biggest thing that I've seen in my move back to the community is the acuity and the decreased level of care provided."

From the families' perspective, the end result was that client needs were only one, and not even the most important factor determining services. Indeed, the increasingly complex negotiations around cost consumed large amounts of resources which could have been spent in direct service delivery. This prompted several parents to suggest that if the government gave the families the equivalent amount of dollars that it takes for CCACs to co-ordinate and contract the care, families could organize appropriate care more efficiently and have more dollars left to purchase more services. They strongly argued in favour of direct funding to parents, completely bypassing CCACs.

Finally, families associated managed competition with a decline in continuity of care. For many families whose children had been receiving home care services from the same agency and the same nurses for several years, managed competition brought with it more frequent changes both of provider agency, and individual pediatric professionals in the home. This resulted in a difficult transition for children and families alike, because they had developed strong relationships with individual nurses. In some communities, pediatric nurses ended up being employed by agencies that eventually secured nursing contracts, so disruption to families was less severe. A

manager/director from a northern CCAC commented that, unlike many other CCACs, they were “lucky” because even though the provider agency changed through the RFP process, the individuals delivering the care stayed the same.

## **5.0 Conclusions**

This report has presented results from a multi-year, multi-methods study of pediatric home care in Ontario during a period of significant policy change. While the needs of Canadian children have been much emphasized in rhetoric by political leaders at all levels, our research aimed to analyze systematically the state of pediatric home care in Ontario "on the ground."

In addition to this report, our research findings have been presented in numerous academic and professional venues, and they are the basis of a PhD. dissertation by Karen Spalding, a member of the research team (see *Appendix A: Knowledge Transfer*). In the sections below, we summarize our major conclusions.

### **5.1 Pediatric home care not yet a cohesive policy field**

A first conclusion is that pediatric home care remains a fragmented policy field. When available, publicly-funded services for children and families may flow through a range of agencies, programs and ministries, under different legislation and funding mechanisms, but with relatively little integration and coordination. Our key informants estimated that up to 20 different ministries and programs provided some form of home care services to children under widely varying terms and conditions, and that when services beyond home care (e.g., school programs) were considered, the complexities were multiplied exponentially. While some provinces, including Ontario, are now moving, or have already moved to establish ministries focused on the needs of children, these initiatives are in their early stages.

A lack of integration and coordination is not an Ontario-specific problem. Our earlier national study of services for children found few examples of integrated systems of care across the country (Spalding, Hayes, Williams and McKeever, 2002). However, home care in Ontario provides an excellent example of how, lacking a coherent policy framework, services for the growing number of children who require them may be influenced by a range of macro, meso and micro factors, including changes in the health care system and health policy; changes in proximate policy fields such as education; the characteristics and resources of funding and provider agencies; the qualifications and attitudes of case managers; and the availability and experience of the professionals delivering care to children and families. Although in principle, pediatric home care services should be determined by the needs of children and families, these other external factors are often as important or more important, producing considerable variation in both the volume and mix of publicly-funded services available. While some children and families do well in terms of accessing the services that they require, many face formidable challenges.

### **5.2 The organization of pediatric home care varies substantially**

We observed a mix of different organizational arrangements for the funding, allocation and delivery of pediatric home care in Ontario's CCACs.

Here we recall that Ontario's home care reform had a number of major outcomes. First, home care was removed from the provincial health insurance plan (OHIP) and thus from Medicare's universal entitlements. While individuals are guaranteed an assessment, they are not



automatically entitled to services. CCAC services are fully publicly funded when they are provided, but clients may receive them only when they are deemed to be eligible, and when services are available within capped budgets set by the province.

Second, eschewing "cookie cutter" approaches to policy-making, Ontario's reform effectively regionalized home care in the province. CCACs were to develop local solutions to local problems. During the period of the research, provincial "steering" mechanisms were focused primarily on ensuring that CCACs operated within their budgets, and that provincial service "ceilings" or maximums for individual clients were enforced, although the province did not establish corresponding service "floors" or minimums.

As a result, CCACs reported a range of different organizational approaches to pediatric home care. While most CCAC director/managers and case managers stated that there was a growing awareness of the importance of pediatric home care, none had a dedicated or "protected" pediatric budget. The exception was for private school services which were mandated and funded through a separate budget allocation as a result of a special political arrangement between these schools and the province. Nor were there specific individuals at the management level who were solely responsible for children's programs; these were combined with other responsibilities. For example, although 10 CCAC respondents had the title of Director or Manager of Paediatric or Children's Services, all had additional duties for therapy services, palliative care, or medical equipment contracts. For the most part, responsibility for pediatric home care was subsumed under the more general category of "client services."

This lack of specific organizational arrangements for pediatric home care appeared to have both pros and cons. On the positive side, directors/managers, as well as case managers, had considerable degrees of freedom to move resources between service categories and client groups. As demand for pediatric home care increased between 1997 and 2002, resources appear to have been shifted from services used primarily by seniors (e.g., personal support), to resources used to a greater extent by children and families (e.g., shift nursing). On the negative side, few mechanisms were put in place to regulate or evaluate the outcomes of shifting resource allocation patterns. Indeed, it proved difficult even to gather data to document pediatric home care utilization during this period; the CCAC data analyzed in our study had to be generated manually by CCAC personnel who generously took the time to do it.

### **5.3 Pediatric home care needs increased**

There was overwhelming agreement among our respondents that pediatric home care needs had grown substantially. A major factor leading to increased need was connected to advances in medicine and technology which have meant that more premature and low birth weight babies now survive, along with children with previously life threatening conditions (e.g., cancer, acquired brain injury (ABI), congenital heart defects (CHD), and cystic fibrosis (CF)) although both groups subsequently require care for most or all of their lives.

Other factors, particularly a shift of care out of hospitals and institutions, have increased need for pediatric home and community care specifically. While hospitals used to be the primary site for much pediatric care, changing social values (as well as technological advances) had pointed toward the home as a more desirable care context since families play such a central role in the physiological, social and psychological development of children. As many of our research participants emphasized, the shift from hospital to home mirrored a shift away from the idea of the individual child receiving treatment in an isolated, medical environment, to the idea of the child and family receiving an appropriate range of health and social supports promoting their health and well-being as a unit.

Further increasing the need for home care were changes in proximate policy fields such as education. Many CCAC respondents noted that as boards of education cut numbers of Educational Assistants (EAs), more children had arrived at the doorsteps of the CCACs. As an erosion of the capacity to provide individualized attention to children with special needs in the classroom took place, and there were fewer opportunities for professionals sent by CCACs to develop care plans which could be implemented in the classroom, more children, including those who had not historically been home care clients, now required care, placing additional strains on CCAC budgets and prompting some to withdraw services from this group altogether.

This emphasizes the extent to which children's needs span multiple policy fields, and the extent to which changes in proximate fields may "spill over" into others. It also emphasizes the complexities of providing care in home and community, as compared to care in the more defined context of a hospital. Thus, the shift from hospital must be seen not simply a shift in the site of care; it entails a profound shift in the unit of care, the logic of care, the institutions of care, and care needs.

#### **5.4 The gap between needs and services widened**

As needs grew, the CCAC utilization data show that children took up an increasing proportion of their resources. They also used disproportionately large volumes of services such as shift nursing and speech language pathology, although disproportionately small volumes of other services such as personal support.

Nevertheless, we found broad consensus that there was a growing gap between pediatric home care needs and available services. Even if service utilization by children and families increased somewhat as a proportion of all CCAC services, it was widely perceived that needs grew at a faster pace. Particularly as CCACs experienced budget constraints, parents felt that they had moved from "care management," focused on the needs of children and families, to "cost management," focused on the need to reduce costs and balance budgets. Strategies employed by CCACs included the implementation and management of wait lists particularly for school rehabilitation services; changes in treatment goals and delivery modalities including the use of "block therapy" which meant that children received a fixed number of treatments regardless of need and then went back to the waiting list; systematic reviews of "active caseloads" often

resulting in service reductions; and management of expectations, making it clear to parents in particular that they should expect to do more as CCACs did less.

The June 2001 budget freeze imposed by the province contributed to this gap, although it was not the source. Thirty of 43 CCACs reported that the freeze had made little difference to children's services since previously tight budgets had already resulted in service constraints for all needs groups. Nevertheless, 13 CCACs indicated that the cap had produced significant additional service reductions for children and families. School programs were hit hardest because the majority of school children required "non-medical" services such as therapy for articulation and fine motor problems. Indeed, one reason why more children and families had not been directly affected was that CCAC service cuts had often been aimed first at "non-medical" services such as homemaking; since families were often expected to do homemaking themselves, few had ever received these services in any case.

### **5.5 Managed competition produced "perverse outcomes"**

The introduction of managed competition was widely seen to have had a range of negative consequences for pediatric home care. Although the competitive bidding process had been justified as a way of achieving "highest quality, lowest cost" based on the ideological argument that competitive market forces would produce innovations and efficiencies that collaboration could never produce, there was broad agreement among CCACs, provider agencies and parents, that managed competition had in fact achieved a range of "perverse" outcomes.

First among these was a decline in the number of provider agencies willing to bid on CCAC contracts for specialized, low volume services in uncertain markets. This was compounded by a decline in the number of individual professionals willing to work in the home care sector as they experienced downward pressures on their wages and working conditions. Particularly outside of urban areas where there continue to be few specialized pediatric providers, competitive forces, weak to begin with, were further attenuated; CCACs attempting to divest their staff faced challenges of such magnitude that 7 failed to do so. In the absence of significant competition, but increasing demand, market forces drove prices up, accompanied by rising administrative costs required to "manage" the bidding process, monitor providers and locate pediatric professionals to provide services. Rising costs, in turn, impacted negatively on service volume and access to services since fewer services could be purchased with the same dollars. Now, more parents faced the double jeopardy of having not only to "top up" CCAC services, but to top them up at higher market prices.

Second, managed competition posed important quality issues. Parents indicated that continuity of care was compromised as familiar providers were lost and new agencies and individuals came into their homes. In addition, the drive for cost containment produced growing pressures to substitute generalists for pediatric specialists, and to use lower paid, and less skilled workers both as a means of containing costs, and as a way of meeting service volumes. The development of "best practices" also suffered as provider agencies were unwilling to share innovations or new knowledge for fear of losing a competitive edge. While we did not gather evidence directly

measuring the quality of care, our data thus suggest that managed competition did produce important structural barriers to quality.

### **5.6 Pediatric home care policy emerged "from below"**

Filling the vacuum created by a lack of provincial policy, by few explicit CCAC guidelines for the allocation of limited resources between and within needs groups, and by little collaboration between the major actors in the field, were CCAC case managers who took on increasingly important roles as resource allocation decision-makers.

On the one hand, this role may be justified by the fact that case managers, because of their proximity to clients, are in a favorable position to understand needs and implement appropriate service plans. Their wide discretion presents strong opportunities to individualize care to the needs of children and families, and to build integrated care packages out of the diverse programs and services available within and beyond the CCACs. Indeed, we heard from many dedicated case managers who went well above and beyond the requirements of their jobs to ensure that children and families fared as well as possible.

On the other hand, such wide discretion with few decision-making supports also produced major inconsistencies both in approaches to determining need and allocating resources. For instance, in our focus groups, we heard some case managers describe their roles as advocates who would put together the best package of services possible to meet the needs of children and families as a unit. In contrast, other case managers characterized their role in terms of reducing parents' expectations about the services they would receive, and having families take on greater responsibility for care. Here, personal attitudes appeared to have had considerable weight as some case managers would aim to add to the resources already available to the family, while others would begin by subtracting family resources from those the CCAC should provide. Such subjective views could thus produce quite different resource allocation decisions. They could also result in pressures for mothers to reduce paid employment in favour of unpaid work in the home; ironically, once mothers became more available to provide care due to a reduction of paid work, CCAC case managers might then cut their services. One parent described the extreme case of literally having to move to another CCAC to find a more sympathetic case manager.

Two important issues arise. The first has to do with the extent of variation both within and between CCACs in service allocation. How much variation is acceptable? What factors may reasonably be taken into account when making allocation decisions? Is it acceptable, for instance, to assume that families with mothers employed outside the home should get a different level of services than families where mothers stay at home? While our data provide no definitive answer, they do point to an awareness in the field that there should be greater consistency in decision-making, and that resource allocation decisions should be based on clear principles.

The second related issue has to do with the cumulative effects of the many individual decisions of case managers in the more than 40 CCACs across the province. Lacking a clear policy framework, these decisions amounted to policy being made from the "bottom up." While "bottom

up" approaches may produce local solutions to local problems, they can also pose challenges to equity, transparency and accountability. Lacking an evidence trail, it is almost impossible to document or evaluate decisions made at this level. Neither good decisions, and best practices, nor poor decisions can be reviewed in any systematic way.

### **5.7 Pediatric home care "medicalized" but without Medicare entitlements**

Finally, whether or not it is possible to document and analyze the impact of individual resource allocation decisions, it is clear that they had an important cumulative impact on pediatric home care. As CCACs responded to resource constraints, higher priority was given to "medical" services such as nursing over "non-medical" services such as rehabilitation and homemaking. This, of course, parallels trends within hospitals which, during the course of recent waves of restructuring, have also emphasized "core" acute care services over "non-core" services such as rehabilitation. It is also consistent with recent health policy shifts in Ontario which have seen such services as physiotherapy and optometry pushed out of provincial health insurance plan coverage.

Nevertheless, this trend runs counter to one of the major justifications of the shift of pediatric care from hospitals to home and community, which is that care would be progressively "de-medicalized" in the sense that it would be located within the context of the family home, and that needs would be defined more broadly to take into consideration the range of health and social supports required to maintain the integrity and well-being of the family as a unit.

Here it is important to recall that even as the scope of pediatric home care narrowed to focus more squarely on acute care, home care under Ontario's CCAC reform, including its acute care components, were no longer under Medicare coverage. What this means is that acute care services which would have been fully publicly funded in hospitals, were now fully publicly funded in the home, but only when they were available; under budget constraints, the gap between needs and services widened. Instead of broadening the scope of care, Ontario's reform thus had the reverse outcome as non-medical services were given lower priority. However, outside of Medicare's entitlements, and its guarantee of care under uniform terms and conditions, access even to medical care became increasingly problematic, as it was subject to widely varying local circumstances.

## **6.0 Next Steps**

A major strength of the research presented in this report is that it uses multiple methods and data sources to document and analyze issues and trends around the funding, allocation and delivery of pediatric home care in Ontario during a period of policy change. While our data have gaps, they paint the most comprehensive picture to date of home care developments in the province between 1997 and 2003 and their impact on children and families.

They also point to several problematic aspects of pediatric home care in Ontario. They suggest, for instance, that managed competition does not work well, at least for relatively small needs groups like children and families requiring specialized services, particularly outside of urban areas. Instead of driving costs down, and stimulating an increased supply of high quality services, it appears that managed competition has instead contributed to higher service and administrative costs, while establishing structural barriers to quality, and making evaluation very difficult.

However, our data do not speak as eloquently to what could or should be done to improve home and community care for children and families. If, as we have seen, managed competition does not work well, what is a better alternative? If standard guidelines and protocol are needed to guide resource allocation between and within CCACs, what should these look like?

Even while raising such questions, which the results of our earlier national study suggest are relevant to jurisdictions across the country, the research reported here was not designed to answer them. This doesn't mean there aren't answers, only that specific efforts need to be made to identify and assess promising solutions locally and nationally. In moving from hospital to home and community, information about pediatric care has become increasingly dispersed, particularly in provinces like Ontario where there have been no central means for documenting and analyzing utilization patterns, or for developing and transferring innovations.

Yet, we heard many positive references to attempts by CCACs, provider agencies, and individual pediatric professionals, to find innovative solutions at the system, organization, and individual levels. First and foremost, these need to be identified and evaluated systematically. It would be very useful to know what approaches have been tried, how well they have worked for children and families, and the conditions under which they have worked best. For instance, in comparison to Ontario's competitive model for purchasing home care services on a regional basis, how well have more collaborative, or centralized models worked in other jurisdictions? Then, "lessons learned" need to be communicated to decision-makers across the country in order to ensure that the best use is made of available resources in the interests of children and families.

We believe that by establishing such a core of applied knowledge, an important step would be taken toward reversing the fragmentation and "one offs" which now characterizes the field of pediatric home care. We also think that such information would help to push the needs of children and families higher on the policy agenda in a period when evidence is supposed to drive health care policy and resource allocation.

Finally, while this research focused on home and community care, it is clear that policy decisions in proximate fields like education have profound implications for children and families. This points to the potential of cross-sectoral policy analysis as well as initiatives which bridge the current discontinuity between services for children and services for young adults.

## *References*

Baranek P, Deber RB, Williams AP. *Are We Home Yet? Reforming Home and Community Care in Ontario*. Toronto: University of Toronto Press, 2004.

Bartels-Desrosiers, M., & Cavangh-Zellers, K. (1989). Focus groups: A program planning technique. *Journal of Nursing Administration*, 19(3), 20 - 25.

Bazeley, P., & Richards. L. (2000) *The NVivo qualitative project book*, London, UK: Sage Publications.

Beaudin, C. L., & Pelletier, L. R. (1996). Consumer-based research: Using focus groups as a method for evaluating quality of care. *Journal of Nursing Care Quality*, 19(3), 28-33.

Berg, B. (2004). *Qualitative research methods for the social sciences (5th ed)*. San Francisco, CA: Pearson Education, Inc.

Canadian Association for Community Care. (1995). *Home based care for medically and psychologically fragile children: Phase 1 report*. Ottawa, ON: Canadian Association for Community Care.

Canadian Institute of Child Health. (2000). *The health of Canada's children: A CICH profile (3rd ed.)*. Ottawa, ON: Author.

Canadian Institute for Health Information, Statistics Canada. (2000). *Health care in Canada: a first annual report*. Ottawa, ON: Author.

Chappell, N. L. (1994). Home care research: what does it tell us? *Gerontology*, 34(1), 116-20.

Coyte, P. C., Young, W. (1997). *Reinvestment in and use of home care services. technical report No. 97-05*. Toronto, ON: Institute for Clinical Evaluative Sciences.

Coyte, P. C., Young, W. (1999). Regional variations in the use of home care services in Ontario 1993/1995. *Canadian Medical Association Journal*, 161(4), 376-90.

Havens, B. (1998). *Canadian home care: what are the issues for long-term care?* Presented at the National Conference on Home Care. Toronto, ON: Canadian Association of Home Care.

Hayes, V. E., Hollander, M. J., Tan, E. L. C. & Cloutier, J. E. (1997). *Services for children with special needs in Canada. A report prepared for the Canadian Association of Community Care and Health Canada*. Victoria, BC: Health Network, Canadian Policy Research Networks Inc.

Health Canada (1999a). *Public home care expenditures in Canada, 1975-76 to 1997-98* Ottawa, ON: Health System and Policy Division, Health Canada.



- Health Canada. (1999b). Provincial and territorial home care programs: A synthesis for Canada. Ottawa, ON: Minister of Public Works and Government Services.
- Health Canada. (1999c). Report on the national roundtable on home and community care: Home care development. Ottawa, ON: Minister of Public Works and Government Services.
- Hollander M. J. (1994). The costs, and cost-effectiveness, of continuing care services in Canada. Ottawa: Queen's-University of Ottawa Economics Working Paper No. 94-10.
- Hollander, M. J. (1999). Substudy 1: Comparative cost of analysis of home care and residential care services. Preliminary Findings. Report to Health Transition Fund. Victoria, BC: Health Canada.
- Jackson, R. A. (1994). Home care: the cornerstone of health renewal in Nova Scotia. *Leadership in Health Services*, 4, 5-14.
- Jessop, D. J. & Stein, R. E. K. (1994). Providing Comprehensive Health Care to Children With Chronic Illness. *Pediatrics*, 93(4), 602-607.
- Kirby, M. (2002). The health of Canadians - The federal role: Final Report, (Vol. 6). Ottawa, ON: Government of Canada.
- Kitzinger, J. (1995). Introducing focus groups. *British Medical Journal*, 311, 229 - 302.
- Klug, R. M. (1993). Clarifying roles and expectations in home care. *Journal of Pediatric Nursing*, 19(4), 374-376.
- Kohrman, A. F., Kaufman, J. (1997). Home care for children with technologic needs. In: R. F., Wallace, R.F. Biehl & J.A. Blackman (Eds.), *Mosby's resource guide to children with disabilities and chronic illness* (pp. 411-420). St. Louis: Mosby.
- Lawton, V. (2000). Ottawa's historic step for children. *Toronto Star*, Sept. 12, p. A1.
- McKeever, P. (1992). Mothering chronically-ill, technology dependent children: An analysis using critical theory . Unpublished doctoral dissertation. York University, Toronto.
- McKeever, P. (1996). The family: Long-term care research and policy formulation. *Nursing Inquiry*, 3, 200-206
- Morgan, D. (1998). *The focus group guidebook*. London, UK: Sage Publications.

National Council of Welfare. (1999). Poverty profile 1997. Ottawa, ON: Minister of Public Works and Government Services.

Nyamathi, A., & Shuler, P. (1990). Focus group interview: A research technique for informed nursing practice. *Journal of Advanced Nursing*, 15, 1281-1288.

Romanow, R. (2002). Commission on the future of health care in Canada: Shape of the future of health care. Ottawa, ON: Government of Canada.

Shapiro, E. (1992). There's no place like home. In: R.B. Deber and G.G. Thompson (Eds.), *Restructuring Canada's health services system: How do we get there from here?* (99-104). Toronto: University of Toronto Press.

Slaughter, P., Pinfold, P., Flintoft, V., Gort, E., Thiel, E., Blackstein-Hirsch, P., Axcell, T., Paterson, M., Cameron, C., Estabrooks, C., Mercer, S., Goel, V., & Williams, J. I. (1999). Focus group in health services research. Technical Report No. 99-02-TR. Report for the Institute for Clinical Evaluative Studies (ICES): Toronto, ON: ICES.

Spalding, K. L., Hayes, V. E., Williams, A. P. & McKeever, P. (2002). Services for children with special needs and their families: Analysis of interfaces along the continuum of care. Technical report 5. Victoria, BC: Hollander Analytic Services Inc. Retrieved, September 28, 2003 from <http://www.hollanderanalytical.com/downloads/continuum-tech-5.pdf>

Stein, R. E. K. & Jessop, D. J. (1984). Does pediatric home care make a difference for children with chronic illness? Findings from the Pediatric Ambulatory Care Treatment Study. *Pediatrics*, 73(6), 845-853.

Stein, R. E. K. & Jessop, D. J. (1991a). Long-term mental health effects of a pediatric home care program. *Pediatrics*, 88(3), 490-496.

Stein, R. E. K. & Jessop, D. J. (1991b). Who benefits from a pediatric home care program? *Pediatrics*, 88(3), 497-505.

Williams, A. P., Barnsley, J., Leggat, S., Deber, R. B., Baranek, P. (1999a). Long term care goes to market: managed competition and Ontario's reform of community-based services. *Canadian Journal of Aging*, 18(2), 125-51.

Williams, A. P., Deber, R. B., Gildiner, A., Baranek, P. (1999b). From medicare to home care: state retrenchment and the profitization of Canada's health care system. In: D. Coburn, P. Armstrong, H. Armstrong (Eds.), *Medical sociology*. Toronto, ON: University of Toronto Press.

Wright, M. (1995). Behavioral effects of hospitalization in children. *Journal of Pediatrics and Child Health*, 31, 165-7.

## *Appendix A: Knowledge Transfer*

### Doctoral Dissertation

Spalding K. Policy By Default: How Changes in Ontario's Home Care Sector Have Impacted on Providers, Children and Families. Department of Health Policy, Management and Evaluation, University of Toronto, December, 2004.

### Invited Presentations

Williams, A.P. & Spalding K. "Outcomes of Managed Competition in Ontario: Results from Two Recent Studies". Invited Presentation to CCAC Procurement Review, Ontario, Honorable Elinor Caplan, Chair, Toronto, January 25, 2005.

Spalding, K., Williams, A.P., Deber, R., McKeever, P. "The Changing Landscape of Pediatric Home and Community Care: Implications for Children, Families and Providers in Ontario." CCAC/CHN Workshop on Maternal and Children's Home Care/School Care Services in the Greater Toronto Area, Toronto, Ontario. June 11, 2003.

Williams, A.P. & Spalding, K. "How Changes in Home and Community Care in Ontario are Impacting on Children and Families: Challenges and Opportunities." Invited keynote presentation to Future Planning for Children With High Needs, Thames Valley District Health Council. London, Ontario, October 10, 2002.

Spalding, K., Williams, A.P., McKeever, P. & Deber, R.B. "Home Care for Children and Youth: Complexities, Challenges and Opportunities." Invited presentation to Ontario Association of Community Care Access Centres (OACCAC) 2002 Conference: Health Care Partners...Leading the Way Through Change. Toronto, Ontario, June 11, 2002.

Spalding, K. "Pediatric Home Care: Analyzing the Impact of the Shift from Hospital to Home and Community on Children with Complex Care Needs (CCN) and their Families." Invited presentation at The Hospital for Sick Children Nursing Research Series. Toronto, Ontario, April 25, 2002.

Williams, A.P., Spalding, K., Deber, R. & McKeever, P. "Prescriptions for Pediatric Home Care: From Hospital to Home and Community: Children with Complex Care Needs." Invited presentation to Children and Youth Home Care Network 2nd National Forum: Addressing the Challenges of Making Home Care for Children and Youth Evidence-Based. Toronto, Ontario, October 22, 2001.

### Peer Reviewed Presentations

Spalding, K., Williams, A.P., Deber, R., & McKeever, P. "The changing landscape of paediatric health care: Implications of the shift from hospital to home on health care providers, children and

families." Transforming Health Care Through Nursing Research: Making It Happen 2004 Canadian Nursing Research Conference, London, Ontario. May 12-15, 2004.

Spalding, K., Williams, A.P., Deber, R.B., McKeever, P. "Pediatric Home Care Under Managed Competition: The Case of Ontario's CCACs." Canadian Home Care Association Conference, Vancouver, BC, Canada, November 21-22, 2002.

Spalding, K., Williams, A.P., Deber, R.B. & McKeever, P. "Pediatric Home Care: Analyzing the Impact of the Ongoing Shift from Hospital to Home on Health Care Organizations, Health Professionals and Patients." RNAO and PedNIG Leadership in Pediatric Nursing Conference. Toronto, Ontario. October, 2001.

Spalding, K., Williams, A.P., Deber, R.B. & McKeever, P. "Prescriptions for Pediatric Home Care: Analyzing the Impact of the Shift From Hospital to Home and Community on Children with Complex Care Needs." Ontario Community Services Research and Evaluation Network Symposium. Richmond Hill, Ontario. April, 2001.

#### Poster Presentation

Williams, A.P., Spalding, K., Deber, R., McKeever, P. "Highest Quality, Best Price? Outcomes of Managed Competition for Pediatric Home Care in Ontario". Children and Youth Home Care Network 3rd National Forum: Bringing it Home: CYHN in Local Contexts. Banff, Alberta. February 17th - 20th 2005

#### Papers Accepted for Presentation

Spalding, K., Williams, A.P., Deber, R., McKeever, P. Health Care Reforms in the Home Care Sector: Implications of Managed Competition on Pediatric Services. International Health Economics Association (IHEA) 5th Annual Congress: Investing in Health. July 10th - 13th, 2005.

**Appendix B: Text of CCAC Telephone Survey Questionnaire**

*I want to begin by reminding you the answers you provide to the survey will remain confidential in that the data will be reported in aggregate format to ensure that no individual or specific CCAC will be identified. You may refuse to answer any question and/or stop the survey at anytime. I also want to ask if you would mind if I tape record this solely for the purpose of assistance with note taking. The tape will not be transcribed verbatim but it will just help to go back to the tape for verification of answers if I don't capture all the details when writing notes during the phone survey. The tape will be destroyed immediately after I have fully completed the survey.*

**Section A: Background information on respondent**

*First, I would like to begin by taking just a moment to verify your contact information.*

- A1. Respondent's title/position  
Title/position \_\_\_\_\_
- A2. Professional Designation/Training \_\_\_\_\_
- A3. Number of years in current title/position  
Years \_\_\_\_
- A4. Number of years in the home care field  
Years \_\_\_\_
- A5. Previous employment history \_\_\_\_\_

**Section B: Organization of children's services in CCAC**

*Now I would like to ask you some questions about how children's services are categorized and organized within your CCAC.*

- B1. What age range does your CCAC use to define "child" or "children?"  
\_\_\_\_ years of age to \_\_\_\_ years of age
- B2. Could you tell me briefly how services for children are organized in your CCAC?  
*Prompts: (refer to organizational chart for this specific CCAC)*

Overall Management

- Separate children's program or programs (specify)
- Manager or Director of *children's services* specifically?
- Manager or Director of *children's services* with other responsibilities as well (specify)
- Manager or Director of *other services* with responsibility for *children's services* as well (specify)\_\_\_\_\_

#### Case Management

- Do you have Case managers for *children's services* specifically?  
Number \_\_
- Case managers for *children's services* with other responsibilities as well (specify other responsibilities and number)\_\_\_\_\_
- Case managers for *other services* with responsibility for *children's services* as well (specify "other services and number")  
\_\_\_\_\_
- How are case loads grouped in your CCAC? (e.g. by region, age, diagnosis, other)
- Total number of case managers in your CCAC? \_\_\_\_\_

B3. Does your CCAC have case coordinators located in hospitals in your catchment area?

No  
Yes

If Yes, do any deal with children - which hospitals (please list)

\_\_\_\_\_

B4. Do staff in your CCAC who are case managers for children's services have specific training and/or background in child and family care?

No  
Yes (specify)

\_\_\_\_\_

B5. Does your CCAC have specific guidelines or assessment tools for case managers to use to determine what services children receive?

Yes, specific to children (could you send us a copy?)  
Yes, but general and used for other clients also (could you send us a copy?)  
No – how do case managers decide? (Specify)

\_\_\_\_\_

B6. Does your CCAC have a dedicated budget line for children's services?

Yes (Is it PROTECTED)

No, children's services part of other budget lines (specify how budget is divided up and amounts for this fiscal year related to children's services)

---

\*\* it is often divided into "nursing", "therapy" "medical supplies" etc. and then both adults and kids are divided out of this

- B7. Is budget for services to private schools separate or "protected"?  
Is this a large part of your services?
- B8. In your CCAC, who has primary responsibility for determining what proportion of the overall budget is spent on children's services (as compared to services for adults)?

Prompts:

ED  
Board  
Manager(s)  
Case managers

---

### Section C: Current Services

*Now I would like to ask you about the current children's services in your CCAC.*

- C1. Has your CCAC issued RFPs related to children's services? (Could either be separate or included as part of another one)

YES (go to C2)

NO (explain why not - see\*\*) (GO TO C5)

\*\* may not have had an RFP if services less than \$100,000 or some staff may not have been divested yet

- C2. How are your RFPs related to children's services structured?
- Was there a specific RFP for children?
  - Incorporated into adult ones by types of services (nursing, OT/PT/SLT, PSW, social work, labs, medical supplies)
- C3. What, if any special considerations or specifications were included in the RFPs that related to children's services? (e.g. how are the needs of children and families incorporated into the RFPs?)
- Did the RFP specify that children's services were to be delivered by pediatric care specialists (RPNs, RNs, OTs, Pts)? How was this defined?

- Did the Medical supplies/equipment supplier have to have child sized supplies/equipment

C4. Was the RFP for children's services developed in collaboration with any other CCAC(s)?

No

Yes (specify) \_\_\_\_\_

C5. How many providers does your CCAC contract with to deliver services and/or equipment/supplies to children?

(#) Nursing \_\_\_\_\_

(#) Medical Supplies \_\_\_\_\_

(#) Therapy (OT, PT, SLT,) \_\_\_\_\_

(#) Personal Support \_\_\_\_\_

(#) Nutrition \_\_\_\_\_

(#) Homemaking \_\_\_\_\_

(#) Social Work \_\_\_\_\_

C6. Could you tell us who are the providers currently contracted for children's services? Does your CCAC have any contracts or special arrangements with children's treatment centres?

NO

YES - Please describe

C7. How important do you think it is that specific services (nursing, rehab, homemaking/psw) are provided by pediatric specialists?

Nursing = V.import – important - neutral - somewhat import - not at all important

Rehab = V.import – important - neutral - somewhat import - not at all important

PSW = V.import – important - neutral - somewhat import - not at all important

C8. Are these services for children being provided by pediatric care specialists on a regular basis (RN, RPN, OT, PT) in your region?

Yes - regularly, often, sometimes

No, why not?

Prompts:

- Pediatric care specialists not considered necessary
- Pediatric care specialists not available
- Pediatric care specialists too costly (not worth the costs)
- Specialist services not considered a priority
- Volume of demand is too low for specialist services



Section D: Trends in children's services over the past 5 years

*I'm going to ask you to compare and contrast children's services today and 5 years ago (or from the time your CCAC first started).*

D1. Currently, what percentage of the your total CCAC caseload do children represent? \_\_\_\_\_

How does this compare to 5 years ago?

D1a. In relation to children's services do you track them by different categories such as acute care, school, long-term care or complex care needs?

If YES, approximately what percentage does each category represent out of all children's services (at end we will be asking for trends over the last few years in these categories)

Do you track the "complex care children" who require high levels of monitoring (i.e. the children eligible for the respite funding)?

If yes, how many of these children do you serve? What % do they represent?

D2. Over the past 5 years, by about what percentage has the total number of admissions for children *increased* or *decreased* in your CCAC?

% \_\_\_ Increase

% \_\_\_ Decrease

D2a) Where have the changes in referral patterns occurred?

Prompts:

- Community based referrals (doctor offices, self referrals) Increased/Decreased
- School based referrals *Increased/Decreased*
- Hospital/Rehabilitation Centre based referrals *Increased/Decreased*
- Children's treatment centre referrals *Increased/Decreased*
- Other \_\_\_\_\_ *Increased/Decreased*

D3. Have there been changes in the type of care children require in home and community over the past 5 years?

Prompts:

- nursing
- OT/PT/SLT
- homemaking/personal support

D4. In your view, what factors have contributed most to these changes in children's services in your CCAC over the past 5 years?

If increased:

a) Is it related to increased volume of children requiring services overall?

b) Is it related to the need for CCAC to provide services that previously would have been provided through another institution or agency (pushed out of hospital, school cutbacks etc)

Prompts:

- Changes in service patterns shift of patients out of long-term care institutions
- Change in children's services provided by school boards
- Change in children's services provided by other community agencies
- Changes in the needs of the clients (children and families)
- Increase in survival rates for medically fragile children
- Increase in life expectancies for children with chronic care conditions
- Increase in multiple births
- Increasing complexity of care needs
- More single parent families require more social supports

D5. We are interested to know about the capacity of your CCAC to meet children's needs over the past 5 years?

Has the capacity of your CCAC kept pace with demand?

- Yes, how
- No, why not (how much related to budget?)

List of possible answers (check if applicable)

- the capacity of my CCAC to provide children's services has kept pace with demand over the past five years
- not able to keep pace due to human resource shortages
- families are now expected to bear a greater proportion of the total costs of care for their children than they were 5 years ago
- other

D6. Are there any waiting lists for services for children in your region?

- No
- Yes, if yes for which services (usually school therapies); **reason** (i.e. human resource shortage) and **how long is the waiting list** (OT, PT, SLT)?

Is there wait list for in-home services - if yes, which ones and why?

- D7. In terms of the amount and number of services children receive through your CCAC, in your opinion, how do they fare in comparison to other client groups such as seniors, or adults discharged from hospital who have similar level of needs?

List of possible responses (check if applicable)

- children have received more compared to adults with similar needs
  - increased demand from other needs groups has meant fewer CCAC services for children
  - other
- D8. Within children's services, in your opinion, are there particular groups of children (i.e. acute care post hospital discharge) who receive a greater share of services from your CCAC compared to another group of children (i.e. children needing school services)?
- Yes, please specify why (i.e. those waiting for services don't get them such as OT in schools) \_\_\_\_\_
  - No
  - Not applicable
- D9. In your opinion, what impact (if any) have the CCAC budget constraints of June 2001 had on children's services in your CCAC? (Flat line budget)

Prompt:

Ask what actions the CCAC took in response to the flat line budgets in 2001. (E.g. Most reviewed each case - ask if kids were affected and if any services in particular were cutback)

\*\* ask if any Priority tool or check list was developed to facilitate these cutbacks - if yes could we have a copy

Possible answers (check if applicable)

- No impact
- Overall volume of services to children reduced
- Personal Support/Homemaking services to children reduced
- Nursing services to children reduced
- Rehabilitation services to children reduced
- Service intensity reduced for current clients (children)
- Service intensity reduced for new CCAC admissions (children)
- Service intensity reduced for both new and current clients (children)
- No new referrals accepted
- Waiting lists established
- Guidelines developed by CCAC
- Each case reviewed and changes made by case manager
- Other \_\_\_\_\_

D10. What do you see as the key trends and issues in the future that will have the greatest impact on home and community services for children in your region?

Possible answers (check if applicable)

- Lack of coordination with other agencies
- Budget constraints
- Increasing demand
- Human resources shortages
- Other \_\_\_\_\_

D11. Are there any initiatives on the horizon that your CCAC will be involved with or that you are aware of related to pediatric home and community care in your area?

D12. In our next research stage we are interested in interviewing case managers about their work -- could we contact you when we are at this stage to discuss this with you?

#### Section E: Utilization data from the CCAC

We would like information on referrals, admissions, and caseloads for children, over the last 5 years. Also budget for children compared to rest of clients either as amounts or % of total budget. We are also interested in the amount of services such as nursing, OT, PT, SLT, SW, homemaking by hour or units yearly, over the last 5 years in total and then for children -

**Is this data that you track for children and is it possible if we e-mail this request to you that you could either send back in the form you have it or fill in the chart for us?**

*Appendix C: CCAC Utilization Data Template*

<b>General CCAC Information</b>	<b>'97-'98</b>	<b>'98-'99</b>	<b>'99-'00</b>	<b>'00-'01</b>	<b>'01-'02</b>
Total CCAC <b>BUDGET</b>					
Total # of <b>CLIENTS SERVED</b>					

<b>Admissions for Children's Services</b>	<b>'97-'98</b>	<b>'98-'99</b>	<b>'99-'00</b>	<b>'00-'01</b>	<b>'01-'02</b>
Total number of <b>REFERRALS</b> for children to your CCAC					
Total number of <b>ADMISSIONS</b> for children by your CCAC					
Children as a % of your CCAC total <b>CASELOAD</b>					
Children's services as % of CCAC total <b>BUDGET</b>					

<b>Categories of Children</b>	<b>'97-'98</b>	<b>'98-'99</b>	<b>'99-'00</b>	<b>'00-'01</b>	<b>'01-'02</b>
Total number of <b>IN-HOME</b> children clients					
Total number of <b>SCHOOL</b> clients					
Total number of children with <b>MEDICALLY FRAGILE NEEDS</b> (i.e. children who are eligible for the "enhanced respite" funding)					

<b>Nursing Services</b>	<b>'97-'98</b>	<b>'98-'99</b>	<b>'99-'00</b>	<b>'00-'01</b>	<b>'01-'02</b>
Total number of <b>NURSING VISITS</b> for children **Please indicate how many hours are included in 1 visit					
Total number of <b>NURSING</b>					

<b>VISITS</b> for all CCAC clients					
Total number of <b>SHIFT NURSING</b> hours for children					
Total number of <b>SHIFT NURSING</b> hours for all CCAC clients					

<i>Therapy Services</i>	'97-'98	'98-'99	'99-'00	'00-'01	'01-'02
Total number of <b>PHYSIOTHERAPY</b> visits for children					
Total number of <b>PHYSIOTHERAPY</b> visits for all CCAC clients					
Total number of <b>OCCUPATIONAL THERAPY</b> visits for children					
Total number of <b>OCCUPATIONAL THERAPY</b> visits for all CCAC clients					
Total number of <b>SPEECH LANGUAGE THERAPY</b> visits for children					
Total number of <b>SPEECH LANGUAGE THERAPY</b> visits for CCAC clients					

<i>Other Services</i>	'97-'98	'98-'99	'99-'00	'00-'01	'01-'02
Total number of <b>PERSONAL SUPPORT/HOMEMAKING</b> hours for children					
Total number of <b>PERSONAL SUPPORT/HOMEMAKING</b> hours for all CCAC clients					

## *Appendix D: Focus Group Protocol*

### **Wording for Provider Focus Group**

1. Over the past five years what changes have you seen in services to children and families provided through the CCACs?

Probes:

- What services are the CCACs contracting out for?
- Are there services that CCACs have stopped providing to children and families?
- Comment on coordination of services.
- Comment on your relationship with the CCACs.
- Comment on your relationships with other provider organizations.

- 1b. To what do you attribute these changes?

Probes:

- Impact of changes in CCAC budgets
- Have the provincial guidelines and service maximum had an impact on children's services?
- What impact has managed competition had on children's services?
- What impact has nursing shortage (other health care professional shortages) had?
- Did changes in hospital discharges impact CCACs at all and if yes, how?
- Were there changes in needs of children requiring home and community care services (i.e. higher acuity at home, more complex medical care)?

2. What impact has the change from the former home care program to CCACs had on your organization?

- What was the impact of the RFP process on your organization?
- Now that you are working within a competitive environment and CCACs monitoring your performance has that changed how your organization functions (hiring, staffing practices, quality management)?
- Given the competitive environment please comment on the relationship between staff/providers when staff from two different organizations have to provide services to the same child/family household.

3. Please respond and explain your responses to the following questions:

- (i) Currently, are children and families doing better or worse, in terms of availability of services through the CCACs, compared to 3 years ago?
- (ii) Compared to other client groups, such as seniors or adults with disabilities, are children and families are now doing better or worse in terms of services provided through the CCACs?