

## **An Intersectoral Response to Children with Complex Health Care Needs**

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### **Introduction**

The purpose of this paper is to stimulate debate on how to define and enact public responsibility to children with complex health care needs and their families. National and provincial policies define accountability at a macro level and are not intended to be prescriptive at the micro level. Indeed, principals, teachers and service providers would be critical of the involvement of policy makers in micro-management. Yet, decision-makers focus on the shortcomings of existing policy and not on the shortcomings of management. For example, the Children and Youth Home Care Network has called for "governments at all levels to assign higher priority to developing coherent policies for children with special needs and families, particularly in the home and community". Spalding and colleagues reported that service integration and coordination would not improve until there are "fundamental changes at the broader system level....". There is no urgent need for policy to 'catch up' with reality. Rather there is a need for principals, teachers and service providers to develop programs that support policies.

This paper details a case study of an evidence-based program that provides the critical link between the policy and good practice. This program involves Community Care Access Centres, schools and Saint Elizabeth Health Care, a complex-care nursing provider. The case study illustrates how public responsibility has been successfully enacted at a local level within existing policies for children with complex health care needs.

### **Statement of the problem**

Children with complex health care needs have a profound impact on families and on the educational system. Parents believe that their employment status is affected and we know that they have difficulty in finding childcare. The impact on the educational system, which has increased over time and is projected to further increase, is driven by three factors. First, the Canadian Charter of Rights and Freedoms ensures that every child with either a mental or physical disability has the right to access educational services. Compliance with the Canadian Charter, the Education Act and regulations in Ontario requires each school to provide all special needs children with a free and appropriate public education in the least restrictive setting. School principals are required to ensure that an Individual Education Plan (IEP) is developed for each child who has been identified as "exceptional". Second, children who previously would not have lived are now surviving, and through technology are being cared for in the community. Finally, Canadians want greater choice and input into planned services, and want to be confident that these services are efficient, effective and of high quality.

To meet the needs of the growing number of children, educators must work with individuals from sectors outside of education. Sectors are distinct public service systems such as health and education. Intersectoral policies define the shared responsibilities for the welfare and well-being of a distinct population group. In Ontario, the intersectoral mechanism for children who require health support services is Policy/Program Memorandum Number 81 (PPM 81). PPM 81 outlines the responsibilities of three sectors: Education, Health, and Community and Social Services [Ontario Ministry of Education, 1984 #5]. The Ministry of Education is responsible for the administration of oral medication, physical assistance, physio/occupational therapy, and speech and language services. The Ministry of Health and Long Term Care is responsible for the injection of medication, catheterization, manual expression of bladder/stoma, postural drainage/suctioning, tube feeding, and speech therapy. The Ministry of Community and Social Services is responsible for all services in children's residential care/treatment facilities.

The Ontario intersectoral mechanism for children with complex health care needs has been implemented in Toronto by five Metro Toronto Community Care Access Centres (CCACs) through the School Health Support Services (SHSS) program. These CCACs are responsible for co-ordinating in-home and in-school community-based health services for children and youth, in particular the provision of an extensive care for children with complex long-term disabilities. They see to the planning, co-ordinating, and delivering of professional SHSS programs support.

The SHSS program enables children with health support needs to attend school with their peers. In addition, the SHSS provides health related education, teaching, and consultation services to staff and parents in the school setting. At the local service level, the Metro Toronto CCACs contract through a "Request For Proposal" process, with three health care agencies to provide nursing care in the school-based program. The three agencies are 1) Saint Elizabeth Health Care (SEHC), 2) Victorian Order of Nurses (VON) Toronto-York Region, and 3) Comcare Health Services Limited.

Saint Elizabeth Health Care (SEHC) is one of the health care providers invited by CCACs to respond to principals' request to deliver health care in an educational setting. The organization has been an active participant in the delivery of

paediatric programs since 1908. In its early years, nurses provided mostly prenatal and paediatric care, making their way to homes on foot or by streetcar. Essentially a Toronto-based nursing organization until 1994, SEHC now provides a full range of health care and services through 17 Service Delivery Centres from Windsor to Cornwall, and as far north as Thunder Bay. It contracts with over half of the CCACs in Ontario and delivers more than two million visits to over 150,000 individuals and families annually.

SEHC's multidisciplinary team of more than 2,500 staff includes Registered Nurses and Registered Practical Nurses, Occupational Therapists, Physiotherapists, Personal and Home Support Workers, Nutritionists, Speech Language Pathologists, Social Workers, Chaplains and Mental Health Professionals. With well-established programs in the areas of nursing, personal support and rehabilitation, SEHC was one of the first home health care organizations in Ontario to be awarded an accreditation by the Canadian Council on Health Services Accreditation. The clinical areas of excellence are Child and Family, Long-Term Care and Gerontology, Mental Health, Palliative Care and Rehabilitation. Some examples of SEHC's specialty services include Advanced Wound Care, Home Infusion, Diabetes Management, Crisis Intervention and Maternal Newborn Care.

In addition to expanding geographically and broadening its scope of services, SEHC is now offering professional consulting services nationally and internationally, and leveraging technology to provide quality, accessible care. To help SEHC successfully lead community health care into the 21st century, the Saint Elizabeth Health Care Foundation was incorporated in 1997 to raise charitable support for the enhancement and expansion of superlative home health care services in Canada. The Foundation supports advances in health care research and technologies, continuing education and technical training, and the ongoing development and implementation of innovative programs and services. As a testament to SEHC's very caring values and commitment to making a valuable contribution to the communities it serves, the Foundation has sponsored the printing and distribution of two illustrated, easy-to-follow guides by Harry van Bommel, respectively titled *Caring for Loved Ones at Home* and *Family Hospice Care: Pre-planning & Care Guide*. Over 100,000 copies of each book have been distributed, free-of-charge, to hospitals, hospices, home care organizations and individuals to help family caregivers effectively manage and respond to the home care needs of their loved ones.

### **Child and Family Program**

Saint Elizabeth Health Care provides high quality family-centred care based on its commitment to research of child and family issues and the implementation of research/evidence-based practice. The Child and Family Program is guided by principles of family-centred care and the organization's values respect the unique needs and expectations of its client families. Professionals with advanced knowledge in community-based child and family care co-ordinate SEHC's comprehensive interdisciplinary team approach. This approach ensures seamless consultation and collaboration with experts to mobilize a range of resources and health care options to meet unique child and family needs. SEHC's teams recognize the diversity of the community environment and adapt care according to the social, ethical and economic factors that affect families. The Child and Family Program includes the following services:

- Perinatal Services
- Complex Care School Nursing Services
- Complex Care Home Nursing Services
- Acute Care Nursing Services

From birthing mothers to infants and adolescents, the Child and Family Program promotes optimal health and wellbeing through health teaching, illness management and support to families in adjusting to ongoing health challenges. SEHC also provides health teaching to professionals and caregivers to support the wellbeing of children in their care.

SEHC's definition of health is guided by the World Health Organization's determinants of health and includes physical, intellectual and emotional/social dimensions. The philosophy of family-centred care is built on the cornerstones of collaboration, information sharing, encouragement and support. Staff respect the lifestyles, values, beliefs and culture of families and respond with accessible, flexible and empowering services. For example:

- SEHC supports families to participate in all decisions about care planning and delivery.
- SEHC respects the family's knowledge and expertise in caring for their child.
- SEHC builds on family strengths and foster independence.
- SEHC adapts interventions to meet the child and family's changing needs.

- SEHC customizes care strategies that support the child and family's unique response to health and illness.

The goal of SEHC's children's services is to promote the health maturation of the child within the context of the family/community. SEHC assists the child and family to achieve, maintain and promote optimal levels of health; facilitates rehabilitation and improvement of the child's ability to function; identifies threats to the child's health and well-being; and facilitates the management of health challenges.

### **Program Features**

Saint Elizabeth Health Care's paediatric nurses are educated and experienced in advanced paediatric nursing. They are additionally certified to provide specialized services for all age groups. These include:

- Provision of IV and TPN therapy
- Wound management
- Diabetic treatment and teaching
- Suctioning and chest percussion/postural drainage
- Tube feeding
- Irrigations
- Catheterization
- Chest tube care
- Ostomy care
- Ventilator care
- Tracheotomy care
- Pain management
- Behavior management
- Central line care
- Cardio-respiratory care
- Psychosocial assessment and support
- Cast care

### **Practical problems with implementation of Policy/Program Memorandum Number 81**

SEHC's Child and Family Team assessed the quality of care received by children with complex health care needs. Several weaknesses were noted:

- Parents commented that they were not contacted prior to school enrolment.
- Continuity of care was compromised by nurse turnover.
- Parents wanted more frequent communication about school events.
- Communication among health care providers, the school and the CCAC was sub-optimal.
- The lack of coordination/integration with the school authorities undermined the quality and accountability of services.
- There were no clear guidelines regarding the service protocols.
- There were no standards for staff qualifications.
- There were limited opportunities for the providers to improve their skill set.
- Standardized monitoring of the care delivered in the school was limited.
- Performance appraisal of nurses was not conducted.
- Inadequate attention to problems reduced accountability.
- Limited advocacy services increased the costs for parents.
- The lack of daily leadership reduced the quality of partnership services.

## Case study

### ***Rationale and Description***

In recent years, many public sector organizations have examined the subject of accountability. This has been initiated by extensive changes in the delivery of services and in the increasing use of partnering arrangements to deliver public programs. To an increasing extent, there is some form of shared accountability. In our case study SEHC nurses, teachers, principals, three Ministries, the CCAC and the family shared the accountability. These partners could not afford to wait for the introduction of policies that require organizations share accountability. Instead, the partners introduced change voluntarily through an effective accountability framework that built on the Auditor General of Canada's five principles of effective accountability :

*Clear roles and responsibilities* – For all sectors in the accountability relationship, roles and responsibilities must be well understood and agreed upon.

*Clear performance expectations* – The health care objectives pursued and outcomes expected are to be explicit, understood and agreed upon.

*Balanced expectations and capacities* – Performance expectations must be clearly linked to and aligned with each sector's capacity to deliver.

*Credible reporting* – Credible and timely information must demonstrate what was achieved, and what was learned.

*Reasonable review and adjustment* – Fair and informed review and feedback on performance must be carried out by all sectors, achievements recognized, corrections made, and appropriate consequences for individuals was carried out.

### ***Description of protocol***

The protocol developed by SEHC incorporated the 5 principles of shared accountability and was designed to address documented shortcomings in care delivery.

#### *Clear roles and responsibilities*

- Children are now admitted to the school program before the first day of school. During the summer months, a Primary Nurse meets with the child and family in the home. A partnership is initiated with the family at this time. Effective collaborative planning is ensured at all times with the family, CCACs and the school staff.
- The CCACs assess the needs of the child or youth and their families and communicates that assessment to the nurse.
- If additional visits are required, then the CCAC is asked to approve payment.
- The Primary Nurse meets with the teacher before the start of school to discuss the child's educational, health and psychosocial goals. A collaborative planning process is initiated.
- SEHC's Manager of Child and Family Services meets with principals to clarify roles and responsibilities; telephones parents and arranges to have satisfaction surveys conducted. Professional relationships are developed and resources needed to support nursing activities are put in place.
- SEHC visits principals with CCAC Case Managers. Meetings may include nurses delivering services at the school.
- SEHC finds similar employment for the Primary Nurses during the summer months and has documented that the current retention of these well-qualified nurses is very high.
- In schools where more than one nurses provides services, a team leader communicates with CCACs, principals and SEHC.
- There is improved partnership between SEHC Service Coordinators, school authorities and parents.

- A communication log is updated and sent home daily to the parents.
- Prior to the introduction of the communication log, nurses were phoning parents on an as needed basis to communicate issues such as need to replace equipment, requests for more feeding supplies, changes in health status etc. (Nurses were finding it difficult to make personal contact with parents during the workday, and so much communication was in the form of messages left on answering machines or brief phone exchange at times inconvenient for families and outside of work hours for nurses. In addition, many of the children in the program were unstable, and nurses wanted to know how the child had slept or about seizure activity at night. For children receiving overnight nursing, this communication was in the form of a voicemail report from the night nurse to the school nurse. Some children were transported to school accompanied by a nurse, so nurse/parent contact happens at the beginning and end of the school day.)

Note, however, that a significant number of children were exceptions to the above generalizations. Some parents were sending notes to the nurse in the child's backpack. Educational assistants, teachers or intervenors would read these notes, however, and nurses often found them unhelpful for a variety of reasons.

The Communication Log was created to address this issue. It is clearly labelled and kept in a large envelope marked confidential. It travels daily in the child's backpack. It allows the nurse to communicate daily and to address a broad range of issues from the child's developmental successes to number and quantity of feeds. Parents can also respond and ask questions about their child's health. This daily communication allows the nurse to expand her care giving beyond the child to include parents or primary caregivers. Nurses and parents are exchanging journals, newspaper articles of interest and photographs. Nurses are reporting high satisfaction from the improved therapeutic relationship that includes parents.

#### *Clear performance expectations*

- Primary Nurses attend professional development activities arranged by the tertiary care hospital for children.
- Training such as g-tube feeding and deep suctioning are provided to Primary Nurses by the tertiary care hospital.
- Nurses are receiving training at tertiary hospitals specifically from care providers in the hospital who are providing care to these children so the training is customized to the unique needs of the child being admitted to the school program. SEHC's relationship with the Hospital for Sick Children is such that the transition from hospital to community is smooth. Health care needs are not compromised as the child enters school.
- Regular meetings are held through the years on Professional Development days.
- In addition school nurses are attending meetings as a program team 5 times per year mainly for clinical education and to discuss operational issues and challenges unique to school nursing. Significant transfer of knowledge occurs from expert school nurses to novices who are working within a politicized, unionized educational environment. Nurses learn about leadership and how to establish respectful relationships with multiple disciplines.
- There are standards for staff qualifications.
- Clear guidelines regarding the service protocols have been established.
- Skills in communication, roles and responsibilities in school politics are developed to enhance multidisciplinary engagement. Professional relationships are built with school personnel and teachers.

#### *Balanced expectations and capacities*

- SEHC meets with principals of all schools in late August to set expectations and how to work together.
- SEHC liaises with other sources of funding to streamline service delivery with the consent of the child and parents.
- To deliver quality care, SEHC offers extended hours of respite care for working parents, both before and after school.

#### *Reasonable review and adjustment*

- Periodic review meetings and a conflict resolution process are established for all stakeholders. SEHC's

Manager of Child and Family Services conducts site visits, audits charts, and appraises the performance of all Primary Nurses on an annual basis. SEHC's Manager of Child and Family Services resolves minor issues directly; and is involved in problem resolution of more substantial issues with the CCAC.

- School personnel communicate minor problems directly through nurses to SEHC before reaching the CCACs and SEHC communicates with CCACs.

#### *Credible reporting*

- SEHC visits schools and meets with principals, teachers and caregivers in the school.
- SEHC conducts performance appraisals with nurses.
- SEHC conducts site visits to ensure health and safety.
- SEHC audits client charts.
- Parental satisfaction is regularly monitored.

#### *Clientele*

From 1999 to 2002, SEHC provided school based complex health care service to 131 children. Of this number, 27% (36 children) were 5 years of age or less, 36% (47 children) were from 6 to 10 years of age, 23% (30 children) from 11 to 15 years, and the 16 to 20 years olds represented 14% (18 children). Females totalled 58 (44%) and males totalled 73 (56%).

Analysis of the administrative data confirmed that these children had complex health care needs. Seventy-eight (78) diagnoses were identified for children served in the school health program. The most frequent diagnoses were: 44 developmental delay (56%), 44 seizure disorder (56%), 26 cerebral palsy (33%), 10 asthma (13%), 10 feeding problem (13%), 9 diabetes (12%), and 8 quadriplegia children (10%). As large as 73 % of the total children served had multiple diagnoses, underlining the complex nature of the health care needs. The most frequent reasons for referral to the school program were: G-tube feeding, chest physiotherapy, g-tube medication, suctioning, and tracheotomy care.

#### **Methodology**

The perceptions, attitudes and opinions of principals and complex care nurses caring for these children by SEHC were obtained through 1 to 1.5 hour key informant interviews at each school. The interviews were audio taped with the permission of the interviewees, which were later cross-checked with the notes taken during the interviews. Three team members used modified content analysis as a procedure to make valid inferences from text. One investigator reviewed the transcripts and notes from the interviews and identified themes. Another investigator independently examined the groupings of themes and made some revisions. The revised list then served as the foundation for another investigator to reanalyze the key informant interviews. A few new themes were identified and agreed to during this process.

#### **Results**

Themes identified through modified content analysis were grouped under three headings: Enablers, Outcomes, and Areas for Improvement.

#### ***Enablers***

Four enablers identified by the principals and the Primary Nurses were four of the key components of the SEHC protocol: 1) ongoing support; 2) ongoing monitoring; 3) Communication; and 4) Professional development. The interviewed nurses recommended that all nurses and teachers caring for children with complex health care needs meet with their Supervisor prior to the start of school to discuss roles and responsibilities and ensure that environment/resources support their activities. The nurses felt that this orientation was critical in fostering an awareness of the roles and responsibilities of individuals in each sector.

In addition to these four components of the SEHC program, the principals and nurses identified respect and CCAC resources as enablers. Primary Nurses felt that the principals respected their skill set. The principals felt that the nurses were respectful of the educational environment and participated in school functions. Finally, the resources provided by the CCAC (Time, Talent, Information and Supplies) were seen as enablers.

#### ***Outcomes***

Four outcome-related themes were identified through the modified content analysis: 1) Increased quality of and longevity of life; 2) Increased access for children with complex health care needs; 3) Principals' satisfaction; and 4) Improved access to health care services by principals. According to the Primary Nurses and principals, after receiving medical and education services, the children have made improvement in their functional goals and maintained that improvement. For example, advanced gross motor skills and speech sound production were improved in some of the children. The Primary Nurses said they were highly satisfied with the support services they delivered which are family-centred and functionally oriented. Furthermore, changes in government policy have permitted the delivery of health services at schools that were formerly provided only in intensive care units in institutions.

### ***Areas for Improvement***

Two themes were identified as areas for improvement: 1) Increased awareness; and 2) funding or wage parity. The key informants expressed their concern over the limited awareness of other professionals and the public of the SHSS program. The nurses indicated that they wanted other nurses, even within their own health care agency, to be aware that there are highly skilled nurses working in the educational sector. Finally, inadequate funding support was the last theme identified in the modified content analysis. These nurses have chosen this work because they view the work as a calling. However, there is a chronic shortage of skilled nurses willing to work with the children with complex health care needs. The nurses stated in the interviews that this shortage was in part related to the substantially lower wages paid to community nurses.

### **Discussion**

Based on the interviews conducted, we conclude that SEHC successfully implemented a program for children with complex health care needs. The principals' and nurses' comments on the program were organized into themes related to enablers (ongoing support, monitoring, coordination of services, extensive communication, and professional development), outcomes (increased quality of life, improved access) and areas for improvement (increased awareness and funding). The enablers, or accountability processes, processes led to integrate care with health care providers becoming a part of a team focused on the child and the family.

Case managers from the CCACs were perceived by the nurses to be key members of the team. CCACs were created to deliver community based care with improved accountability and consistent quality services through the implementation of standards, best practices and management systems. In this case study, the nurses indicated that the CCACs' case managers did play a pivotal role in the provision of individualized and co-ordinated care. The case managers use a common assessment tool to determine eligibility for service and do help in the development of appropriate care plans. They focus on the student well being and help the nurses obtain the resources that they need to deliver high quality care.

The nurses and principals were unambiguous about the achieved outcomes: these children with either a mental or physical disability have access to educational services because of the services that they provide. The children referred for care in school settings have multiple problems and require extensive care. Only a few years ago these children would have resided in intensive care units, with a short life expectancy. Now these children have ventilators on the back of their wheelchairs and are attending school. Access is only possible because these SEHC nurses were supported by an infrastructure and acquired complex health care skills from the Hospital for Sick Children through additional training and through other clinical experts in the field.

SEHC chose to address one of the two identified areas for improvement. Within the current funding arrangements, SEHC cannot increase salaries of nurses. However, SEHC did decide to address the lack of awareness of other professionals and the public of the SHSS program. The school nurses received regular updates on the purpose and status of this research project and some of them were also interviewed. A poster presentation of the findings was shared at the Canadian Association of Paediatric Health Centres Conference in June 2003. A school nurse attended the conference and returned to share her learning with her colleagues at a meeting in August. She was immensely proud to have met with so many experts in paediatrics and highlighted the school program of which she had been a part for many years. At this meeting the manager presented a video from the conference and shared the poster of the research findings. Many school nurses commented that they had not understood the program from the broad perspective demonstrated in the poster.

Additionally they had no appreciation of the quality of the whole program but only of the small part they played as individual school nurses. This raising of esteem and sense of pride has had significant impact on the nurses' practice. This current school year 2003/04 has 0 high/low risk occurrences and 98% client satisfaction in nursing services across multiple dimensions such as cultural sensitivity, respect, mutual care planning, health teaching, nursing skills and knowledge (100% clients sampled). The nurses' enthusiasm has led to a project to publish a book of experiences in school nursing in late 2004 and each member of the school nursing team will contribute a story. The children with complex health care needs were helped through this continuous quality improvement initiative. A small acknowledgement of the care delivered by these dedicated nurses through this credible reporting helped SEHC achieve, at least partially, accountability for these children at a client level.

This success in alleviation of the fragmentation of services between sectors for children and their families was possible because several preconditions are met. These preconditions were: a shared vision, engaged stakeholders, teamwork, a focus on concrete objectives, and a monitoring of progress towards those objectives. Our findings are thus consistent with

the preconditions documented in the Report of the Federal/Provincial/Territorial Advisory Committee on Population Health .

The preconditions to successful intersectoral collaboration have been known for some time. Yet, examples of successful partnerships are rare. The 2001 Provincial Auditor's report on special needs education grants to school boards noted that PPM 81 was working only in a few jurisdictions . In these jurisdictions the 'respective partners treated the guidelines as policy, communicated well among themselves to ensure that their respective responsibilities were clear, and provided levels of service consistent with the needs of their school-aged populations' . The Ministry of Education responded that it was working with other ministries, agencies, community and education partners, and parents to develop service co-ordination models.

We call for a review of specialized community based paediatric services by principals, bureaucrats and health care providers. Hospital based specialized paediatric services have been recently reviewed . Community based ones have not undergone such a review. Recommendations for the delivery of all specialized paediatric health care services in Canada could be based on this case study.

There was no urgent need for policy to 'catch up' with reality. Rather there is a need for the cross-sectoral development and implementation of programs that support policies. The Canadian Public Health Association , in its submission to the Commission on the Future of Health Care in Canada entitled "A Fine Balance: A Public Health Perspective on Health System Reform," recommended the establishment of mechanisms for intersectoral collaboration. We support this recommendation but believe that to sustain these intersectoral mechanisms, additional resources are required. SEHC chose to invest in an infrastructure that benefited the nurses and the children and their families.

In summary this well-designed program properly implemented and resourced had a positive impact on children with special needs, their families and the professionals caring for them. This intersectoral protocol for children with complex health care needs in education may serve as a good model for other intersectoral integration efforts.

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