Understanding Aging and Disability Perspectives on Home Care: Uncovering Facts and Values in Public-Policy Narratives and Discourse*

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RÉSUMÉ

Tous les problèmes ayant trait aux politiques gouvernementales peuvent être délimités par leur dimension empirique (les faits) et leur dimension normative (les valeurs), et par l'interrelation entre ces deux dimensions. Le lien entre les faits et les valeurs sur lesquels repose le débat politique sur les soins à domicile dans le système de santé canadien est examiné par la lorgnette d'un schéma analytique fondé sur la « narration ». La documentation formée de rapports et de recommandations sur la politique concernant les soins à domicile est examinée en vertu de cette structure conceptuelle – en particulier, les publications et les rapports du gouvernement fédéral, d'organisations canadiennes et des milieux du vieillissement et de l'incapacité. Enfin, des observations et une conclusion sur la portée du discours politique sur les soins à domicile, et sur les différences entre les sphères du vieillissement et de l'invalidité dans ce débat, sont proposées pour guider le lecteur dans le dédale de l'élaboration des politiques publiques.

ABSTRACT

Every public-policy problem can be defined in terms of its empirical (''facts'') and normative (''values'') dimensions and the interrelationship between them. An understanding of the connection between facts and values at the foundation of the home care policy debate in the Canadian health-care system is developed through the application of an analytical framework based on the concept of ''narrative frame'' analysis. The literature on home care policy reports and recommendations is examined within this conceptual structure – including especially publications and reports from the federal government, national organizations, and the aging and disability communities. Finally, observations and conclusions about the significance of home care policy discourse, and of the differences between the aging and disability constituencies in this debate, are offered as a guide for deconstructing the public-policy process.

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We don't see things as they are; we see things as we are.

Anaïs Nin (Baldwin, 2000, p. xii)

The real voyage of discovery consists not in seeking new landscapes, but in having new eyes.

Marcel Proust (1981, p. 260)

Introduction

Recognizing that we see things as we are, and rising to the challenge of seeing them with new eyes, inevitably involves a reflection upon values – whether personal, professional, or public. The essence of public policy discourse and debate, in particular, lies in promoting reflection on the central role played by values in determining what questions to ask for empirical study, and subsequently in deciding what course of action to take in response to the factual information discovered through research and analysis. Every compelling public policy problem can be defined in terms of its empirical ("facts") and normative ("values") dimensions and the interrelationship between them; and, more importantly, the potential solutions to this problem are determined by its definition.

So it is with Canadian health care policy in general, and home care policy in particular. Indeed, the title of the Romanow Commission Report, *Building on Values: The Future of Health Care in Canada*, suggests that the very foundation of the health care system in Canada is values, which are stated in the report to be "equity, fairness, and solidarity" (Commission on the Future of Health Care in Canada, 2002, p. xvi). Importantly, the establishment of a uniform home care policy across Canada was described in the Romanow Report as the "next essential service" to be added to those currently available through the Canada Health Act. It is evident that momentum is building for the establishment of a national home care policy to replace the highly variable provincial and territorial policies now in place.

Given the importance and immediacy of the home care policy debate, the initial focus of this discussion is on developing an analytical framework to reveal the "deep structure or meaning" behind extending the foundational values of the Canadian health care system into the home care policy arena. Subsequently, this examination reviews studies, recommendations, and official positions taken by interested parties to assess both general positions on home care policy and those more specifically addressing the unique needs of older adults and adults with disabilities. The overall purpose of this analysis is to further an understanding of the empirical and normative bases of policy in the home care policy discourse.

To achieve these goals, an analytical framework based on the concept of "narrative frame" is first developed from which to examine the literature on home care policy, especially that from the federal government, national organizations, and the aging and disability communities (including professional associations, advocacy organizations, and policy research centres). It is through applying this framework to the actual public reports, position papers, research findings, and recommendations on home care that the "deep meaning" behind the public-policy discussion becomes apparent. Finally, observations about the significance of home care policy discourse, and of the differences among constituencies in this debate, are offered to summarize the discussion and apply its insights to public policy in general.

Facts and Values in Public Policy: Developing a Narrative Frame Approach

Facts and Values

The development of a critical lens through which to examine policy discourse requires an understanding of the role that values play in framing and solving significant public policy problems. Policy makers often like to believe that the provision of enough factual information about a complex social problem – empirical data based on careful research – is sufficient to make informed choices from alternative ways of solving it. However, as Potter (1969) reminds us, every public policy "problem" consists of both an empirical description of the state of affairs and a normative dimension in which some cherished value or set of values is affected. Thus, the definition of any social "problem" and a set of recommended "solutions" to it are also a function of the interplay between facts and values.

Values give us the questions to ask, and we gather facts in our pursuit of answers to questions – which, in turn, force us back on our original intentions in asking those questions (Rein, 1983). Values shape the facts in which we are interested, the ways by which we seek to determine them, and the amount of credibility we place on them. Similarly, facts may enhance, diminish, or otherwise call into question our values and value assumptions. The relationship between empirical evidence and ethical interpretation may be made even more apparent in cross-national comparative analyses, such as between Canada and the United States (Clark, 1993a, 1993b, 1999).

This line of inquiry is especially important in the Canadian context because of the overt attention devoted to values and values-language in the policy arena. For example, in their research on uncovering meanings in Canadian public policy statements, Iannantuono and Eyles (1997) draw attention to the power of language used in policy discourse, suggesting the importance of analyzing patterns and uses of language to construct and deconstruct the world of public policy; or, as they put it, "the meaning of words and the wording of meanings" (p. 1611). Similarly, Fast and Keating (2000) state that "the words we use, and how we use them, are critical to both research and policy making" (p. 2). For example, in empirical analyses the numerical and technical language of science can be used to lend power and authority to official pronouncements or positions. In contrast, values may be more implicit in the type of language used in policy documents, and uncovering them may require explicit interpretive analysis. Reflecting on the power of language used in policy discourse, Kenny (2004) concludes, "The words used highlight some beliefs and values and obscure others. The framing of the discourse therefore influences the construction of meaning and the valuing of beliefs" (p. 5).

The tasks of identifying the values underlying particular public policy problems and elucidating proposed policy options in light of relevant moral principles have been described as the role of "public ethics" by Jonsen and Butler (1975). Kelman and Warwick (1978) suggest a similar approach to analyzing the ethical dimensions of social interventions and present an explicit framework for doing so. Importantly, there is a strong vein in Canada of using this approach to understanding the values underlying public policies. For example, Peters (1995) conducted an empirical study of public opinion polls and augmented it with extensive focus group discussions of the interrelationships between public policies and social values. She concludes that values emerge from public discourse and are essential ingredients in framing the ways in which policy options are stated and selected.

Similarly, the work on values in Canadian health-policy analysis by Giacomini and colleagues (2001, 2004) recognizes the importance of values as drivers of policy development and implementation, though values, rhetoric, and discourse are complicated. Stated values can be used as powerful imperatives or empty platitudes; they can be employed as genuine guidelines or as confusing guideposts to obscure and obfuscate. Marmor, Okma, and Latham (2002) recognize the suspicion with which social scientists have traditionally regarded the concept of "national values", but they also suggest that such values may play an important role in "creating a political community and in guiding its actions. Statements of values may inspire, unite, even 'constitute' a people" (p. 2). Kenny (2004) states that "public policy is a moral endeavour that involves decisions about who we are and who we desire to be as a country" (p. 2).

Critical Narrative Frames

The development of a critical "narrative" approach can be useful in interrogating public policies to expose their underlying empirical and normative foundations. This method relies on envisioning the emergent policy discourse as a "story" embodying language that reveals both facts and values. Documents such as Canada's *Achieving Health for All* themselves can tell a story (Iannantuono & Eyles, 1997), and the perspectives of different policy makers or advocacy groups on a particular issue – such as home care – can be read as subtexts to the main "story" or text (Levine & Murray, 2004). Critical narrativity (Biggs, 2001) draws attention to the story underlying a particular way of framing a public policy problem, and it invites the search for "counter-stories" with different perspectives on the issue (Roe, 1994). This creates a space where "multiple voices" must be heard in the development of a definition of a policy "problem" and the selection of a range of "solutions" to it. As Biggs suggests, narrativity opens a space between rhetoric and experience that permits the interrogation of the issues at stake.

This approach is similar to the concept of policy "frames" suggested by Rein (1983). A frame is a way to understand how we see, what we say, and how we act in the world; it integrates theory, facts, interests, and action. Metaphorically, the concept of "perspective" as a way of viewing the world captures the essence of what is a frame: "a way of inquiring, of making sense as well as masking sense of the world in which we live" (p. 99).

The approach to be used in the analyses of this paper combines the concepts of narrativity and frame into the approach of ''narrative frame'' to capture both the sense of an emergent story and our own unique perspective on its development. The combining of ''emergent'' with ''perspective'' suggests that this is a journey toward deeper understanding of both ourselves and our own way of encountering the world (as Nin suggests, ''We don't see things as they are; we see things as we are'') and of others' ways of understanding and experiencing the same world (''The real voyage of discovery consists not in seeking new landscapes, but in having new eyes,'' according to Proust). This is ultimately a process that leads to an understanding of the ''deep structure or meaning'' of public policy debates and discourse, in much the same way as the ''critical gerontology'' perspective, based on considerations of moral and political economy, has helped to further an understanding of the underlying policy context for older adults (Minkler & Estes, 1999).

The Dominant Narrative Frame: The Federal ''Voice'' in Home Care Discussion

Current Situation and Brief Background

In Canada, home care has been defined as ''an array of services which enables clients, incapacitated in whole or in part, to live at home, often with the effect of preventing, delaying, or substituting for long-term care or acute care alternatives'' (Health Canada, 1999a, p. 4). It has three main functions: (1) to substitute for more costly acute care services (e.g., hospitals), (2) to substitute for long-term care in a nursing home, and (3) to support clients with health and functional deficits in maintaining their independence and preventing functional decline for as long as possible (Keefe, 2002; Shapiro, 2002). In contrast to home care, community care is a broader concept, encompassing a wider array of community-based services and supports.

Before 1970, home care programs tended to be local and community-based, focused on acute care needs and sponsored by hospitals or such agencies as the Victorian Order of Nurses. Starting in the 1970s, some provinces initiated the development of broader objectives for home care, including support services for older adults and adults with disabilities (Health Canada, 1999a). Currently, the Canada Health Act includes home care services under the category of Extended Health Care Services, meaning that they are not insured and not covered by restrictions on user fees or extra-billing. Funding support is provided by the federal government through general transfer payments for health and social services, but each

province and territory has developed its own model of how to provide home care services (Canadian Home Care Association, 2003b; Health Council of Canada, 2005b; Health Council of Canada, 2006). The result, as Shapiro (2002) suggests, is one of service inequities based on such factors as geographic location and user charges – all of which run counter to the principles of universality, accessibility, comprehensiveness, portability, and public administration that underpin other health care services.

The sense of urgency in addressing this situation is further underscored by the growing emphasis on home care as an alternative to acute care and institutional long-term care settings, fuelled by advancing medical technology, changing demographics, and growing recognition of consumer preferences. The number of home care recipients increased by over 60 per cent during the period 1995–2002 and now includes approximately 850,000 Canadians. Home care programs are faced with increasing costs tied to the maintenance of service levels, against a backdrop of fixed funding. In 2001, $2.5 billion was spent on home care through the publicly funded system, accounting for only 3.5 per cent of the total public health care expenditures in Canada. During this same year, 20 per cent of home care expenditures came from private pay, and there was significant variation in the percentages of provincial/territorial budgets allocated to home care – from 1.2 to 6.5 per cent. In addition, the annual average aggregate funding on home care across Canada has declined from 15 per cent during the period 1990–1995 to 9.2 per cent in 1996–2001 (Canadian Home Care Association, 2004a).

Part of the current policy debate is based on the recognition of a potential conflict among the different functions of home care, particularly a fear that the acute care substitution goal of home care will eclipse the maintenance/prevention objective in a national home care policy at a time when both objectives can be met only with expanded resources (Keefe, 2002; Shapiro, 2002). Importantly, an awareness of these trends has spurred new thinking about the ethical issues unique to home care in Canada (Preto & Mitchell, 2004).

Emergence of Discourse at the Federal Government Level

A review of major public documents, reports, and position papers by non-profit professional associations, advocacy organizations, and policy research centres suggests that the emerging and dominant public-policy ''voice'' in home care discussions, debates, and dialogues in Canada is that of the federal government. It is this voice that we will characterize

as the primary narrative frame or "text" in this discussion, and direct quotations will be used to provide examples of the actual language employed in developing this emergent "story". Indeed, some national organizations, such as the Canadian Home Care Association (2004a), explicitly state that "the federal government must take a leadership role and work with the provinces, territories and stakeholders to develop an integrated health care strategy that includes home care" (p. 7). A recognition of the federal government's moral leadership is also evident in statements that acknowledge its traditional role in creating a national health care system based on the principles of universality, accessibility, comprehensiveness, portability, and public administration (Canadian Association for Community Care and Canadian Home Care Association, n.d., p. 2).

Importantly, these positions suggest that values are being appealed to for justifying the application of the original principles of the Canada Health Act to home care services. By invoking these "fundamental values", the organizations supporting the federal government's role are suggesting its leadership now in the home care arena is simply an extension of its traditional moral authority in the past in the establishment of a national policy on health care.

Recent Discourse on the Development of a Canadian Home Care Model

In a provocative article published in a major Canadian journal on health-care issues, MacAdam (2000) suggests that it is time for a Canadian home care model. She outlines the major policy issues and models – including a review of some initiatives to date – that have created momentum for the development of such a model. Her argument suggests that the outline of an emerging Canadian home care system might be found in the core values or principles of the Canada Health Act, as well as in the recent reports and recommendations from concerned stakeholder groups and national conferences on this subject. The discussion that follows is summarized in Table 1, which maps significant values against governmental agencies and other stakeholders in characterizing specific policy positions and recommendations.

For example, the National Conference on Home Care was convened by Health Canada under the auspices of the Health Transition Fund in 1998, with the stated objective of bringing stakeholders together to foster dialogue on the complex issues associated with national approaches to home care in Canada (Health Canada, 1998). The conference was the result of an earlier report produced by the National Forum on Health in 1997, calling for increased integration of

home care within the publicly funded health care system. In the 1997 Speech from the Throne, the federal government stated its intention to work with provincial and territorial governments in addressing the expanding need for home care services (Health Canada, 1999a).

Participants in the 1998 National Conference on Home Care reviewed approaches and identified gaps in the system of home care, while assessing whether it should be the next most urgent challenge in the modernization of medicare. A strong consensus emerged from the conference that the federal government should assume leadership by committing to the development of an integrated and coordinated national home and community-based care program. Importantly, concern was raised about emphasizing short-term care needs rather than recognizing the long-term home care supports that are necessary for reducing family caregiving burden and the inappropriate use of residential and acute care services (Health Canada, 1998).

Again in 1999, Health Canada (through Home Care Development, or HCD) sponsored a National Roundtable on Home and Community Care, whose objectives were to (1) provide a forum for participants to exchange information on accomplishments and ongoing activities in home and community care, (2) identify priorities for future action, and (3) discuss potential strategies and partnerships for moving the home care agenda forward in Canada (Health Canada, 1999b). Recognizing the importance of the Social Union Framework just agreed to by provincial, territorial, and federal governments for the development of a national home care program, the conference reinforced the growing momentum represented in the "research, information gathering, and analysis on all aspects of home care in Canada" by HCD. Participants also cited the "values that Canadians consider important for the development of home care, including those related to protection, equity, fairness, support for independence, mobility, and valuing and respecting the needs and contributions of individuals, families and communities" (p. 2) as the basis for continuing to develop a national program. By describing these principles or guidelines for policy development as "values", the power of values language was invoked to lend moral suasion to the growing momentum of a national home care program in Canada.

Subsequently, a Health Network Discussion Paper, released just before the much-anticipated Romanow Commission Report (Fooks & Lewis, 2002), reviews and summarizes the major emerging themes in key Canadian health care reform reports at the national

Table 1: Dominant narrative frame: Mapping values against policy stakeholders with corresponding positions and recommendations

Stakeholders	Values Accessibility	Comprehensiveness	Economic/Cost	Multiple/Other
National Conference on Home Care (1998)		Need for (1) integrated and coordinated national home and community-based program, and (2) emphasis on long-term (not just short-term) needs		Federal government should assume leadership
National Roundtable on Home and Community Care (1999)	Need for a national home care program			Protection; equity; fairness; support for independence; mobility; valuing and respecting needs and contributions of individuals, families, and communities
Romanow Commission Report (2002)			(1) Investing in home care can save money, but (2) need to prioritize needs in mental health, post-acute, and palliative care	Quality of care and life are improved by investment in home care
First Ministers (2003)			Coverage limited to short-term, acute home care services	Universality, accessibility, portability, comprehensiveness, public administration
Hollander Report (2003)		Need to address home care needs of persons with chronic health conditions	Failure to support home care adequately could lead to upward cost spiral in health-care system	Government needs the political will to shift current policy to cover costs of an integrated home care system
Ten-Year Plan to Strengthen Health Care (2004)			Emphasis on needs in short-term post-acute care, acute community mental health care, and palliative care	Universality, accessibility, portability, comprehensiveness, public administration
Health Council of Canada (2005)		Government must address needs for home care services targeted on long-term and chronic care		
Health Council of Canada (2006)		Home care should be expanded and extended to those with chronic illnesses	Home care is under-valued and under-funded, leading to higher costs in the health-care system	
Canadian Association for Community Care	Need to reduce funding gaps for services	Need to include long-term care for those with chronic illnesses in a comprehensive national home care program		Support for individual independence by preventing unnecessary hospitalization
Canadian Home Care Association		Need to include long-term care for those with chronic illnesses in a comprehensive national home care program	Need to determine what services are most important	(1) Universality, accessibility, portability, comprehensiveness, public administration; (2) government must act decisively to lead and take political action

and provincial levels during the previous five years. Interestingly, although it identifies home care services as one of these themes, it devotes only a small segment of the report to this issue, suggesting primarily that ''currently home care is not defined as a medically necessary service under the Canada Health Act and therefore public funding is neither mandatory nor uniform across the country'' (p. 13). Another voice in the emerging dialogue anticipating the release of the Romanow Report was that of the Canadian Association for Community Care, which issued a press release in November 2002 ''anticipating positive recommendations . . . to strengthen home and community care, and reduce the serious funding gaps for these services across Canada'' (Canadian Association for Community Care, 2002a).

The Romanow Commission Report and Beyond

The Romanow Commission Report devotes an entire chapter to home care, suggesting that it is ''the next essential service'' in a revision of the Canada Health Act (Commission on the Future of Health Care in Canada, 2002). Citing research by Hollander and Chappell (2002) that investing in home care can save money while improving the quality of care and of life for those who might otherwise be institutionalized, the report nevertheless goes on to suggest that priority be placed on determining the most important needs and developing a national platform of services to be delivered uniformly across Canada. The recommendation is to focus at the outset on only three areas of priority: mental health, post-acute care, and palliative care.

This reluctance to open home care services to a wider spectrum of need was foreshadowed by Penning (1996) in her assessment of the fears of policy makers. She alludes to their concerns that the provision of a comprehensive system of home care will cause a substitution or ''woodwork effect'' in which individuals and families in need will emerge from informal care settings and demand formal services paid by government. She refers to the ''disconnect'' between social science research and policy-making, in which the findings from empirical studies are either discounted or ignored by policy makers who fear the unintended consequences of their policy actions – in this case, research suggesting that informal care is *not* decreased or reduced by the provision of formal services. Yet, as she suggests, the ''myth of family abandonment'' persists, in spite of the best efforts of researchers to lay it to rest.

Yet another factor that may be operating here is the belief in ''familism'' on the part of the government, namely that families have a natural and first-line caregiving responsibility for frail members; only when the family caregiving resource is exhausted is it the government's responsibility to step in to provide support (Clark, 1993b). This belief may include a lack of recognition of the important role played by women as caregivers (Neysmith, 1993).

In light of this concern it is interesting to note the initial reactions, or ''textual commentaries'', provided by non-governmental groups to the Romanow Report's recommendations on home care. The recommendations were quickly praised as ''first steps'' and a ''good beginning'' for their support of strengthening home care nationally, but critics were also quick to point out that their focus was too narrow and short-term, avoiding dealing with the chronic and long-term care needs of a significant and growing population (Canadian Association for Community Care, 2002b; Canadian Home Care Association, 2002).

Moving the home care narrative along, early in 2003 first ministers agreed on a vision, principles, and an action plan for the renewal of the Canadian health care system, once again invoking Canadian values as embodied in the five principles of the Canada Health Act: universality, accessibility, portability, comprehensiveness, and public administration. Importantly, however, home care recommendations included coverage limited to short-term, acute home care services and a compassionate care benefit for family caregivers (Health Canada, 2003). Again, reaction to this accord suggested that it was a positive first step, but that ultimately ''a comprehensive national home and community care program must include both longer-term maintenance and preventive services to support independence and prevent unnecessary hospitalization'' (Canadian Association for Community Care, 2003).

Interestingly, a position paper released just prior to the First Ministers' Health Accord by the Canadian Home Care Association (2003a) called for the extension of publicly funded home care services as part of the medicare envelope, again invoking the principles of the Canada Health Act and suggesting a package of services that should be included. It is significant that there was a recognition of the potential conflict between important Canadian values and the financial realities of limited budgets: ''The challenge is one of determining which home care services should be defined as 'medically necessary health services' without compromising our social values or overextending scarce resources'' (p. 11).

In addition, a policy paper released in 2003 (Hollander, 2003) suggested that both the Romanow Commission and the First Ministers Health Accord

left a major gap in their policy recommendations by not addressing the home care needs of individuals with chronic health conditions. Empirical research is cited that home care is a cost-effective strategy in chronic care and an alternative for care in a long-term care facility, and that it should be included in a broader, integrated system of continuing care. The paper went on to suggest that policy makers may be reluctant to support such care out of concern about significantly increasing costs, and that a failure to support home care adequately could initiate a cost spiral leading to increasing overall costs in the Canadian system. What is missing, its author suggests, is the political will to shift the current policy to cover more adequately the costs of an integrated home care system.

In this case, factual information gathered by comprehensive research is being used to bolster the argument for policy changes that have not been made – according to the author – for lack of moral or political leadership from the federal government. This situation represents an example of competing interpretations of the empirical basis for public-policy development, suggesting both that facts may either erode or enhance moral leadership by government and that different values may affect how the facts are acknowledged or interpreted. As if in response to these concerns, two position statements from the Canadian Home Care Association (2004a, 2004b) released in rapid succession focused on the need for the government to recognize the urgency of the home care policy situation and to move decisively beyond mere rhetoric to take real political action.

The subsequent announcement in September 2004 of a new Ten-Year Plan to Strengthen Health Care was based, in part, on the earlier groundwork laid by the first ministers in 2000 and in 2003 (Health Canada, 2004). Again acknowledging the pre-eminence of the principles articulated in the Canada Health Act, this plan reiterated the need for unified action in meeting national priorities for health care renewal. With regard to home care, the accord, however, did little to address the concerns of critics from the past by continuing to recognize the needs only for home care in the following contexts: short-term post-acute care, short-term acute community mental health care, and palliative care at the end of life.

The formation of the Health Council of Canada was intended to monitor progress in achieving health care renewal and to advocate further changes where needed. Its first report in January 2005 (Health Council of Canada, 2005a) was designed to accelerate the pace of change in the health care system. It observed that government recommendations and

initiatives to date had emphasized short-term, acute, and palliative home care initiatives. It recommended that government invest more fully in home care services targeted at long-term and chronic care needs to realize their full potential benefits.

Once again, the factual basis used by government for the development of home care policy is disputed by a non-governmental organization, with facts based on research being used to call into question empirical assumptions regarding the anticipated growth in costs associated with a comprehensive national home care program. A background paper accompanying this report summarized the gaps between what governments had promised and what had actually happened (Health Council of Canada, 2005b). The next annual report from the Health Council of Canada (2006) also had a section focusing specifically on home care. The report observed that home care is under-valued and under-funded, leading to higher costs in other parts of the health care system. It recommended that home care services be expanded, especially for those with chronic illnesses.

Summary of Home Care Policy Discourse

Overall, the federal government's narrative frame in the emerging discourse on home care policy seems to be one of tension between the ethical imperative of the Canada Health Act, with its attendant collectivist principles, and the assumed "factual reality" of concerns over the potential costs and consequences of home care policies that are not carefully targeted. Wanting to exercise the political will and moral leadership that is expected of it, the government nevertheless is restrained and constrained in its actions, preferring a more conservative response embodied by the expression "start low and go slow" on the home care policy front. This is not a surprising response from government to a situation of perceived uncertainty over the impacts and associated costs of expanded public policy in an area of increasing service demand.

What *is* interesting, however, is how evidence to the contrary of apparent governmental concerns is acknowledged and interpreted. In spite of empirical research that suggests little, if any, substitution effect of formal for informal care – and, indeed, the potential for significant cost savings with long-term home care for chronic conditions – the federal government's cautious stance indicates that the interpretation of facts viewed from a conservative perspective is more compelling than the assertion of important social values. Although they may have the power of historical application and moral suasion, these values nevertheless cannot trump the interpretation of data,

no matter how accurate or based on empirical research. Put another way, values have rallying power and can be wielded to mobilize public opinion in support of programs, but they still fall short when it comes down to the concrete realities of public funding for potentially expensive programs.

Alternative Narrative Frames: The Aging and Disability Perspectives

Against the dominant narrative or "text" of the discussion of the federal government's emerging role in the home care arena are the "subtexts" and "counter-stories" provided by groups having an interest in the outcomes of the public policy debate and discussion on home care. These are the aging and the disability communities. Here, the term *subtext* refers to a perspective that is basically consistent with the overall empirical and normative dimensions of the text, whereas *counter-story* refers to a radically different perspective that may call into question the fundamental ordering of facts and values in the prevailing dominant text. These subtexts and counter-stories are summarized in Table 2, which maps significant values against stakeholders in the aging and disability communities in characterizing specific policy positions and recommendations.

The Aging Community Subtext

It is interesting to note how relatively subdued is the voice of the gerontological community in the public dialogue on home care in Canada. This may be due, in part, to the assumption on the part of those agencies and associations identified with the needs of older adults and their families that they are already considered to be a major target group when home care policies are discussed. Indeed, most studies, papers, and recommendations mention the needs of older adults explicitly, or implicitly through such phrases as "those with chronic illnesses" or "those with long-term care needs" – assuming that these categories are identified primarily with older adults. In addition, the aging of the population is often mentioned as a key factor in the growing demand for home care services.

A few exceptions to this generalization are the Canadian Association on Gerontology's official position published as an editorial in the *Canadian Journal on Aging* in 1999, stating, "Home care is not currently available to Canadians on a universal basis; it falls outside of the realm of Medicare...Yet for many, home care is considered a necessary part of an appropriate and integrated health care system" (p. i). The editorial goes on to consider the research on cost-effectiveness, funding levels, and needs of

Table 2: Subtext and counter-story: Mapping values against policy stakeholders in the aging and disability communities with corresponding positions and recommendations

Stakeholders	Values			
	Accessibility	Comprehensiveness	Economics/Cost	Multiple/Other
Canadian Association on Gerontology (1999) National Advisory Council on Aging (2000)	Home care is not available to all Canadians Needs for home care services are going unmet	Home care should be part of an integrated health care system	Home care prevents and delays institutionalization	Governments should move to ensure a universally accessible, comprehensive home care program Federal government must act as role model and use moral suasion to advance home care
Roeher Institute (2002)	Need access to personal disability supports for persons with disabilities	Need improved family supports for informal caregivers		(1) Services should be guided by full citizenship of persons with disabilities, along with greater consumer control and responsiveness; (2) values of equality, respect for diversity, fairness, individual dignity and responsibility, and mutual aid and responsibility should guide the creation of an inclusive community
Roeher Institute (2003)	Lack of accessible and affordable in-home supports and services	Need improvements to home care through changes in the Canada Health Act and provincial care policies and more self-managed care		(1) Deficit model excludes and marginalizes persons with disabilities; (2) need to create more inclusive communities with a just investment in persons with disabilities

informal caregivers, and it concludes with the recommendation that "federal, provincial, and territorial governments move without delay to ensure a universally accessible, comprehensive home care program for Canadians" with adequate funding, national standards, and appropriate services (p. ii).

Similarly, the National Advisory Council on Aging (NACA) adopted an official position on home care in 2000, which included the statement that it had "come to the conclusion that while some progress has been made on the road to universal home care, the subject needs to remain at the forefront of discussions on how to revitalize the health care system. Governments must take action without delay" (p. 1). With recommendations that echo the principles of the Canada Health Act, NACA goes on to reiterate its strong historical support for home care services, asserting that "home care prevents and delays institutionalization and promotes the social integration of seniors. It responds to the changing health needs of older Canadians in a flexible, holistic manner and provides support to their informal caregivers" (p. 5). Citing mounting evidence for still unmet needs for home care services and widespread support for the development of a national home care system, the report asserts, "The federal government has a responsibility to act as a role model for other jurisdictions and other employers. This is an opportunity to use moral suasion as another method for advancing home care" (p. 14). The use of the term *moral suasion* is noteworthy here, as it explicitly incorporates values language in advancing a public policy agenda – a theme that has been explored already in this discussion.

The Disability Community Counter-Story

The provision of home care services to adults with cognitive, physical, or developmental disabilities is also an important issue; however, discussion of it tends to be embedded within a larger framework of discourse on community supports and is overtly based on an explicit set of articulated values and principles that are characteristic of policy papers and positions of the disability community in general. Because of its fundamentally different way of framing the debate on this issue, this discourse may be considered a "counter-story" to the dominant home care policy narrative. For example, in a policy paper on caregivers of persons with disabilities in Canada (Roeher Institute, 2003), the discussion of policy implications of informal versus formal caregiving begins with a strong ideological statement regarding the deficit or medical model of disability and its implications, which include excluding persons with

disabilities from mainstream community structures and services, resulting in their being marginalized and characterized as burdens to families and society.

Following this statement comes the specific observation that there is a perceived lack of accessible, affordable, in-home supports and services for informal caregivers, suggesting that the shortage of flexible and responsive home care is one of the major causes of the negative consequences of providing informal care. Solutions to this problem are perceived to be the creation of communities that are more inclusive, including improvements to home care through changes in the Canada Health Act and provincial care policies and a move toward more self-managed care. In addition, "a fair and just investment in people with disabilities and those who provide care to them" (p. 10) would involve greater public investment in in-home and community access supports.

Another policy paper on improving access to community supports (Roeher Institute, 2002) greatly expands on this position, including a much more fully developed statement about the rights of persons with disabilities: "[The] provision of disability supports in Canada should be strengthened through: a guiding vision of the full citizenship of people with disabilities and improved access, enhanced portability, more consumer control and greater responsiveness to individual needs" (p. 1). Similar language involving rights and citizenship is evident in a position paper prepared by the Home Support Action Group in British Columbia, calling for the promotion and protection of home support services within a national plan (Home Support Action Group & Krogh, 2002).

Subsequently in the Roeher Institute (2002) report, there is stronger support for the inclusive community and the principles and values it embodies – equality, respect for diversity, fairness, individual dignity and responsibility, and mutual aid and responsibility – as well as the rejection of objectification, marginalization, and exclusion of persons based on gender, level of ability, race, age, and sexual orientation. Only after this statement of basic principles are the key policy issues addressed, including access to personal disability supports for persons with disabilities and the adequacy of family supports for informal caregivers. In general, it is clear that home care issues are conceptualized within the much larger, and ideologically driven, framework of supports provided within an inclusive community.

This narrative frame or perspective of the disability community based on questions of individual rights and the meaning of disability and impairment is well

developed in the literature, not only in Canada but also in the United States and the United Kingdom. For example, Donoghue (2003) suggests that the medical model of disability – which defines a disability as an inability to perform a "normal" life activity on the part of the individual – still dominates over the social constructionist model – which holds that society has created disability by choosing not to remove structural constraints that would enable individuals with disabilities to participate and gain access to social resources. Drewett (1999) confirms that the conceptualization of access issues on the part of persons with disabilities to social services and health care as a "human rights" concern seems to be growing, though she questions whether this is preferable to a more traditional "needs-based" approach. Still other theorists of disability raise questions about the nature of impairment and disability in an epistemological sense (Goodley, 2001), while some explore the meanings attached to dependence, independence, and interdependence (Greiner, 2003; Reindal, 1999).

In terms of the implications of this discourse for the actual provision of health care and human services, Pedlar and Hutchinson (2000) suggest that historically in Canada much of the innovation in these systems has been the result of social movements, most notably the parent/consumer movement, with its emphasis on individual empowerment, community participation, and family involvement. Recently, the retreat of government from assuring access to services by persons with developmental disabilities, and the growing reliance on market-driven for-profit services, have, however, reversed these historical gains and led to the re-emergence of forces that lead to the commodification of disability.

Bridging the Gap between Aging and Disability Perspectives

This discussion started with the premise that there are theoretical and practical differences between the aging and the disability perspectives on home care ("seeing the world as they are"), and that an understanding of these differences could lead to an appreciation of how "having new eyes" might inform and expand our understanding of the empirical and normative elements in home care policy discourse. An alternative way of conceptualizing the challenge of clarifying and changing our thinking is based on the proposed conceptual framework of "narrative frame" – that there can be a dominant narrative and sub-narratives, a primary text and subtexts, and stories and counterstories that shape the policy discourse on the general topic of care at home. Using this characterization, the task might best be described as "the creation of a

unified narrative frame that accommodates both perspectives and helps to move our understanding of the policy discourse forward." In this spirit, some observations, conclusions, and recommendations are suggested below, centred on the following themes: (1) models matter, (2) values may be valuable, and (3) program and policy payoffs are possible.

Models Matter

There is a growing discourse in gerontology on how the models we use to describe and prescribe the experience of aging matter with regard to expectations for growing older and to program and policy development for older adults. Models are implicit in the emerging narrative frames used to justify interventions that define a problem and propose a range of solutions to it. For example, the successful aging paradigm (Rowe & Kahn, 1987, 1997), with its emphasis on individual characteristics and behaviours, has been criticized as failing to recognize the broader social, economic, political, and environmental dimensions and determinants of health in old age (Holstein & Minkler, 2003). Similarly, the growing alarm over the increasing biomedicalization of aging raised by such authors as Estes and Binney (1989) and Kaufman, Shim, and Russ (2004) has implications for both clinical practice and policy development and implementation. As mentioned earlier, disability discourse has a well-developed history of analyzing models and meanings of disability. Two examples are the issue of the medical model versus the social constructionist model explored by Donoghue (2003) and the nature of impairment and disability examined by Goodley (2001).

The efforts of some in the gerontological community to differentiate between old age and disability, such as through the "successful aging" versus the "usual aging" paradigms, may undermine the development of a rich and critical discourse on the meaning of aging that could be learned from the example of the explicit emphasis of such groups as the Independent Living Movement on the social, economic, and political contexts of disabilities (Kennedy & Minkler, 1999). In this regard, the aging community has much to gain from the more open dialogue on conceptual models that is a hallmark of the disability community. For example, joint models of consumer empowerment within the fields of aging and developmental disabilities are beginning to emerge (Cohen, 1988). They emphasize the importance of giving the client or consumer ultimate control over decision making and resource use (Clark & Sousa, 2000). In Canada, Keefe (2002) suggests that the development of self-managed care programs has its roots in the

Independent Living Movement, rather than in services for older adults.

Values May Be Valuable

Invoked in debates and discourse in a *pro forma* fashion, general statements about values may not be particularly effective at moving an agenda ahead in the policy arena. They may provide a necessary framework for discussion, but they are unlikely to force progress on the policy front or lead to further understanding of the normative dimensions of policy options.

However, when used to galvanize ethical action, mobilize moral support, and uncover underlying assumptions and questions, values may be more valuable. In this sense, values border on ideological statements, drawing attention to the importance of ideas and insights that shed new light and understanding on previously unexplored dimensions of issues and problems, helping us to "see with new eyes". For example, principles promoted by the Independent Living Movement have been articulated as the right of all persons to live in the community as full, respected members in exercising choices related to housing, transportation, education, and employment, and in participating in the social, economic, and political life of their communities (Kennedy & Minkler, 1999).

Similarly, the discussion on the dimensions and distinctions around autonomy in the gerontological community (e.g., Carter, 2002; Collopy, 1988; Collopy, Dubler, & Zuckerman, 1990) resonates with a discourse on the significance of dependence, independence, and interdependence in the disability community (e.g., Greiner, 2003; Reindal, 1999). Older adults and adults with disabilities may be caught between a social ethic of independence and a service ethic that constructs them as dependent, whereas the development of an ethic of interdependence suggests that all persons, with and without disabilities, are tied into a common community of interrelationship. We must embrace "values supporting enhanced respect, choice, community involvement, skills, and social relationships that underlie what makes life worthwhile for people of any age or ability" (Clark & Sousa, 2000, pp. 135–136).

These concepts may culminate in the "ethic of care" approach proposed by Kenny (2004), which focuses less on rights and rules and more on human dignity and the common good. It does not envision individuals as autonomous, but rather as rooted within such relationships as familial, social, work-related, and political. The concept of "ethic of care" also resonates with the feminist ethic of care position (Lloyd, 2004), in which the fundamental focus of ethical concern is the caregiving and care-receiving relationships within a community, particularly their elevation to social and political discourse rather than being seen only as private matters (Parks, 2003). An ethic of care approach simultaneously broadens the discourse on such specific public policy issues as home care and expands the values framework that may be applied more generally to the development and implementation of health care policies. It may provide a set of moral directions to guide the design of public policies and programs, as suggested in the United States by the President's Council on Bioethics Report (2005), titled *Taking Care: Ethical Caregiving in Our Aging Society.*

Program and Policy Payoffs are Possible

Finally, increased collaboration between the aging and the disability communities over such issues as home care policy may be likely to happen not so much because of the potential for a common values dimension to their unified narrative frame, but because of the recognition that the two service systems, which are largely parallel and non-intersecting in many countries, are converging as a result of the overall aging of societies in general.

For example, in the United States in the late 1980s and early 1990s there was a growing recognition that the two systems would be challenged to increase their cooperation as a result of the growing numbers of older adults with lifelong or developmental disabilities (e.g., Ansello & Eustis, 1992; Ansello & Rose, 1989), especially in settings such as home care (Eustis & Fischer, 1992). The 1987 Wingspread Conference on Aging and Lifelong Disabilities was convened to bring together senior level administrators from the aging and disabilities service systems to begin to forge a common agenda and a shared partnership. In their report that summarized the findings and recommendations of this conference, Ansello and Rose noted that the two systems were continually being drawn into interactions by the evolving status of their clients and that the perceived differences between the two systems should be reconceptualized as "opportunities to broaden their collective expertise and respond to the needs of older adults, both with and without disabilities" (cited in Janicki & Ansello, 2000, p. 533). A recognition of this trend has led to the "aging with lifelong disabilities" movement that promotes greater program and policy collaboration around support for caregiving families, education of service providers, and increased cooperation in service systems.

Conclusion

Deconstructing the emerging discourse on home care policy in Canada requires an analysis of facts and values in policy statements and positions regarding programs and services for populations of older adults and adults with disabilities. An examination of the evolving primary text or story of home care policy, along with the consideration of subtexts and counter-stories, has helped to reveal the underlying structures, assumptions, and tensions in this unfolding public-policy debate. Whether these narrative frames will converge, or continue as separate and distinct, remains to be seen.

However, what is clear is that seeing the issues of home care through the new eyes of others – by using a narrative frame approach – allows us to encounter the health care policy world in a fresh way. In this sense, what is to be gained in this analysis is an increased understanding of why it is so important to examine the process of public policy discourse, and not only its outcomes. The essential purpose of exploring the issues of home care in this way is to find new insights into the perennial human search for community, caring, and connectedness, set against a backdrop of public policy discourse and debate that grapples with how best to distribute the always limited resources in any society. The fact that different countries and communities do this balancing differently only points to the importance of social values in defining what problems we seek to address and how we struggle to solve them.

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