



Children and Youth Home Care in Canada

Background

As recently as two decades ago, children who were born with, or developed serious medical conditions or disabilities spent the majority of their lives in institutions – away from their families because of their high level of care needs and/or required continuous monitoring. Now, many of these children are living in their homes and communities with their family. Over the past decade, there has been a significant trend away from institutionalized care to home and community care (Havens, 1998; Health Canada, 1999a, 1999b, 1999c; Coyte & Young, 1997; CIHI, 2000; Spalding, Hayes, Williams & McKeever, 2002; Williams, Spalding, Deber & McKeever, 2005).

This has created a significant increase in the population of children and youth living within the community who are reliant upon home and community care services. Several major trends contributing to this increase include: 1) advances in medical technology and knowledge, allowing health care professionals to effectively assess, diagnose, and treat children's conditions with greater accuracy; 2) increases in the number of children surviving serious illnesses that require ongoing health care and/or technological support throughout the rest of their lives; and 3) system restructuring that results in children being discharged from institutions sooner with more acute and long term care needs. Although there has been a major shift in the site of care from institution to home, there have not been changes in policies and health care delivery to keep pace with the needs of this population

(Peter, E., Spalding, K., Kenny, N., Conrad, P., McKeever, P., & Macfarlane, A., 2007).

Home and community care for children and youth includes health care that is provided in homes and community settings to children with short or long-term illness and/or disabilities and their families. Community settings are places where children and youth can grow and develop. These include but are not limited to: schools, day hospitals, and day care centres (CYHN, 2007).

Care to these children comes from various providers and professionals such as: nurses, personal support workers, physicians, physio- and occupational therapists, dieticians, parents and foster parents. The professionals provide a multitude of services including: nursing, rehabilitative services, palliative care, respite care and school health support.

In designing and delivering home care services, children cannot be considered as just small adults, but rather, the services and care that children receive must be uniquely tailored to meet their continuously changing developmental needs. In particular, these providers must consider the needs of the whole family and not just the individual child (CYHN, 2002). Due to the specialized and often complex care needs of this population, families are placed on waitlists for home and community services posing a serious problem for this population. Health human resources and flexible funding policies as children move across the continuum of care are two important areas that require further attention by policy makers and health care organizations (CYHN, 2002;

Spalding, et al., 2002; Hollander & Prince, 2008).

Currently in Canada, all hospital care for children is provided as a universal entitlement under the terms and conditions of the Canada Health Act (CHA, 1984). While Medicare provides access without economic barrier for all “medically necessary” services delivered by doctors or care provided in hospitals, it does not require coverage for services delivered by other health care professionals outside of hospitals. While home and community care services may be publicly funded and available on a universal basis, there is no requirement for provincial governments to fund them.

This results in significant differences across jurisdictions, regarding the types of home and community care services are available to children and the terms and conditions that must be met to receive them (Peter et al., 2007). Children represent a small, but growing proportion of home care clients and their care needs can be medically complex and therefore very costly. However, most new policy initiatives and resources in the home care sector focus on the seniors population since governments priorities are related to this large aging population.

Current Issues

Currently, there are three major issues facing children and youth requiring home and community care services: 1) specialized health human resources, 2) timely access to services, and 3) integration of services. The first major barrier is the shortage of specialized and experienced paediatric professionals who are able to meet the unique psychological, social, developmental and care needs of children and their families across Canada. (Spalding et al., 2002; Canadian Homecare Human Resources Study, 2001). There are insufficient numbers of speech-language pathologists, developmental paediatricians, psychologists, psychiatrists,

nurses, occupational therapists, and physical therapists to provide services to children and families (Williams et.al., 2005; Spalding & Salib, 2008). Secondly, compounding this shortage of specialized health human resources is the difficulty gaining access to needed home and community services which exacerbates waiting lists for services and frequently compromises quality of care due to the overburdened providers. It is crucial that children have access to these services in a timely manner as they undergo continual development. If provided within the appropriate time frame the treatments could potentially have a positive effect that could last a lifetime. However, if care is not provided when needed, then the window of opportunity within in a child’s growth and development could be lost forever, and have life long negative effects. Lastly, once these services do become available, a mechanism for integration of services requires an intensive level of coordination as compared to adults, since services span multiple sites and organizations for these children; homes, schools, day cares, rehabilitation centres, hospitals, camps, and home and community care services (Hollander & Prince, 2008).

Moving Forward

It is important to determine the changes that are required in order to improve home and community care for children and youth. This requires the collection of data and evidence in areas such as funding, allocation and delivery of services. Children and their families’ needs must be matched by these data in order to enhance and guide policy developments, establish services to meet their needs or address the gaps in training the next generation of health care professionals with a specialization in paediatric home and community care (CYHN, 2002; Williams et al., 2005).

Two recent systematic reviews have highlighted the challenges in gathering evidence in the field of paediatric home and community

care. First, the Cochrane Systematic review by Cooper et al., (2006) evaluated 1655 titles, only yielding 5 randomized controlled trials (RCTs) with a total of 771 participants which focused on specialized home-based nursing services for children with acute and chronic illness. The 5 RCTs of children aged 0-18 with acute and or chronic illnesses allocated to specialist home-based nursing services were compared with conventional medical care. Outcomes studied included the: utilization of health care services, physical and mental health, satisfaction, adverse health outcomes and costs. Examination of the results of individual RCTs shows improved satisfaction with home-based care with no adverse impact on physical health outcomes for children. However, there was no evidence that specialist home-based nursing services reduce access to hospital services or length of stay. Further trials are required, measuring health, satisfaction, service utilization and long-term cost evaluation.

Second the systematic review by Parker et al., (2006) examined the costs and effectiveness of paediatric home care and included medically fragile infants, technology dependent children, as well as those with mental health issues. Their review utilized 20 various electronic and other sources which identified 1730 relevant records with only 10 studies being RCTs. Parker et al. (2006) acknowledged the rapid growth in research in the area of paediatric home care and indicated the need for alternative research methods (not just RCT) to answer key questions related to the practical and ethical aspects of paediatric home care.

In 2003 Clarke conducted a systematic integrative review of literature published since 1993 that examined delivery systems and/or models of care, for children and youth who require health services in their home and/or community. A total of 66 references and 15 websites were reviewed and critiqued. The critiques were synthesized by level of evidence (CEBM, 2008; Pearson, 2002) conclusions drawn

and four grades of recommendations were proposed, based on internationally accepted grades of recommendations. These include:

- 1) Research - A Canadian research agenda for home and community care of children with chronic illnesses/disabilities & their families is needed to encourage the setting of priority areas, programs of research and outcome measures and indicators.
- 2) Approaches to Care - Home and community care approaches for children and youth should be based on an agreed upon set of principles.
- 3) Best Practices - Best practices identified from empirical findings and expert opinion may be relevant to the development of comprehensive, continuous home and community care approaches, but require further research and evaluation.
- 4) Paediatric Caregiver Competencies - Both professional care providers and lay volunteers should meet defined sets of competencies and participate in continuing education programs, based on the context of care.

It is apparent that home and community services for children and families are an essential and growing element of health and social care delivery for all Canadians. The need to facilitate, fund, and support more research in home and community care for children and families as well as the mechanism for knowledge transfer and uptake by program planners, professionals care givers, and government and policy decision makers is vital to this population. Because of the increasing number of children with long term health concerns, with increasingly complex, highly technical, and acute conditions, living in their homes and communities, it is more important now than ever to ensure appropriate services are available for all in the community.

Currently, there is an urgent need for public health policy to understand this reality, so that children and families across Canada, including

rural and isolated areas, have access to needed home care services. Although it is widely held that more funding is a panacea, a place to start effective reform for improved home and community care for children and families is with

a thorough assessment of what we currently have, followed by a systematic assessment of alternative models for crossing the multiple ministries, departments and programs currently in place.

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