Social Science & Medicine 64 (2007) 1624–1635

SOCIAL SCIENCE & MEDICINE

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Neither seen nor heard: Children and homecare policy in Canada

Elizabeth Peter[a,*], Karen Spalding[b], Nuala Kenny[c], Patricia Conrad[d,e], Patricia McKeever[a,f], Amy Macfarlane[a]

[a] *Faculty of Nursing, University of Toronto, 155 College Street, Toronto, Ont., Canada M5T 1P8*
[b] *Ryerson University, Canada*
[c] *Dalhousie University, Canada*
[d] *Department of Health Policy, Management and Evaluation, University of Toronto, Canada*
[e] *The Canadian Health Services Research Foundation, Canada*
[f] *Bloorview Research Institute, Canada*

Abstract

Changes in public policy have led to increasing numbers of children with disabilities and complex medical needs being cared for in the homes of Canadians. Little work, however, has explored the ethical implications of these policies. This paper focuses on some of the shortcomings of current policy and describes a developing method for policy analysis with an explicit focus on ethics that could be adopted in other nations. Three forms of analyses—descriptive, conceptual and normative—conducted on Canadian homecare policy documents describe various dimensions of Canadian homecare policy. The descriptive analysis demonstrated that the jurisdiction of homecare services is dispersed across numerous programs and ministries with no single structure for policy implementation and accountability. The needs of children and youth are rarely mentioned in home healthcare policies, but instead are addressed under broader social policies that are focused upon children and family. The conceptual analysis revealed four over-arching themes that represent the predominant elements of a value-structure that underlie homecare policy. They include: (1) home and community care as ideal; (2) the importance of independence and self-care of citizens; (3) family as primary care provider; and (4) citizenship as entitlement to rights and justice. Overall, these themes tend to reflect a neoliberal ideology that shifts the responsibility of care from the state to the individual and his/her family. A normative framework based on critical healthcare ethics is used in the paper to make recommendations to redress the current imbalance between state and family support. For example, including homecare services within the Canada Health Act (CHA) or the development of separate legislation consistent with the principles of the CHA would make it possible to ensure that the principles of universality, accessibility, portability and public administration, as opposed to principles that reinforce competitive individualism, direct the provision of homecare services in Canada.

Keywords: Canada; Health policy; Ethics; Children; Home care

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*Corresponding author. Tel.: +1 416 946 3437; fax: +1 416 978 8222.
E-mail addresses: elizabeth.peter@utoronto.ca (E. Peter), kspaldin@ryerson.ca (K. Spalding), nuala.kenny@dal.ca (N. Kenny), pat.conrad@chsrf.ca (P. Conrad), p.mckeever@utoronto.ca (P. McKeever), a_macfarlane@yahoo.com (A. Macfarlane).

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doi:10.1016/j.socscimed.2006.12.002

Introduction

As a result of health system restructuring and public preferences, more acute and long-term healthcare and related services are provided in the homes of Canadians. These services prevent, delay, or substitute for long-term and acute institution-based services. Technological and medical advances have allowed for more treatments, assistive technologies, and monitoring devices to be offered and used in the home. It is not unusual for people, including children, who formerly might have spent much or all of their lives in hospitals or long-term care institutions to receive care at home (Goldberg, Gardner, & Gibson, 1994; Hayes, Hollander, Tan, & Cloutier, 1997). The demand for homecare services is rising as more clients of all ages are discharged from hospital earlier and still require care. From 1995 to 2000 alone the number of Canadians receiving homecare increased by 140%. This trend continues today. The average public healthcare spending on homecare has decreased, however, from an average of 15% of healthcare spending in 1990 to 9.2% in 2000. Private spending, however, has increased by 60% (CHCA, 2003). With respect to children, the demand is also increasing as more children who have survived previously fatal conditions, such as brain injuries, congenital cardiac anomalies, and organ failure, live in the community with lasting and often extensive care needs. For example, in the province of Ontario children's homecare services increased as a percentage of overall caseloads from 11.0% to 12.4% from 1997 to 2002 (Williams, Spalding, Deber, & McKeever, 2005). While more robust statistics regarding children and their need for homecare services are non-existent, children have been identified as a Canadian subpopulation that is receiving inadequate homecare services (CARP, 1999).

The ongoing shift to home and community healthcare has major implications for children, families, healthcare professionals, healthcare organizations and governments. Families must provide and coordinate often complex and heavy care for their children with minimal publicly funded homecare and respite services. Simultaneously, they must also provide nurturance, protection, stimulation, and care for the child, siblings, and other family members. Furthermore, families and health professionals must often provide care in homes that are not adequate for caregiving and with inadequate resources (Coyte & McKeever, 2001). A recent national study by Spalding, Williams, Hayes, and McKeever (2002) that examined the continuum of care between hospital and home for children with special needs found that little progress had been made in addressing previously identified homecare policy issues for children and families. Services provided to children with special needs in their homes are fragmented and unequally distributed in most Canadian communities. Ongoing fiscal pressures have reduced the basic home and community supports to an unprecedented low.

These problems with homecare policy are of great ethical importance. Our public policy choices make statements about who we are as a society. If public policy is a moral endeavor, then how do we clarify its ethical dimensions and implications? Little work has been done to explore these ethical aspects of homecare policy for children and youth. In fact, despite the importance of ethics in health policy, an explicit formal tool for normative policy analysis is non-existent (Hoedemaekers, 2003; Kenny & Giacomini, 2005). Homecare policy for children provides an excellent case-in-point not only because it has not been previously analyzed from an ethical perspective, but also because it represents many ethically important aspects of healthcare delivery, i.e., the role of family, vulnerable citizens such as children, limited resources, and the community as a site of care. Children can get easily lost because they have no direct voice, they are a small and diverse population, and there is a social belief that children's needs should be met by parents, not recognizing the special burden of complex, medical care.

Through the analysis of Canadian homecare policy for children and youth, this paper highlights some of the current shortcomings of current policy and describes a developing method for policy analysis with an explicit focus on ethics. First, an overview of the place of homecare services within the Canadian healthcare system is provided. Second, a description of three forms of analyses—descriptive, conceptual and normative—conducted on Canadian homecare policy documents is provided to draw attention not only to various dimensions of Canadian homecare policy, but also to provide an example of a method of policy analysis that could be used by others engaged in policy or ethics research; and third, recommendations are given.

Canadian homecare services

Canada's healthcare system can be described as an interlocking system of 10 provincial and three territorial health insurance plans known as "medicare". This publicly funded system provides access to universal coverage for medically necessary hospital and physician services. These services are administered and delivered free of charge by the provincial and territorial governments. With the assistance of the federal government, the provinces and territories fund healthcare services. To receive their full allocation of federal funding, these health insurance plans must meet the five criteria of the Canada Health Act (CHA) (CHA, 1985): comprehensiveness, universality, portability, accessibility and public administration. The federal government also provides direct provision of healthcare services to specific groups, such First Nations people living on reserves, Inuit, members of the Canadian Forces and the Royal Canadian Mounted Police and eligible veterans (Health Canada, 2005).

While hospital and physician care is provided as a universal entitlement under the terms and conditions of the Canada Health Act (CHA) (CHA, 1985), provinces and territories may choose to cover the costs of some or all homecare services, but there is no legal obligation for them to do so. There is no minimum standardized "basket of services" for Canadians, including children and families requiring homecare (Williams et al., 2005) which leaves many Canadian families vulnerable to limited public support.

Public homecare spending is relatively low in Canada as it is in all OECD countries. Canada spent approximately 0.2% of its GDP in 2000 on homecare funding, favoring long-term care in institutions (0.8% GDP), especially for the elderly. This spending is lower than in countries like Sweden at 0.8% and Norway at 0.7%, but is similar to the US at 0.2%. These variations reflect not only differences in beliefs regarding the role of the state in financing healthcare, but also cultural beliefs regarding the role of family in providing support for those who require long-term care. Overall, however, even in countries with comparatively comprehensive coverage, spending on long-term care, of which homecare is an essential component, is only 10–20% of total health spending (OECD, 2005).

Descriptive analysis

The descriptive analysis systematically identified key home care policy elements that are relevant to children and youth. Because the provision of homecare services is a provincial and territorial responsibility in Canada, provincial and territorial documents—legislation, regulations, guidelines, and discussion papers were primarily used in this analysis. The federal documents reviewed included national discussion papers and federal roundtables related to homecare as well as The First Nations and Inuit Community Care Program, which is a federal responsibility.

Seventy-one of the 585 documents retrieved were reviewed in depth (see Tables 1 and 2). The strategy used to select policy documents for analysis was based on examining those documents that most clearly influence the delivery of homecare services. Sixty-eight of these policy documents represent institutions. Institutions refer to the structures and processes used by governments to deliver public policy, such as legislation, regulations, and guidelines in determining how services are to be funded, allocated, and delivered. While institutions do not solely determine policy outcomes, they consolidate

Table 1
Provincial and territorial policy documents

Legislation, regulations and guidelines
Yukon Health Act. R.S.Y. 2002, c. 106.
Yukon Home Care Program Policy & Procedure Manual, 2002.
Children's Act. R.S.Y. 2002, c. 31.(Yukon)
Consolidation of Hospital Insurance & Health Social Services Administration Act R.S.N.W.T. 1988, c. T-3. (Northwest Territories)
Program Standards: Home Care, 2000. (Northwest Territories)
Consolidation of Child & Family Services Act S.N.W.T. 1997, c. 13. (Northwest Territories)
Consolidation of Hospital Insurance & Health Social Services Administration Act, R.S.N.W.T.1988, c.T-3. (Nunavut)
Consolidation of Child & Family Services Act S.N.W.T. 1997, c. 13. (Nunavut)
Continuing Care Act, R.S.B.C. 1996, c. 70. (British Columbia)
Regional Health Authorities Act. R.S.B.C. 1996, c. 180. (British Columbia)

Table 1 (*continued*)

Legislation, regulations and guidelines
Continuing Care Programs Regulation. B.C. Reg. 146/95. (British Columbia)
Community Home Care Nursing Services Policy Manual, 1988-1996. (British Columbia)
Community Rehabilitation Services Standards Manual, 1993-1995. (British Columbia)
Home & Community Care Policy Manual, 1983-2002. (British Columbia)
Child, Family & Community Service Act, R.S.B.C. 1996, c. 46. (British Columbia)
Nursing Support Services Program Guidelines, 2003. (British Columbia)
At Home Program Guide, 2003. (British Columbia)
Child & Family Development Service Standards, 2004. (British Columbia)
Public Health Act. R.S.A. 2000, c. P-37. (Alberta)
Regional Health Authorities Act. R.S.A. 2000, c. R-10. (Alberta)
Co-ordinated Home Care Program Regulation 296/2003, Public Health Act. (Alberta)
Home Care Program Policy Manual & Supplementary Appendices, 1995. (Alberta)
Alberta Home Care Assessment for Children (AHCAC) Assessment Form: Directions for Use, n.d.
Family Support for Children with Disabilities Act. R.S.A. Unproclaimed, c. F-5.3. (Alberta)
Family Support for Children with Disabilities Act: Discussion Guide on Draft Regulations, 2003. (Alberta)
Regional Health Services Act. S.S. 2002, c. R-8.2. (Saskatchewan)
Child & Family Services Act. S.S. 1989-90, c. C-7.2. (Saskatchewan)
Family-Centred Services Policy and Procedures Manual, 2004. (Saskatchewan)
Children's Services Manual, 2003. (Saskatchewan)
The Regional Health Authorities Act. C.C.S.M. 1996, c. R34. (Manitoba)
Manitoba Home Care Program Policies Manual, 1999. (Manitoba)
Children's Special Services Policy and Procedure Manual, 2002-2003. (Manitoba)
Children with Disabilities in Care Receiving Support from the Exceptional Circumstances Fund, n.d., sent 23/07/04. (Manitoba)
Long-Term Care Act. S.O. 1994, c. 26. (Ontario)
Community Care Access Corporations Act. S.O. 2001, c. 33. (Ontario)
Homemakers & Nurses Services Act. R.S.O. 1990, c. H10. (Ontario)
Health Insurance Act. R.S.O. 1990, c. H.6. (Ontario)
Regulation 552/90, Health Insurance Act. (Ontario)
Child & Family Services Act. R.S.O. 1990, c. C11. (Ontario)
Guidelines for the Special Services at Home Program, 1991. (Ontario)
Eligibility Criteria for Respite Enhancement Funding for Medically Fragile and /or Technologically Dependent Children. (Ontario)
Ontario Disability Support Program Act. S.O. 1997, c. 25, Schedule B.
Assistance for Children with Severe Disabilities Regulation 224/98, Ontario Disability Support Program Act.
Assistance for Children with Severe Disabilities, Formerly the Handicapped Children's Benefit, 1998. (Ontario)
An Act Respecting Health Services & Social Services. R.S.Q. 1999, c. S-4.2. (Quebec)
Chez Soi: Le Premier Choix: La politique de soutien à domicile, 2003. (Quebec)
Regional Health Authorities Act. C.S.N.B. 2002, c. R-5.05. (New Brunswick)
New Brunswick Extra-Mural Program: Provincial Policy Manual, 2003.
Family Services Act. C.S.N.B. 1980, c. F-2.2. (New Brunswick)
Home Support Services Standards, 2001. (New Brunswick)
Community-Based Services for Children with Special Needs Program Standards, 2001. (New Brunswick)
Health Authorities Act. S.N.S. 2000, c. 6, s. 1. (Nova Scotia)
Home Care Nova Scotia Policy and Procedure Manual, 1997.
Children & Family Services Act. S.N.S. 1990, c. 5, s. 1. (Nova Scotia)
Guidelines and Procedures for the In-Home Support Program, 2000. (Nova Scotia)
Manual of Standards, Policies, and Procedures for Children in Care and Custody, 2004. (Nova Scotia)
Health & Community Services Act. R.S.P.E.I. 1988, c. H-1.1. (Prince Edward Island)
Rehabilitation of Disabled Persons Act. R.S.P.E.I. 1988, c. R-12. (Prince Edward Island)
Social Assistance Act. R.S.P.E.I. 1988, c. S-4.3. (Prince Edward Island)
Disability Support Program Policy. (Prince Edward Island)
Child Protection Act. R.S.P.E.I. 1988, c. C-5.1. (Prince Edward Island)
Health & Community Services Act. S.N.L. 1995, c. P-37.1. (Newfoundland & Labrador)
Self-Managed Home Support Services Act. S.N.L. 1998, c. S-13.1. (Newfoundland & Labrador)
Provincial Home Support Services Policy Manual (draft 2004). (Newfoundland & Labrador)
Child, Youth & Family Services Act. S.N.L. 1998, c. C-12.1. (Newfoundland & Labrador)
The First Nations and Inuit Community Care Program: Program Criteria, 2000. (Federal)

Table 2
National homecare reports

Report
Canada. Standing Senate Committee on Social Affairs, Science and Technology. (2002). *The Health of Canadians—The Federal role. Final report on the state of the health care system in Canada. Volume six: Recommendations for reform.* (Chair: The Honourable Michael J. L. Kirby). Ottawa: Author
Commission on the Future of Health Care in Canada. (2002). *Building on values: The future of health care in Canada—Final report.* (Commissioner: Roy J. Romanow). Ottawa: Commission on the Future of Health Care in Canada. (Cat. No. CP32-85/2002E-IN)
Commission on the Future of Health Care in Canada. (2002). *Homecare in Canada: A discussion paper*. (Commissioner: Roy J. Romanow). Ottawa: Author

the power of certain ideas and interests and structure conduct (Baranek, Deber & Williams, 2004; Doern & Phidd, 1992). The provinces and territories have a responsibility to decide which and to what extent health services, outside the CHA, such as homecare, are publicly funded.

The three remaining policy documents are national home care reports and discussion papers (see Table 2) that represent ideas and interests. Ideas represent the beliefs, values, and knowledge that shape a policy field, while interests refer to those groups who are in a position to influence policy choices (Doern & Phidd, 1992). These policy documents were chosen because they are highly influential national reports that critique the current Canadian system and provide policy recommendations with the purpose of improving healthcare services including homecare.

The descriptive analysis revealed that the jurisdiction of homecare services is dispersed across numerous programs and ministries with no single structure for policy implementation and accountability. Provincial and territorial homecare policies tend to be framed by type of service provision, e.g. nursing and rehabilitation services, as opposed to the population type they serve. Consequently, the needs of specialized populations such as children and youth are rarely mentioned in homecare policies, but instead are addressed under broader social policies that are focused upon children and family services. While these policies are important to the welfare of children and youth, they do not adequately ensure that the needs of children with disabilities or complex medical needs who are living outside of institutions, and thus outside the boundaries of the CHA, are met.

With the exception of the Standing Senate Committee on Social Affairs, Science and Technology Report (2002), the federal documents examined do not acknowledge children and youth as a unique population with specialized homecare needs. This report acknowledges that in some provinces children and youth comprise 15% of homecare clients.

Conceptual analysis

The conceptual phase clarified and made explicit the values, principles, and assumptions within the policy documents. According to Yeo (1996), conceptual analysis is employed "to sort out the various meanings of key concepts and to unpack terms loaded with values and questionable assumptions" (pp. 18–19). It is a useful method in policy analysis because policy has an "irreducibly moral dimension insofar as it involves a decision about how to act toward affected others who are not involved (or indirectly involved) in actually deciding what to do about an identified problem" (Malone, 1999, p. 18). The moral dimension may not be readily visible but can be made visible through the analysis of underlying assumptions and values.

Since this conceptual analysis focused on clarifying and making explicit values and principles in various health policy documents, some sense of what values are is required. Values are views about what is important. In the political and policy arenas they are beliefs about the ends or goals of social institutions and the virtues they *ought* to embody. Schwartz (1993) has defined values as "principles, or criteria, for selecting what is good (or better, or best) among objects, actions, ways of life, and social and political institutions and structures. Values operate at the level of individuals, of institutions, and of entire societies" (p. 155). Values can compete with one another. For example, this occurs when respecting the autonomy of individuals conflicts with our desire for efficiency or effectiveness. When this occurs, the task becomes the prioritization of values, or how to protect as many as possible in our choices and action (Giacomini, Hurley, Gold, Smith, & Abelson, 2004).

Data were then abstracted from these documents using the following categories: text that (1) defined homecare, (2) made reference to Medicare or the Canada Health Act, (3) mentioned children, youth, parents, and/or families, (4) described the meaning, condition, or importance of homes and housing, and (5) contained references to justice, equity, entitlements, rights, responsibilities, citizenship, and public participation.

The following types of analytic questions were raised when conceptually analyzing the documents:

- What is the reasoning, if any, given for the presence/absence of policy elements?
- What conception of justice is present explicitly or implicitly?
- What values are operating? Are they made explicit?
- What assumptions are operating regarding key concepts such as children, family, women, health, social class, race, and the meaning and condition of the home itself?

Four over-arching themes were identified in the abstracted data. These themes represent the most predominant concepts of a values nature that underlie homecare policy for children and youth. They include (1) home and community care as ideal, (2) the importance of independence and self-care of citizens, (3) family as primary care provider, and (4) citizenship as entitlement to rights and justice.

Home and community care as ideal

The policy documents generally conceptualize home and community care as ideal, describing it as being normal and natural, less costly, and a public preference. It is also thought to promote independence, to foster well-being, overall health, and inclusion, and to prevent institutionalization and medicalization.

Quebec's homecare policy (2003) states:

> Offering services in the home does not come down to a simple shift in the site of care, for example from the rehab center or hospital to the home. The home is a place of intimacy where an individual carries out activities, maintains interpersonal relationships, fulfills social roles, in short—an environment of life. Home intervention always comes within the scope of a familial reality and particular culture. For this reason, the home cannot be considered simply a "site" of care. (La Vision, 4)

This excerpt reveals idealized attributes of home and community that are commonly held in Canadian society. Home is not just another place, but rather is a special place where relationships are nurtured and lives are built. From this perspective, avoiding institutionalization becomes a high priority. Not surprisingly, the stated purpose of homecare in the Commission on the Future of Health Care in Canada Report is "to prevent, delay or substitute for hospital or long-term residential care" (2002, p. 173). Ontario's Assistance for Children with Severe Disabilities Regulation (1998) simply states that the purpose of assistance is "to enable children with severe disabilities to stay at home and out of institutions" (p. 3).

The idea that living in the community is normalizing is reflected clearly in BC's Home and Community Care Policy Manual (2002), which states, "Continuing care services should promote client independence and normalizing living in community based settings" (p. 1), as well as Manitoba's Children's Special Services Policy and Procedure Manual (2002–2003), which states, "Children have the right, regardless of their diverse abilities, to participate in typical activities and functions of community life (e.g., family, social relationships, school and community activities)" (Introduction, 1.7, p.4).

Some recognition is given to the fact that not all homes are suitable for the receipt of homecare services. The Home Care Nova Scotia Policy and Procedure Manual (1997) stipulates that homecare service providers must be satisfied that an "individual's environment is safe and suitable for the provision of homecare services, both for the individual and for the caregiver" (2.01.01) before the individual is eligible to receive services. Federal reports have also expressed concerns about the housing conditions of many. For instance, the Commission on the Future of Health Care in Canada (2002) states, "Some might even argue that homecare should … provide appropriate housing … since all of that, ultimately, helps to make and keep people well" (p. 4).

The importance of independence and self-care of citizens

A common value in the policy documents is the independence and self-sufficiency of citizens. Individual autonomy, dignity, and freedom of choice are emphasized as key to well-being.

For example, the British Columbia Home and Community Care Policy Manual (1983) states:

> Continuing care services promote the well-being, dignity and independence of clients and their families … Clients and their families should have the information required to make their own decisions about lifestyle and care. Clients have the right to live at risk. As well, individuals, families and communities should do as much as they can to care for themselves without government assistance. (p. 1)

Similarly, the First Nations and Inuit Home and Community Care Program: Program Criteria (2000) stipulates that one of its foundational beliefs is that "Home care must only do things for people they cannot do for themselves in order to preserve their self-worth" (p. 28).

With regard to children and youth, independence, when explicitly mentioned, is a goal to realize in the future. An excerpt from The New Brunswick Community-Based Services for Children with Special Needs Program Standards (2001) states, "It is the hope and dreams of all parents that their children will grow-up to be healthy, confident, accomplished individuals who have realized their potential and are prepared to contribute to society in an independent, productive fashion" (p. 4).

Family as primary care provider

Responsibility for care, with no monetary compensation, is an expectation of the individual and his or her family and other significant others in Canadian society. This labor of love is supplemented with services only when the family is unable to care. The idealization of family care is particularly pronounced in the provincial and territorial policies.

A statement from the Newfoundland and Labrador Provincial Home Support Services Manual (2004) is typical of the data. It states, "Home support services are intended to supplement, not replace, service provided by the individual's family or support network" (p. 2). In particular with respect to children and youth, the Newfoundland and Labrador, Child, Youth and Family Services Act (1998), states that "the family is the basic unit of society responsible for the safety, health and well-being of the child" (7c). As explained by the Yukon Home Care Manual (2002), to a great extent services, such as information, counseling, and emotional support, are offered "to enable the family and informal supports to continue supporting the client in the community" (C.2, Guidelines). Where a self-managed care option is available, such as in the Alberta Home Care Program Policy Manual (1995), "The Home Care Program does not pay for the care provided by family members, either through direct employment or through the use of funding provided under the self-managed care option" (4.5, p. 1).

Some critique of the belief that the family should be the primary care provider, however, is present in the national discussion papers. The costs to family and other unpaid caregivers are highlighted. The Commission on the Future of Health Care Canada (2002) comments that,

> Often, the unpaid caregivers are there because other options aren't available—because there is no government program (or they're full), or the homecare recipient can't afford to pay outright or even to cover user fees, or he or she has been judged ineligible for government support. Unpaid caregivers may spend their own money for equipment for the recipient. They often spend more on heating and food, or have to hire someone to take care of children and housework because they're caring for someone at home. At the same time, unpaid caregivers may lose money and diminish their pensions and savings by being away from work. (p. 6)

The cost is disproportionately borne by women who provide the bulk of unpaid caregiving in the home. The Commission on the Future of Health Care in Canada (2002) document also acknowledges that the cost is disproportionate in the following quote: "Many informal caregivers are more than happy to provide care and support to their loved ones, but the reality is that caregiving is becoming an increasing burden on many in our society, especially women" (p. 184).

Citizenship as entitlement to rights and justice

The analysis revealed an emphasis upon the value of citizenship conceptualized in several ways: fundamental human rights, the right to access necessary health services, and mechanisms to ensure procedural justice in terms of individual decision-making, involvement in the development of home-care services, and the right to an appeals process.

Fundamental human rights are articulated throughout the documents. “Canadians consider equal and timely access to medically necessary healthcare services on the basis of need as a right of citizenship, not a privilege of status or wealth” (The Commission on the Future of Health Care in Canada, 2002, xvi). The Home Care Nova Scotia Policy and Procedure Manual (1997) presents other fundamental rights in the following way:

> Each client has the right to individuality and recognition of his/her uniqueness by recognition of the following basic rights: to be treated with dignity, respect and courtesy, to privacy, to self-determination and the right to accept risk … to maintain relationships with family and friends, to have his/her person and property respected and protected. (3.02.01)

Children’s rights in particular are recognized as well, although mostly in community and social services policies as opposed to homecare policies. The Prince Edward Island Child Protection Act (1998) states, “And whereas children have basic rights and fundamental freedoms not less than those of adults, and a right to special safeguards and assistance in the preservation of those rights and freedoms” (Preamble).

The right to access to home care services is also a dominant theme in not only the provincial and territorial regulations, but also the federal policies and reports. At the provincial level, the wording of Ontario’s Long Term Care Act (1994) is representative. It states,

> The purposes of this Act are to simplify and improve access to community services by providing a framework for the development of multi-service agencies; to promote equitable access to community services through the application of consistent eligibility criteria and uniform rules and procedures. (1f & g)

At a national level, access is a distinct concern given both the vast geography of Canada and the limitations of the Canada Health Act. This concern is articulated well by The Commission on the Future of Health Care in Canada (2002) in the following excerpt:

> Although home care is not currently considered a medically necessary service under the *Canada Health Act*, provinces and territories recognize its value and have taken steps to expand home care under provincial and territorial health plans. But there are wide variations across the country in terms of what types of home care services are covered and how much individuals pay to cover portions of the costs. Because home care has become a partial substitute for care that was previously provided primarily in hospitals or by physicians, and because of the value of effective home care services both to individuals and the health care system, a strong case can be made for taking the first step in 35 years to expand coverage under the *Canada Health Act*. (p. 172)

As it relates to individuals and families, procedural justice is ensured through various formulations of client/family centered care and appeal mechanisms. For example, the New Brunswick Extra-Mural Program: Provincial Policy Manual (2003) states:

> Client centred care is an approach to service delivery which embraces a philosophy of respect for, and partnership with, individuals receiving services. Client centred care promotes: client participation, open exchange of information, client choice in decision making, respect (for choice, diversity, experiences, needs, preferences, values, culture, interests and environment), and flexible service delivery. (4.9.1, p. 1)

Appeal mechanisms for individuals and family to challenge decisions regarding eligibility for services, number of hours, and type of care provider exist throughout the provinces and territories for children and adults.

The documents also establish processes, at least in principle, for communities to become involved in the development and delivery of homecare programs. The British Columbia Home and Community Care Policy Manuel (2002) states, “Health authorities are expected to work collaboratively with community stakeholders, as well as with clients, caregivers and their advocacy organizations in the planning, development, operation and coordination of community support services” (5.A.1, Guidelines). Community involvement is emphasized in the development of homecare services in Inuit and First Nations’ communities. This is illustrated in the following excerpt from the

First Nations and Inuit Home and Community Care Program: Program Criteria (2000):

> As Inuit and First Nations move towards self-government and jurisdiction over the development of health programs and services … the further development of health services, such as continuing care, which are managed and provided by First Nations and Inuit, is critical. (p. 25)

Normative analysis

Normative analysis involved the examination of the identified values, concepts, and assumptions with respect to the values that ought to direct policy and practice. While normative analysis cannot be meaningfully described in a formulaic fashion, it is possible to describe the values that were chosen to inform the critique and recommendations that followed from the descriptive and conceptual analyses. A number of values and beliefs characteristic of critical perspectives in healthcare ethics were adopted, including relational autonomy, care, social justice, and citizenship. Critical healthcare ethics was chosen because it calls attention to the inseparability of politics and ethics in a way that facilitates policy analysis. The first, relational autonomy, entails the conviction that persons are socially embedded and that identities are shaped through social relationships and by a complex intersection of age, race, class, gender, and ethnicity. The focus of relational approaches is to analyze the implications of the social dimensions of selfhood for conceptions of individual autonomy and moral and political agency (Sherwin, 1998). A view of persons as interdependent/relational is helpful in conceptualizing and addressing the needs of children whose lives are embedded within a variety of family forms. The second, care/ethic of care, calls attention to the centrality of moral emotion and receptivity, the vulnerability, suffering, and uniqueness of people, and the importance of relationships. The emphasis on care is essential to any public policy that is focused upon the provision of human services because an ethic of care can address the requirement to respond to human need and vulnerability. The interests and needs of children and their families receiving and providing homecare services are often inseparable; all require care and respite if caregiving in the home is to be sustained. The third, social justice, pays attention to how people are differentially situated by class, race, age, ability, gender and so on. The notion of equity is central here because it recognizes that these differences must be accounted for both when distributing societal goods and upholding human rights (Peter, 2004). The fourth, citizenship, requires that children are not only provided the formal rights of citizenship, including legal, social, and civil rights, but are also provided with the means to be included in the broad political identity of a democratic society that is the means for public participation (Kulynych, 2001). Social justice and citizenship are necessary to situate ethical dimensions of policy within a broad, political understanding of the role of healthcare services within societal structures.

Many of the concepts found in the documents reflect neoliberal ideals that tend to conflict with the values and beliefs of critical healthcare ethics. Neoliberalism presumes that individuals in society receive a fair distribution of goods according to free-market exchanges, that is, state intervention is not needed. Individuals are seen as economically motivated, autonomous, and equally equipped to compete for resources with little responsibility for the well-being of others (Coburn, 2000). Adherents to this sociopolitical philosophy view public and social expenditures, like healthcare, as inefficient. Ultimately, free-market forces and private profits are made a replacement for the collective public good (Williams, Deber, Baranek, & Gildiner, 2001). These beliefs and ideals are hidden in other common societal beliefs and values, such as independence, family and self-care all of which do not recognize profound social inequities that challenge the ability of individuals to care for their health-related needs.

This shift from collective to individual responsibility for care is plainly evident in the emphasis upon independence and self-care of citizens in the policy documents. This emphasis is problematic for two reasons. First, children and youth are not independent and capable of self-care in the same way as healthy adults can be. As a result, children can be subtly marginalized because they fall short of this unrealistic standard. Second, although adults tend to be more independent than children, they too are in need of care from others. The Charlottetown Declaration on the Right to Care (2001), a document created by the National Think Tank on Gender and Unpaid Caregiving (2001), simply states, “Care is an interdependent relationship.” Interdependence is a norm that can foster caregiving in a way that a norm of independence, which may foster self-interest, cannot. Interdependence better recognizes the inherent relationships among family, community, and state that sustain the overall health for children and adults alike. Without resources, the kind of overall health and sustained caregiving described in the documents are not possible.

While family caregiving, particularly for children, can be described as an ordinary activity, the caregiving of many children in the home today can only be described as extraordinary because of its complexity and intensity. Previously, these children would not have survived or would have been cared for in institutions. With limited availability of homecare services tailored for children, families must become adept at providing, and in some instances, brokering specialized care. Thus, while we may want to romanticize family care, the consequences to families are enormous, especially for women. The federal documents examined do acknowledge this problem, but homecare programs themselves do not at this time offer the types of services that would balance the responsibilities of the state and the family.

The entitlement to rights and justice of Canadians should ensure that children and their families are offered adequate and specialized homecare services, but on this score, there is currently a disconnection between Canadian core values and the realities of many lives of Canadians (CPRN, 2005; Jenson, 2004a, b). In other words, there is a disconnection between principles and practice, likely as a consequence of reduced healthcare funding. The CHA is built on the core values of accessibility and universality, which are threatened by the lack of resources and the shift of care to the community. Homecare services fall outside of the scope of the CHA, because the CHA only entitles Canadians to hospital and physician services. As a result, the CHA is increasingly incapable of making possible the kind of universality and accessibility to healthcare services that Canadians have grown to expect and value (Coyte, 2002).

The right to make choices regarding the types of services a homecare recipient will receive is also written into the policy documents examined. This choice is severely limited in reality. There may be choice with respect to the specific homecare services offered, but this choice is limited by strictly enforced eligibility requirements and limits placed on the amount of service allowed. Frequently, the choice is between homecare and no care. Even when institutional care is available, it is often viewed as so unappealing that families may experience themselves as really not having a choice (Carnevale, Alexander, Davis, Rennick, & Troini, 2006).

Participation in decision-making is also present as the right to public participation in the development of homecare policy. The presence of this policy element is laudable, but again, difficult to realize in reality if autonomy is viewed relationally. People who care for medically fragile and disabled children at home experience a degree of isolation and exhaustion (Carnevale et al., 2006) that would likely curtail the kind of civic participation envisioned in the policies examined. Changes in theory, practice, and policy, are required, such as an alternative understanding of the dominant conception of autonomy, which would allow for people with different communication styles to be capable of reasonable public participation. In addition, civic education for children, along with a revised view of political participation in both formal and informal channels, is required to provide children with opportunities for participation (Kulynych, 2001).

There is some recognition in the policy documents that home and community care may not be ideal because some homes are not suitable for caregiving. The receipt of quality homecare depends on the existence of adequate housing for this purpose. Housing may need to be altered significantly for caregiving to be performed by both paid and unpaid caregivers. A recent report from the Canadian Policy Research Network (Varga-Toth, 2005) makes this requirement clear. It states, "Care should be provided in an environment that *meets the needs of both the caregiver and the care receiver*. We cannot assume that the home is the most appropriate or desirable location for care." Not all families are capable of caring and not all homes are suitable for care. Also bringing health services into the home can change the meaning of home and the dynamics of care (Peter, 2002; Twigg, 1999). An appreciation of these spatial characteristics and meanings of home would help the development of policies that sustain the home as a place of refuge and security for children and their families as opposed to a place that is overly medicalized.

Conclusions and recommendations

While there are a handful of policies related to specialized social services, little was found with respect to specialized homecare services related to the medical needs of children.

Currently, there is no structural mechanism to ensure that children and youth, a "small volume" but "high needs" population, are protected within the Canadian healthcare system. Without the protection and assurances of legislation and related regulations and guidelines, access for children and families to needed services could worsen as those with strong competing values and interests argue that homecare is less important and less medically necessary than hospital care.

This perception is grounded in concerns regarding the ability to sustain a health care system providing increasingly expensive "medically necessary" care. In addition, despite all the current political rhetoric about investing in children and the future, an increasing proportion of care is being provided in a policy arena characterized by a relative lack of legal and regulatory constraints leading to decreases in the public funding and delivery of services. Therefore, many more families may need to pay for care for their children either out-of-pocket, through direct service charges, or indirectly, through a loss of income from paid employment when they themselves provide care. This will have a significant impact on the economic and social well-being of children and families, which will be particularly severe for children with long-term care needs and children with chronic illnesses and disabilities who are disproportionately represented in the one in six Canadian children living in poverty (Conference Board of Canada, 2005). Homecare policy needs to address the unique needs of children, youth, and their families in such a way that an appropriate balance is struck between the state and the family to minimize their vulnerability. For those who truly choose to care for their sick, disabled, and dying loved ones at home, society must find a way to make this caring sustainable.

An understanding of public policy as a moral endeavor is necessary to redress the inadequacies of current Canadian homecare policy for children and youth. It is from this perspective that the values that support these inadequacies can be countered. In particular, the values, such as individualism and market justice, that support neoliberalism and are hidden behind an idealization of independence and self-care, need to be challenged and replaced with values that better ensure the well-being of children and their families. Including homecare services within the CHA is one possible way to ensure that the principles of universality, accessibility, portability and public administration, as opposed to principles that reinforce competitive individualism, are maintained across all jurisdictions important to such a national system (Spalding, Canitz, & Hayes, 2000). Another possibility is to enact separate legislation for homecare that would both address the overlap of health and social services sectors in homecare. Regulations would be required to ensure that this legislation would be in keeping with the principles of the CHA (Flood & Choudhry, 2002).

Ultimately, developments in health policy in Canada and elsewhere will be best made if there is an understanding of the relationship between ethics and policy in such a way that the keys values are expressed and retained. Healthcare policy is of profound moral importance because of its power to impact the well-being of citizens. This work has begun to outline how policy can be analyzed from an explicitly normative framework. It represents an approach that can be used and further enhanced in nations, like Canada, that struggle with how best to examine and develop policy that best supports the most vulnerable in increasingly neoliberal societies.

Acknowledgements

We would like to acknowledge the generous support of the Hospital for Sick Children Foundation, Toronto, Canada.

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