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Assessing the Impacts of Health Reforms on Seniors

Part I: A Synthesis Report of Health Reforms and Seniors' Perceptions of the Health System

A Report Prepared for the National Advisory Council on Aging

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Prepared by:

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EXECUTIVE SUMMARY

Due to the potential impact of health reforms, and their lack of evaluation to date, the National Advisory Council Aging (NACA), through its Research and Special Issues Committee, commissioned this project entitled Assessing the Impacts of Health Reforms on Seniors. The goal of the project was as follows:

> To develop an analytical framework to identify appropriate evaluation questions and indicators to assess the impact of health organizational and structural reforms on the availability, accessibility and quality of health care for seniors and their families.

The deliverables for this project are divided into three parts. Part I is a synthesis report on regional reforms in Canada and on seniors' perspectives of the health system. Part II consists of an analytical framework and key indicators for evaluating the impact of health reforms on seniors. Part III is an evaluation guide which could be used by local organizations to conduct their own evaluations. This report provides the findings for Part I of the overall project, that is, the overview of regional reforms and seniors' perceptions of health services.

A literature review of health reforms across Canada was conducted for this project. It was found that while many jurisdictions have adopted a regional model of reform, the actual reform process is more pervasive and more complex than may be recognized. Reform initiatives cover a range of issues. Some or all of these issues may be addressed in regional reforms or in reforms which adopt Primary Care models or Integrated Health Systems. These issues are listed below:

- **Systems Alignment**: efforts to build better and more integrated models of service delivery, mergers (i.e., consolidating several hospitals under one board), alliances and joint ventures, and horizontally and vertically integrated models of service delivery.
- **Organizational Change**: major re-structuring and downsizing of Ministries of Health in response to regionalization; increased emphasis on utilization management, quality assurance and evidence based decision making; more client centered care; and a greater role for family members in the care delivery process.

- **Governance**: greater emphasis on openness and accountability in response to regionalization, greater representation in decision making by the community, and increased activity by advocacy groups.

- **Changes in Educational Methods**: a greater emphasis on formal education and skill development, an increase in the proportion of people taking management training, and a greater demand for more flexible and part-time curricula and distance education.

- **Changes in Management Practices**: a greater focus on facilitation, consensus building and inter-personal skills; a focus on information systems and informed decision making; a need to demonstrate value-for-money; and an emphasis on identifying and adopting best practices.

- **A Renewed Emphasis on Quality**: increased emphasis on quality assurance, clinical practice guidelines and care maps.

- **A Broader Perspective on Health**: increased emphasis on a holistic prevention/wellness model, and increased emphasis on a population health model.

- **Fiscal Restraint**: reductions in the number of hospital beds, or at least a decrease in the rate at which beds are built and put into operation, and reduced rates of growth in most other sectors of the health system.

The three most westerly provinces, British Columbia, Alberta and Saskatchewan, have adopted similar models of regionalization. Regional Boards have been established (mostly with appointed members at this point), and political and administrative authority has been, or will be, devolved to these Regional Boards. Alberta and Saskatchewan have moved relatively quickly to implement regionalization and have already devolved staff and funding to the Regions. However, mental health and substance abuse are still provincial level programs in Alberta. British Columbia has recently completed devolving staff and resources to its regions. Manitoba is also in the process of moving to a more fully developed model of regionalization.

Ontario has chosen not to regionalize and is focusing on a range of matters related to better integration and systems alignment. It is looking at enhanced Primary Care models. These models focus on family practitioners, and some models include the full range of community and home based services (i.e., non-institutional care). The other option under active consideration in Ontario is Integrated Health Systems (IHSs) which are vertically integrated models that can contain the full range of services from home based services to specialized care in an acute care setting.

Québec has had a regional model for some time with a regional board structure and community health centres or CLSCs. Greater authority has been given to the regional boards over the past years. Recently, the government of Québec has expressed interest in an integrated service delivery model for the elderly developed by a consortium of university based researchers. The model is called *systèm de soins intégrés pour personnes âgés en pert d'autonomie* (SIPA) or the system of integrated care for the frail elderly.

New Brunswick was the first province to adopt health reforms when it amalgamated over 50 hospital boards into seven regions, each with its own Regional Hospital Board. (One of the regions has two boards, one English and one French.) Each board is responsible for the operation of hospitals in its region. This is a kind of mixed model and does not represent regional reforms *per se*. Rather it is a kind of amalgamation of independent service agencies in one sector, i.e., hospitals. More recently, steps have also been taken to change 12 Family and Community Social Services Regions into seven regions to match the seven hospital regions.

Nova Scotia has moved to implement four Regional Health Boards. However, responsibilities for Long Term Care and Home Care have not yet been devolved to these Boards due to current efforts to implement a more comprehensive single point of entry system at the provincial level before devolving responsibility to the Regional Boards.

Prince Edward Island has adopted five regions which, like in Québec, cover both health and social services, and it has started an external evaluation of its reform process. Newfoundland has instituted eight Health Boards for hospitals, health centres and nursing homes, and four community Health Boards for community and public health services.

While one can only speculate at this time on the possible impacts of health reforms on seniors, given the lack of existing evaluations, there are at least some potential implications which can be discussed. To the extent that they can be effectively implemented, the reform initiatives discussed above should have positive consequences. Better and more integrated methods of service delivery should result in less duplication of effort and more "seamless" and "transparent" care delivery for

seniors who require services from a range of providers. Providing services through more local administrative structures such as Regional Boards, Primary Care agencies or Integrated Health Systems should allow for more input by seniors at the local level. A greater emphasis on quality, holistic prevention and wellness should also have positive consequences.

However, there are also possible risks in reforms which may result in some negative consequences for seniors. Reform initiatives appear to have relied on structural solutions to what are, at least in part, operational and quality related issues (e.g., enhanced coordination of services and improved service quality), instead of focusing on these issues directly. Suboptimal policies or practices (e.g., amount of staff training) may continue to remain in place or may be exacerbated by reforms and by restraint in overall funding levels.

A comprehensive literature review of seniors' perceptions about what would constitute an appropriate health care system was conducted for this project. It was found that both in Canada, and internationally, seniors were relatively satisfied with the health services they received. It was also found that independence, quality of life, and dignity were important issues for seniors. The social types of health-related services, such as transportation, housing and subsidies for eyeglasses, were seen to be important to seniors because they allowed them to live more independently.

Data from the Health Canada Supplement to the 1994 National Population Health Survey were analyzed for this project. Respondents were asked to rate Canada's health system as excellent, good, fair or poor. There was little difference by age of respondent to questions on this topic. Over 85 percent of all respondents rated health care highly. Seniors with higher household incomes, higher levels of education and higher self-rated health status were more likely to rate the health care system as excellent than seniors with lower incomes, education, and self-rated health status. However, there was little difference between the two groups when the "excellent" and "good" responses were combined.

Respondents were asked to identify what they thought were the major strengths of Canada's health care system. The two major strengths identified were low cost and universality. Rural seniors and

seniors with lower levels of income and education, and lower self-rated health status, were more likely to identify "low cost" as a strength of the system than other seniors. Urban seniors and those with higher income and education levels, and higher self-rated health status, were more likely to identify universality as a major strength. Respondents were also asked to identify what they thought were the main weaknesses of Canada's health care system. The biggest weakness identified was the length of time it takes between calling for an appointment and being seen. Those under 65 years of age considered this to be more of a problem than those over 65. The only major difference, among seniors, was that those with higher household incomes, levels of education, and self-reported health status were more likely to state that a main weakness of the system was that it could be too easily misused and abused.

Two initiatives were undertaken to obtain the views of seniors about what would constitute appropriate health care. One initiative was for NACA members to conduct a series of interviews with seniors and their caregivers. The second initiative was the conduct of consultations with two groups of seniors. The following table presents an overview of the issues which were found to be of importance to seniors and to their informal caregivers.

A number of important lessons were learned in comparing the goals of reforms to the expectations of seniors and of caregivers. Perhaps the most important and critical finding was the degree of disjuncture between the apparent goals of reform and the goals of seniors. The difference was manifested at several levels. For example, while the reform process has focused on structure and process variables, in the belief that improvements in these areas will lead to improved outcomes, seniors have focused on health outcomes directly.

In addition to differences in goals there are also differences in perspective. These differences lead to differences in the <u>methods</u> one may use to evaluate reforms. Reforms have been primarily established from a structural and administrative perspective. This means that there is a focus on larger groups, on equity across groups and individuals, on formal policies, and so on, i.e., a focus on the general or the collectivity. This perspective is likely to be congruent with a more quantitative methodological approach to analysis. While the above matters may also be of interest to seniors,

their focus seems to be more individualistic and particularistic. Seniors' primary concerns are with the care provided at the front lines, and with the experiential meaning of that care. Thus, to evaluate the issues of concern to seniors, one may need to adopt a combination of both quantitative and qualitative approaches to analysis.

TABLE 1: Issues of Importance to Seniors in Regard to their Health Care

1. NACA INTERVIEWS

A. Issues of Importance to Seniors

1. Expectations Related to Services
   - A1.1 Effective
   - A1.2 Sufficient
   - A1.3 Available
   - A1.4 Continuous, predictable
   - A1.5 Acceptable
   - A1.6 Flexible, adaptable
   - A1.7 Affordable
   - A1.8 Accessible
   - A1.9 Timely

2. Expectations Related to Service Providers
   - A2.1 Clear communication
   - A2.2 Caring
   - A2.3 Goes the extra mile
   - A2.4 Anticipated future needs

3. Expectations Related to the Health Care System
   - A3.1 Coordination
   - A3.2 Changes observed from Health Care reform
   - A3.3 Concerns about medications

B. Issues of Importance to Informal Caregivers

1. Expectations Related to Services
   - B1.1 Continuous, predictable
   - B1.2 Family centered
   - B1.3 Acceptable
   - B1.4 Timely
   - B1.5 Affordable
   - B1.6 If affordable, available

2. Expectations Related to Service Providers
   - B2.1 Clear communication
   - B2.2 Competent
   - B2.3 Well trained
   - B2.4 Shows interest
   - B2.5 Makes enough time
   - B2.6 Caring and respectful
   - B2.7 Goes the extra mile
   - B2.8 Anticipates future needs

3. Expectations Related to the Health Care System
   - B3.1 Coordination and monitoring
   - B3.2 Available range of services
   - B3.3 Appropriate settings for care
   - B3.4 Opportunities for self-managed care

2. CONSULTATIONS

1. Major Themes
   - C1.1 Communication
   - C1.2 Caring, respect and dignity
   - C1.3 Control and choice
   - C1.4 Coordination
   - C1.5 Personal responsibility for health
   - C1.6 Competence and training
   - C1.7 Continuity and predictability

1. Major Themes (Continued)
   - C1.8 Cost, entitlements and willingness to pay
   - C1.9 Time and timeliness
   - C1.10 Transportation
   - C1.11 Appropriate settings
   - C1.12 Staffing issues
   - C1.13 Expanded roles for volunteers
   - C1.14 Issues regarding medications

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1. INTRODUCTION

Through anecdotal reports, and their own knowledge of changes in health care delivery, members of the National Advisory Council on Aging (NACA) became concerned about the impacts of health reforms on seniors. Problems noted related to delays in seniors receiving services, lack of coordination of care between the components of the health care system, and health care staff being under such pressure that they were "processing" seniors rather than listening to them and caring for their individual needs.

In addition to the need for medical and hospital services, seniors require services to address their functional needs. The challenges in caring for seniors relate to the coordination of a wide range of supportive health-related services, and to the maintaining of seniors' dignity while they are being cared for by others. It is the little things, such as making a meal, being able to go up and down stairs, being able to clean one's house, being able to groom oneself, and being treated appropriately by others, that lend dignity to one's life and that pose unique challenges to seniors and to their informal caregivers. NACA members grew concerned that the level of "caring" in the health system had started to deteriorate.

Given the potential impact of reforms, and given their lack of evaluation to date, NACA at its February 1996 meeting directed its Research and Special Issues Committee (RSIC) to develop terms of reference for a project to assess the impacts of health reforms on seniors. The RSIC considered a range of factors such as possible research models, the lack of appropriate evaluation approaches, and financial and time constraints. It recommended that, at this time, the most significant contribution NACA could make to the current debate on the impact of health care reforms would be, as a first step, to develop a NACA position on key evaluation issues.

This recommendation was approved by the Council at its May 1996 meeting, and staff were directed to develop a detailed project plan for review and approval by the RSI Committee. In developing its

project plan staff identified that the overall goal of the project would be as follows:

- To contribute to the debate on the evaluation of health care reforms by advancing a NACA position on key evaluation issues and questions which need to be addressed in assessing the impact of changes on the delivery of services to seniors.

The staff also identified that the specific purpose, or key objective, of the project itself would be as follows:

- To develop an analytical framework to identify appropriate evaluation questions and indicators to assess the impact of health organizational and structural reforms on the availability, accessibility and quality of health care for seniors and their families.

The staff entered into contracts with the Health Network of the Canadian Policy Research Networks, an independent, national, policy think-tank, and with Dr. Elaine Gallagher of the University of Victoria, to carry out the project.

In establishing this project, NACA wanted to develop an overall conceptual framework, and a set of key indicators, which would take a seniors centred approach to evaluating health reforms. This evaluation model could then be used by governments, Regional Boards, seniors' agencies, and others to address the key question of concern, i.e., are reforms resulting in health care that meets the expectations of seniors, and of their informal caregivers.

NACA members were also looking to the future in mandating this project as more and more seniors will be cared for by the health system in the coming years. In fact, the proportion of seniors in Canada has been increasing at a higher rate than the rest of the population for some time, and projections indicate that this trend will only increase as baby boomers reach 65 years of age in the year 2011. Thus, how seniors are served by the health care system will become an increasingly important issue over time. For example, while the non-senior population (those aged 0 - 64) is projected to increase by some 18.7% between 1996 and 2016, the corresponding projected growth rate for seniors is 61.1%, or more than three times that of non-seniors. The rate of increase for those

85 years of age or older, who use disproportionately more health services than any other age group, is projected to be 115% for the same period.[1]

The overall project entitled "Assessing the Impacts of Health Reforms on Seniors" has three parts. This document constitutes the report of the first of these three parts. It provides a synthesis of what has happened in regard to health reforms across Canada. It also provides an overview of seniors' perceptions of our health care system and a discussion of the care related issues that are of greatest importance to seniors and to their informal caregivers. This report sets the stage for the next two parts of the project.

The report of Part II of the project provides a framework for evaluating the impact of health reforms on seniors. It also provides a series of questions and key indicators which could be used by those conducting an evaluation as a "menu" of items from which they could select the set of questions and indicators with the greatest relevance to their particular study. The report of Part III of the project provides a "how to" evaluation guide for community agencies that may wish to conduct an evaluation of the impacts of health reforms on seniors in their communities.

2. AN OVERVIEW OF HEALTH REFORMS IN CANADA

2.1 Introduction to Reforms, Restraint and Restructuring

Change is ubiquitous, and the only constant is change. Royal and other Commission reports were produced on the health system in almost every province in Canada in the late 1980s and early 1990s.[2] Most of these reports called for some type of regional reform and advocated the establishment of Regional Boards which would be responsible for the delivery of a range of health services, typically excluding physician services and provincial drug plans. In addition, the cash portion of the federal transfer payment to the provinces was reduced resulting in fiscal pressures at the provincial level. This resulted in two major pressures for change in the health system: changes in structure and changes in financing. In addition, the movement towards change in these two areas opened the door

for other types of change as well. Thus, while most observers think of change in the health care system in relation to regional reforms, the health reform initiatives which have emerged across the country are actually more complex and more pervasive. In addition, much of what has happened to date is a re-structuring of services. Actual reform itself, in the sense of implementing new and improved systems and processes of service delivery, is still in its early stages.

Some provinces such as Ontario have chosen not to regionalize, while others such as New Brunswick have chosen to regionalize on a more limited basis. The health sector is currently grappling with a number of related issues including those listed below:

- **Systems Alignment**: efforts to build better and more integrated models of service delivery, mergers (i.e., consolidating several hospitals under one board), alliances and joint ventures, and horizontally and vertically integrated models of service delivery.

- **Organizational Change**: major re-structuring and downsizing of Ministries of Health in response to regionalization; increased emphasis on utilization management, quality assurance and evidence based decision making; more client centered care; and a greater role for family members in the care delivery process.

- **Governance**: greater emphasis on openness and accountability in response to regionalization, greater representation in decision making by the community, and increased activity by advocacy groups.

- **Changes in Educational Methods**: a greater emphasis on formal education and skill development, an increase in the proportion of people taking management training, and a greater demand for more flexible and part-time curricula and distance education.

- **Changes in Management Practices**: a greater focus on facilitation, consensus building and inter-personal skills; a focus on information systems and informed decision making; a need to demonstrate value-for-money; and an emphasis on identifying and adopting best practices.

- **A Renewed Emphasis on Quality**: increased emphasis on quality assurance, clinical practice guidelines and care maps.

- **A Broader Perspective on Health**: increased emphasis on a holistic prevention/wellness model, and increased emphasis on a population health model.

- **Fiscal Restraint**: reductions in the number of hospital beds, or at least a decrease in the rate at which beds are built and put into operation, and reduced rates of growth in most other sectors of the health system as well.[3]

While most jurisdictions have chosen the vehicle of regionalization to address these issues, others have chosen other methods. The merger of hospitals into eight hospital boards in New Brunswick is often described as regionalization, but it is actually closer to an amalgamation model which seeks better systems alignment through mergers. Thus, it should be noted that while regionalization has received much of the attention, many other changes are occurring, or are being considered. All of the change-related issues noted above can, in fact, take place in conjunction with regionalization. Whether they actually do so is related to the nature of the change process in each respective jurisdiction. Most of the change issues can also be included in reforms which do not focus on regionalization. Perhaps the only regionalization-specific issue noted above is that of a major downsizing of a Ministry of Health. This happens as staff are deployed out to the regions and the Ministry focus shifts from operational issues to issues of policy, planning, evaluation, accountability, and other such matters of oversight and stewardship.

While a wide range of change initiatives are in play across the country, the main reform vehicle still tends to be a devolved model of regionalization. Thus, an overview of regionalization is presented in the next section.

2.2 Regionalization

In Canada, the term regionalization has emerged as the primary term to describe a delegation of authority from the centre to a more local body. The most common form of regionalization across Canada has been "devolution."

Devolution refers to the transfer of some degree of political authority (i.e., transfer of the "board of directors" function over policy making, accountability to the citizenry, and overall stewardship of the service delivery system) from the Minister and Cabinet to a local level of government or a special "Board" responsible for the management and delivery of health services in a given geographic area.

Local boards which receive funding to provide health services are examples of devolution, as are Health Authorities in England and County Councils in Sweden.

Local boards can be composed of people who are appointed by some central authority, such as the Minister of Health, or who are elected by the local population. Boards can also be composed of a mixture of appointed and elected members.

Local boards may or may not have the authority to levy taxes. For example, County Councils in Sweden have the authority to levy taxes. However, the reform initiatives in Canada have not included new powers of taxation for Regional Health Boards.

There are usually a number of goals which are espoused as the purpose for entering into a health reform process. These goals may differ in their scope and emphasis between jurisdictions. Typically, regional reforms are touted as a means to bring decision making about health care closer to the community level. It is noted that people at the local level can have a greater impact into policy and decision making if decision makers are locally accessible. This accessibility, it is believed, will also increase political and administrative accountability and will lead to better management and delivery of health services at the local level. These goals of regionalization can also be thought of as the "pros" or benefits of adopting regional reforms. Some other benefits or goals which may not be noted as actively as those above are cost control and a shifting of the firefighting or trouble shooting functions from Ministries of Health to the regions. It is often believed that local control will lead to greater efficiencies in service delivery, which, it is believed, will reduce costs. Table 1 summarizes the range of benefits of regionalization (or the reasons for adopting regional reforms) which have been identified in the literature. Table 2 presents a summary of the "cons" or the risks inherent in regionalization. The information presented in Tables 1 and 2 is broken down into political and administrative sections. Table 2 also presents a section on risks related to conceptual and planning issues. If the model of regionalization to be used is not clearly defined or is not congruent with actual goals (e.g., a model for greater democratization with a goal of cost constraint), problems may arise.

TABLE 1: The Benefits of Regionalization[4]

Political Benefits	Rationale
Greater Democratization	Allows for greater participation in the democratic process by people at the local community level.
Greater Input into Policy	Allows the public better access and input into the policy-making process because they are closer to decision makers.
Reduction of Regional Disparities	Re-allocation from have to have-not regions can be more easily defended if allocations are made on a per capita or formula basis in a regionalized system.
Spreading The Blame	Regionalization splits responsibility between politicians at the central and local levels, thereby allowing for a spreading of the blame for any failure to meet local needs.
Increased Political Accountability	Local politicians and board members are more likely to be accountable to the local population than are central politicians who are far away.
Strength Through Diversity	In nations, states or provinces made up of diverse and sometimes antagonistic groups, regionalization can give such groups greater autonomy while retaining them in the larger collective.
Administrative Benefits	**Rationale**
Increased Administrative Accountability	Local administrators have to deal with local issues and grievances directly and have to respond to local concerns.
Greater Integration and Coordination of Services	Local officials, reporting to local boards, are more able to overcome institutional, attitudinal, physical and administrative constraints on the effective operation of health services.
Better Planning and Resource Allocation	Local officials are more aware of local circumstances, constraints and opportunities and, therefore, can develop plans that are responsive to, and meet the needs of, local communities. Local citizens are also more likely to have an opportunity to provide input.
Cost Reduction	Due to local knowledge, redundancy and service duplication can be reduced or eliminated by local planners and administrators.
Better Management and Program Implementation	Reducing centralized control over local administration allows local managers the freedom to manage services with fewer "unnecessary" constraints from the centre.
Increased Intersectoral Coordination	In addition to the increased integration and coordination of health services, there is also a greater probability of intersectoral coordination with organizations outside the health field.
Increased Emphasis on Community and Preventive Services	To the extent that local administrators have some form of global budget, it is easier for them to transfer funds between institutional and community services and to emphasize health promotion.

TABLE 2: The Risks Inherent in Regionalization[4]

Risks Related to Conceptual Problems	Rationale
Poor Conceptualization	This may happen when there is not a clear understanding of the various concepts of regionalization. Options such as delegation may be overlooked if there is a rush to devolve authority to newly-created boards.
Poor Fit between Objectives and the System Devised	The system of regionalization adopted may not be congruent with the desired objectives, or different actors may hold different objectives. For example, political and financial goals may clash if politicians desire greater local autonomy through elected boards, while bureaucrats do not wish to provide the additional funds required to establish such boards.
Incorrectly Defining the Appropriate Geographic Unit	The implications of the geographic boundaries chosen for the model to be developed are significant. There is often a tendency for larger geographic units such as regions to centralize at their level. If the goal is to empower local people, control may have to be devolved to very small communities. However, such communities may be too small to have a full range of services. How does one strike the right balance?
Political Risks	**Rationale**
Overcoming the Tendency to Centralization	There are strong, ongoing tendencies towards centralization as Ministers are still answerable in the legislature, irrespective of whether or not local boards are supportive or antagonistic.
Local Potentates	Local boards or other political bodies may be captured by individuals who are already publicly powerful at the local level, who may wish to increase their power, and who may see membership on the new boards as a stepping stone to higher elected office.
Local Opposition	To the extent that political parties opposed to the party in power at the centre are able to capture control over local boards, such opposition groups can use local boards as power bases to oppose the government in power.
Administrative Risks	**Rationale**
Problems of Coordination	Regionalization often reveals that poor coordination and a lack of integration exists among the vertically organized programs located at the centre. It is often difficult for the centre to respond to such problems due to the magnitude of the changes required to correct such problems, e.g., a major reorganization of divisions.
Relations with Decentralized Organizations	Relations between the central administration and the newly regionalized local bodies can easily become strained over a number of matters such as the degree of local authority, accountability requirements, budgets, and other such matters. Strained relations may result in sub-optimal service delivery.
Geographic Boundaries	It is highly desirable that existing sets of geographic boundaries, in place prior to regionalization, be made as coterminous as possible. This may require changes in legislation and may raise concerns at the local level as to which boundaries will be used.
Composition of Local Boards	If boards are elected, they have a legitimate claim to speak for local interests, even against the central government. If they are appointed, they may be more compliant but may be perceived to lack legitimacy and moral authority.

Authority of Local Boards	The power of local boards can range from almost no real authority, to responsibility for planning, to some authority over service delivery, to significant control through the power of taxation. If the rhetoric of local empowerment confronts the reality of continued central control, there may be difficulties.
Method of Funding Services	Local governments or boards are often dependent for funding on the centre. If funding is based on a historical allocation, existing inequities may be perpetuated. If a new population-based, age and sex adjusted funding mechanism is implemented, there may be a political outcry from areas which lose funding through a reallocation of resources.
Budgeting, Expenditure Control and Priorities	If budget control is tight, local boards may be refused permission to transfer funds to restructure service delivery in accordance with local priorities. If control is loose, then the consistency of service delivery across regions may come into question. In addition, local boards may not wish to follow priorities mandated by the central government.
Administrative Control	The degree of administrative control can again vary from tight to loose. Tight control restricts the response to local needs while loose control decreases the authority of the centre to ensure equal services across regions and to protect minorities or unpopular groups from discriminatory practices.
Local Planning	Problems may arise as central governments may provide funding on an annual basis as approved by the legislature, and budgets may not be approved by the legislature until some months into the new fiscal year. Therefore, plans may become subordinate to the operational requirements of staying within budget if actual expenditures for the first quarter are greater than the funding which is ultimately approved.
Impacts on Administration at the Centre	Experience indicates that the process of regionalization often leads to a major restructuring of public servants at the centre from operational activities to planning, policy development, and monitoring. Such changes can cause strain and conflict. Public servants may be reluctant to reduce their authority by giving resources to local boards.
Staffing at the Local Level	Another problem area may be the ability to attract well qualified planners and administrators to work for local boards. There may be relatively few qualified people available. In addition, those who are qualified may not wish to relocate to small or isolated areas. Furthermore, increased local staffing for administration may increase overall costs.

2.3 Existing Models of Health Reform Across Canada

A variety of health reforms are being adopted across Canada. With the exception of a few provinces, most jurisdictions are still in the process of evolving their model of health reform. Even in provinces where reforms have gone the furthest, such as Alberta, Saskatchewan, Québec and New Brunswick, the change process is still in place. An example of change occurring during the process of reform can be seen in British Columbia. The original concept in British Columbia was to have two layers

of regional bodies, Regional Boards (RHBs) and Community Health Councils (CHCs) with the emphasis for local delivery being with the CHCs. This has recently changed to one layer of mixed RHBs and CHCs with less than half of the geographic units originally envisioned. Thus, reforms continue to change and evolve over time.

Because of this continuing evolution, it has been difficult for analysts to pin down and describe health reforms. However, the following provides what is believed to be a reasonably current summary of reforms across Canada and the impact of reforms on Continuing Care services, i.e., Long Term Care and Home Care, at the provincial and regional levels. In addition to Acute Care and physician services, Continuing Care is a major component of the health care service delivery system for seniors.

The three most westerly provinces, British Columbia, Alberta and Saskatchewan, have adopted a reasonably classic model of devolution. Regional Boards have been established (mostly with appointed members at this point), and political and administrative authority has been, or will be, devolved to these Regional Boards. Alberta and Saskatchewan have moved relatively quickly to implement regionalization and have already devolved staff and funding to the Regions. However, mental health and substance abuse are still provincial level programs in Alberta. British Columbia has recently completed devolving staff and resources to its regions.

In Saskatchewan, the former Continuing Care Division was eliminated, and the functional responsibility for these services was integrated with community health. Similarly, the director positions for Long Term Care and Home Care were eliminated in Alberta, and their functions were incorporated into other areas. In British Columbia, the Continuing Care Division was recently eliminated, but a new Assistant Deputy Minister (ADM) level position was created for Acute and Continuing Care. Thus, a specific structure for Continuing Care has been maintained in British Columbia. The key staff under the new ADM are Regional Directors responsible for both Acute and Continuing Care on a macro regional basis.

The shift of resources to community services has, however, continued during the process of reform. For example, in Saskatchewan, Home Care expenditures increased from $31.7 million in the 1991/92 fiscal year to $65 million in fiscal 1996/97 (excluding Northern Home Care). The increase for long term residential care was much more modest going from $230.6 million to $248.2 million from fiscal 1991/92 to fiscal 1996/97. It is also a positive sign that the province of Alberta is conducting a major review of Continuing Care, in conjunction with representatives from its Regional Boards. This review will include consideration of revisions to existing assessment and client classification instruments and the development of performance measures to assess the efficacy of services.

It appears that there has been a reduction in staff in Alberta and Saskatchewan within Continuing Care at the provincial level. For example, Saskatchewan Health reduced its overall staffing from 2,350 employees in 1990 to 640 in 1996. Similar changes occurred in Alberta. However, both jurisdictions have had quite strongly entrenched Continuing Care systems, and it appears that, at least in the larger regions, the concept of Continuing Care has been maintained at the regional level. For example, the Edmonton and Calgary Health Boards both have Directors for what are essentially residential Long Term Care and Home Care. While there have been some changes in personnel, there still appears to be a strong Continuing Care presence at the Regional Board level in British Columbia as well.

Manitoba initially adopted a regional model for its northern health services, a much more modest approach to regionalization, but more recently has moved to more comprehensive regional reforms. Manitoba has also undergone other forms of health reform. For example, in 1993 Manitoba Health had an Assistant Deputy Minister level position for Continuing Care. This position was later changed to an Assistant Deputy Minister for Community Services. This reflects another current trend in health reforms in Canada, that of an increased emphasis on public/community health and primary care, broadly defined to include primary care physicians, public health and community health (i.e., all non-institutional services).

Ontario has not adopted regional reforms. The District Health Councils (DHCs) continue to be advisory bodies. Ontario has instituted a review of hospitals to institute downsizing and amalgamations as appropriate.

Ontario is focusing on a range of matters related to better integration and systems alignment. It is looking at enhanced primary care models. These models focus on family practitioners, and some models include the full range of community and home based services (i.e., non-institutional care). The other option under active consideration in Ontario is Integrated Health Systems (IHSs) which are vertically integrated models that can contain the full range of services from home based care to specialized care in an acute care setting.

The Government of Ontario has also recently announced major changes to the way health and social services will be organized, delivered and financed. In Continuing Care, Community Care Access Centres will serve as the single point of entry to services. In addition, some public health services have been transferred to the municipal level. This initiative can be seen as a kind of partial devolution of responsibility for health care to municipalities, rather than devolution to health regions as has been the practice in other jurisdictions. The Ontario Ministry of Health is planning to initiate a Quality Council to ensure a high standard of service delivery.

Québec has had a type of regional model for some time with a regional board structure and community health centres or CLSCs. Greater authority has been given to the regional boards over the past years. Recently, the government of Québec has expressed interest in an integrated service delivery model for the elderly developed by a consortium of university based researchers. The model is called *systèm de soins intégrés pour personnes âgés en pert d'autonomie* (SIPA) or the system of integrated care for the frail elderly. This model provides for an integrated system of service delivery with single entry and ongoing case management for a full range of community and facility based Long Term Care and Home Care services. An innovative aspect of this project is that it may be funded on a capitation basis. The Montréal regional health and social services board has expressed interest in developing one or more demonstration projects using the SIPA model. Finally,

there has been a major re-structuring of seven hospitals in the Montréal area which has included the closure of some hospitals.

New Brunswick was the first province to adopt health reforms when it amalgamated over 50 hospital boards into seven regions, each with its own Regional Hospital Board. (One region has two boards, one English and one French.) Each board is responsible for the operation of hospitals in its region. This is a kind of mixed model and does not represent regional reforms *per se*. Rather it is a kind of amalgamation of independent service agencies in one sector, i.e., hospitals. More recently, steps have also been taken to change 12 Family and Community Social Services Regions into seven regions to match the seven hospital regions. In addition, aspects of mental health services from Mental Health Programs have been integrated with the Extra-Mural Program and Family and Community Social Services to provide a coordinated approach to the delivery of residential and community based services for the elderly.

Nova Scotia has moved to implement four Regional Health Boards using a devolution model of regionalization. However, responsibilities for Long Term Care and Home Care have not yet been delegated to these Boards due to current efforts to implement a more comprehensive single point of entry system at the provincial level before devolving responsibility to the Regional Boards. There are also four separate "non-designated organizations" which are tertiary services. A major restructuring of the hospitals in the Halifax-Dartmouth area has occurred as well.

Prince Edward Island has adopted five regions on a devolution model which, like in Québec, cover both health and social services, and it has started an external evaluation of its reform process. However, with the election of a Conservative government in the fall of 1996, the Health and Community Services Agency, which was established to provide oversight to the regionalization process, and under which the regions were legally constituted, is to be re-integrated into the Department of Health and Social Services. At present, the regional boards remain in place. Support for the boards has been expressed during a community consultation process. In addition, the government of PEI is in the process of establishing a Seniors Advisory Council.

Newfoundland has instituted eight Health Boards for hospitals, health centres and nursing homes, and four community Health Boards for community and public health services. There does not appear to have been a major shift away from Continuing Care administrative structures at the provincial level in Newfoundland, or in Atlantic Canada, so far.

2.4 Discussion

It appears from the above that the concept of Continuing Care and the best practices for a Continuing Care model[5] may be in some jeopardy as a consequence of health reforms in Canada. The elimination of senior Continuing Care positions in the organizational structures of Alberta, Saskatchewan, Manitoba, and to some extent British Columbia, is a cause for concern. Reductions in the level of institutional memory and expertise in Continuing Care at the provincial level may be an inadvertent by-product of two forces, regionalization and the focus on primary care/community models of service delivery. It does appear to be a hopeful sign, however, that Continuing Care is still considered a major product line of the health care system at the Regional level. There are several other encouraging signs: there is a major review of Continuing Care in Alberta which seems to be supporting most components of the best practices model of Continuing Care; provinces such as Saskatchewan have increased funding to Home Care; and the province of Québec is looking at an integrated model of Continuing Care services.

While one can only speculate at this time on the possible impacts of health reforms on seniors, given the lack of existing evaluations, there are at least some potential implications which can be discussed. To the extent that they can be effectively implemented, the reform initiatives discussed above should have positive consequences. Better and more integrated methods of service delivery should result in less duplication of effort and more "seamless" and "transparent" care delivery for seniors who require services from a range of providers. For example, seniors who leave hospital but need some further support should routinely have Home Care services arranged as part of the hospital discharge process. Providing services through more local administrative structures such as Regional Boards, Primary Care agencies or Integrated Health Systems should allow for more input by seniors at the local level. For example, seniors may be elected or appointed to the Boards of such

organizations and should be able to have an active voice in care related polices and practices. A greater emphasis on quality, holistic prevention and wellness should also have positive consequences. This may allow seniors to avoid hospital care and should allow them to live productive lives in the community for longer periods of time.

However, there are also possible risks in reforms which may result in some negative consequences for seniors. Reform initiatives appear to have relied on structural solutions to what are, at least in part, operational and quality related issues (e.g., enhanced coordination of services and improved service quality), instead of focusing on these issues directly. Suboptimal policies or practices (e.g., amount of staff training) may continue to remain in place or may be exacerbated by reforms and by restraint in overall funding levels. Seniors want to be treated with dignity and respect by competent and caring providers. They also value many of the more "social" aspects of service delivery such as transportation, housing and subsidies for eyeglasses, dentures, hearing aids and so on. Reform initiatives may not impact on these matters directly.

The combination of what has been essentially restructuring, rather than actual reform, and tight budgets can have serious negative consequences for seniors. A great deal of time, energy and resources are required to develop and implement reforms. This puts pressure on limited management and professional resources which could be used in other ways to enhance service delivery. Hospital downsizing may mean that hospital staff have to do more with less. They may or may not receive the needed training to cope with the pressures of moving people through the system more quickly and of taking on added responsibilities. Having fewer and more harried staff may reduce the amount of "caring" that providers can give to seniors. If good coordination mechanisms are not in place, seniors may be discharged from hospital without adequate home and community based supports. Similarly, hospitals may begin to rely more on "casual," lower cost staff to provide service to save money. This may again have negative impacts on care.

If the administration of health care is restructured into smaller units such as Regional Boards, but other Ministries or Departments are not, then it may be even more difficult to bring about needed

policy changes. A Regional Board, Primary Care agency or Integrated Health System may have less ability than a Ministry of Health to negotiate policy changes with centrally organized Ministries in regard to matters such as transportation, housing and other social subsidies.

At present, the jurisdictions which are more advanced in the reform process seem to be shifting from a restructuring phase to a real reform phase of change. In addition, with a balanced budget at the federal level, fiscal pressures may ease over the coming years. On balance, while the restructuring phase has been difficult, there is room for optimism about the future. The eventual implementation of a primary care model should increase the level of coordination among community based service providers. The province of Alberta is engaged in a major initiative to outline a more integrated model of Continuing Care and is revising its assessment and classification systems to improve the quality of service delivery. Alberta is also looking at developing and instituting a system of performance measures which will allow the government, and seniors, to have better information on the quality of care, the level of service coordination and so on. This will improve accountability. Ontario has introduced Community Care Access Centres to provide a single point of entry into Continuing Care. This should greatly reduce any confusion about what services are available, how to access service and so on. Québec through SIPA is also engaged in improving the service delivery system for seniors. New Brunswick significantly reduced facility waiting lists when it introduced single entry a few years ago, and Nova Scotia is developing a single entry model for a wide range of health and social service clientele. These are just a few of the positive reform initiatives which are currently under way. Thus, there is hope for the future. However, seniors and others need to be vigilant to ensure that those in the health industry also continue to work to improve services on the front lines.

3. PERCEPTIONS OF SENIORS ABOUT THE HEALTH CARE SYSTEM

3.1 Introduction

As has been noted, NACA wanted to ensure that the views of seniors were appropriately reflected in the evaluation framework and key indicators. In order to ensure that this would be the case, three steps were taken. A literature review was conducted to see what had been published in the professional literature about seniors' perceptions of what would constitute an appropriate health care system. An analysis was conducted of data from the Health Canada Supplement of the 1994 National Population Health Survey to find out about seniors' perceptions of the existing health system. In order to hear directly from seniors, NACA members, working with Dr. Elaine Gallagher of the School of Nursing at the University of Victoria, conducted one-on-one interviews with seniors and informal caregivers from across Canada. In addition, consultations were held by Dr. Gallagher with two groups of seniors to elicit their views.

3.2 Literature Review

3.2.1 Introduction

A comprehensive literature review of seniors' perceptions about the health care system was conducted using four major library data bases (MEDLINE, CINAHL, Health Star and Age Line). It was found that while there is some literature on the topic of client satisfaction with services, there is almost no Canadian literature on seniors' perceptions about health care systems and service delivery. There was also relatively little material on this topic in the international literature.

3.2.2 Quality of Care

This section will provide some illustrative findings from the literature about satisfaction with care. In Canada, Hollander and his colleagues (1993)[6] reported on a 1987 British Columbia study of client satisfaction with facility and homemaker services in an unpublished manuscript. They found that 96% of respondents were satisfied with the care they received in their Long Term Care facility, and 94% of community dwelling clients were satisfied with Homemaker services. On a five point scale,

facility clients' responses averaged 4.62 when they rated 16 aspects of care. The lowest score was 3.65 for food, and the highest was 4.75 for the friendliness of nurses. The average satisfaction score for responses given by key client contacts such as family members was 4.72. The average satisfaction rating by Homemaker clients was 4.68 for seven aspects of care. The highest score, 4.91, was for the friendliness of the Homemakers, and the lowest score, 4.13, was for the amount of time the Homemakers spent in the home.

High levels of satisfaction with care were also reported by Penning and Chappell (1996)[7] in a recent study of Home Support clients in Victoria, B.C. They found that 79% of Home Support clients in Victoria were very satisfied with the quality of all of the services they received. In addition, 18% were somewhat satisfied for a total satisfaction rate of 97%, a rate similar to that found by Hollander and his colleagues (1993). Penning and Chappell also found that 89% of clients were very satisfied with the costs of care and that 8% were somewhat satisfied, for a total of 97%.

Durand, Krueger, Chambers, Grek and Charles (1995)[8] reported findings from the Canadian Study of Health and Aging on informal caregiver dissatisfaction in regard to clients receiving community based Long Term Care (i.e., home care and home support). Most of the reasons for dissatisfaction in this study related to factors other than the quality of care itself. The three primary predictors of caregiver dissatisfaction were the senior behaving disruptively, the caregiver not living with the senior, and the senior having some impairment in daily living activities. In addition it was found that there was more caregiver dissatisfaction when care was directed to the informal caregiver, or to both the caregiver and senior. Where care was provided only to the client and not the caregiver, the level of caregiver satisfaction was relatively high; 84% of informal caregivers did not report problems with the services delivered.

The quality of care was studied in Finland by Laitinen (1994).[9] Laitinen analyzed the level of satisfaction of clients, their relatives, and their informal caregivers with care in a hospital, a geriatric unit, and a nursing home for persons 75 years of age or older and found reasonably high satisfaction scores (3.9-4.7 on a five point scale). However, the sample sizes in this study were quite small.

Kasper and Riley (1992)[10] studied the satisfaction with care of elderly Medicare beneficiaries in fee-for-service care and Health Maintenance Organizations (HMOs) in the United States and found average satisfaction scores of 15.6 and 15.1, respectively, on an 18 point scale. Kruzich, Clinton and Kelber (1992)[11] studied the levels of satisfaction with care services of residents of long term care facilities in Wisconsin and found that client satisfaction was related to facility characteristics (i.e., staff turnover, wage and benefit levels, perceptions of nurses' fairness, and the extent to which clients could personalize their own rooms). Philp and Ghosh (1992)[12] found high levels of satisfaction among the clients of a geriatric day hospital in Great Britain.

3.2.3 Perceptions and Attitudes Toward Services

An Optima study conducted in Canada in 1991 for Health Canada[13] revealed that seniors found independence and quality of life to be very important and that they should be reflected in the care programs seniors receive. Independence means making one's own decisions and being treated with respect and dignity. Independence is also related to more basic factors such as health, finances and mobility. Quality of life for seniors involves support, human warmth and caring. Quality of life is related to health, financial security, transportation, housing, and elements of personal security. These are the basic elements of independence. Thus, quality of life and independence are strongly linked. Seniors were found to be aware, and appreciative, of the health and social benefits they receive as Canadians and saw holding on to what they already have as a key priority. In terms of improvements, seniors noted that they would like to have more home support options, more palliative care, and more services to deal with problems associated with the mental health of seniors. They also noted an interest in a range of ancillary services not currently covered, or not fully covered, by the health care systems such as financial help with glasses, dentures, hearing aids and medical devices. Improved transportation and more affordable housing in community based locations were also of interest to seniors, as was better information about existing services.

An internal Health Canada report prepared in 1990 analyzed issues raised in letters by seniors to Health Canada. The report notes that seniors were frustrated with differences in provincial policies for eye glasses and hearing aids. In addition, seniors noted that while they received insulin for free,

they had to pay for the needles they needed to self-administer the insulin. Similarly, they were concerned that while there might be coverage for the cost of drugs in provincial drug programs, they still had to pay the pharmacy dispensing fee. Another area of concern was coverage for dental care as most seniors considered dental care to be a necessary medical service. Seniors were also concerned that they might not receive the Home Support services (homemakers, aids, etc.) that they required, and that the availability of Home Support services differed across jurisdictions.

McConnell (1990)[14] has noted that coverage for Long Term Care has emerged as an important public policy issue in the United States. In a survey of persons 45 years of age and over, some 70% of Americans ranked Long Term Care as a major priority area for federal spending. The next highest priority areas were aid to the homeless and low-income housing. The environment was ranked as a priority by just under 40% of respondents, and defense was ranked as a priority by about 20% of respondents.

3.3 Findings from the 1994 National Population Health Survey

3.3.1 Introduction

A search was conducted of the major health and social surveys conducted since 1985. It was found that relatively few surveys had health policy or health systems related questions. It was also found that surveys which had such questions had relatively few questions. However, a reasonable number of questions on health services and health policy were found on the 1994 National Population Health Survey (NPHS), in the Health Canada Supplement to the survey. The Health Canada Supplement to the NPHS contains a series of questions about the actual and potential use of different health services and about perceptions of the Canadian health care system. These data were specifically analyzed for this project and are presented below.

3.3.2 Potential Use of Alternative Care Services

As noted earlier in this report, there are those who would like to see health services organized into a primary care model with community health centres. Findings from the NPHS seem to indicate that seniors are somewhat more conservative or traditional in their preferences about how health services

are delivered than non-seniors. Table 3 presents data on the willingness of respondents to receive services in alternative settings, or by health providers other than physicians.

TABLE 3: Acceptability of Alternative Methods of Service Provisions

Type of Alternative	Age (% responding Yes)		
	20-64 (%)	65+ (%)	Number of cases (n)
Would you go to a health clinic, rather than a hospital or private doctor's office, for a routine physical exam?	44	29.8	11961
Would you allow nurse to give you a routine physical exam?	76.7	68.2	4905*
Would you go to a health clinic rather than a hospital or private doctor's office to receive shots (immunization)?	67.9	51.1	11985

* This question only includes respondents who stated that they would go to a health clinic for a routine physical exam.

Seniors were considerably less likely to say that they would be willing to receive services in a health clinic rather than in a hospital or a doctor's office. Looking at seniors' responses only, each set of questions in this section was also analyzed by gender, level of education (less than high school, some high school, high school graduation, and above high school graduation), annual household income ($1-$14,999, $15,000-$29,999 and $30,000 or more), restrictions on daily activities (yes or no), place of residence (urban or rural), and self-reported health status (excellent, very good, good, fair or poor). In terms of the questions about the acceptability of alternative care options among seniors, women were somewhat less likely to accept the alternative models than men. However, those with higher household incomes ($30,000 per year) were more likely to find care in a clinic acceptable than those with lower incomes. Finally, rural seniors were more likely to accept a physical exam by a nurse (75.7% vs. 65.8%) while urban seniors were more likely to accept receiving shots at a clinic (65.4% vs. 34.6%).

3.3.3 Seniors' Perceptions of Canada's Health Care System

The survey contained three questions asking respondents to rate health services. These are listed below:

- Overall how would you rate health care in Canada?
- How would you rate the health care system in your province?
- How would you rate the quality of health care that you personally have received in the past 12 months?

Respondents were asked to rate health care as excellent, good, fair or poor. There was little difference by age of respondent to these questions. Some 85% - 92% of all respondents rated health care highly. Seniors with higher household incomes, higher levels of education and higher self-rated health status were more likely to rate the health care system as excellent than those with lower household incomes, lower education levels and lower self-rated health status. However, there was little difference between these groups when the "excellent" and "good" responses were combined.

Respondents were asked to identify what they thought were the major strengths of Canada's health care system. Table 4 provides an overview of which factors were identified by Canadians as the main strengths of the system. There was relatively little difference by age. The two major strengths identified were low cost and universality. Rural seniors were more likely than their urban counterparts to identify "low cost" (63.3% vs. 53.1%) and portability (31.1% vs. 26.2%) as strengths of the system. However, urban seniors rated universality more highly (52.3% vs. 45.7%). Seniors with lower levels of income and education, and lower self-rated health status, were more likely to identify "low cost" as a strength of the system. Seniors with higher income and education levels and higher self-rated health status were more likely to identify universality and the range of services as major strengths.

TABLE 4: The Main Strengths of Canada's Health Care System

Areas of Strength	Age (% Yes)		
	20-64 (%)	65+ (%)	Total (%)
No Cost/Low Cost	60.1	57.9	59.7
Access (Urban and Rural)	37.6	30.5	36.2
Quality of Care	36.3	38	36.6
Universality (Available to Rich and Poor)	57.7	51.5	56.5
Portability (Available when visiting other province)	22.4	18.5	21.6
Free to Choose Doctor and Location of Treatment	38.8	37.5	38.5
Range of Services Available	27.2	22	26.2

n=11,877

Respondents were also asked to identify what they thought were the main weaknesses of Canada's health system. Table 5 presents the findings about the perceived weaknesses of our health system. The biggest weakness identified was that the system was too easy to misuse or abuse. The only major difference among seniors on this question was that those with higher household incomes, levels of education, and self-reported health status were more likely to state that a main weakness of the system was that it could be too easily misused and abused. The second biggest weakness was the length of time it takes between calling for an appointment and being seen. Those under 65 years of age considered this to be more of a problem. It is also interesting to note that 17.6% of respondents cited cost as a weakness. In this light, it should be remembered that only about 70% of all health spending is currently paid for by governments in Canada; thus citizens pay directly, or through insurance, for over one quarter of the costs of health care.

TABLE 5: The Main Weaknesses of Canada's Health Care System

Areas of Weakness	Age (% Yes)		
	20-64 (%)	65+ (%)	Total (%)
Too Long Between Call and Appointment or Visit	29.2	20.1	27.4
Quality of Care	8.3	5.6	7.8
Lack of Available Services	14.8	9.1	13.7
Cost of System	18.7	13.5	17.6
Lack of Technology/Equipment/Test	9.8	3.8	8.6
Too Easy to Misuse/Abuse	53.3	51.8	53

n=11,873

3.4 Seniors' Expectations Regarding Health Care

3.4.1 Introduction

As noted earlier, two major initiatives were undertaken to obtain the views of seniors about what would constitute appropriate health care. One initiative was for NACA members to interview seniors and their caregivers. The second initiative was for Dr. Elaine Gallagher of the School of Nursing at the University of Victoria to consult with two groups of seniors. The data from both initiatives were analyzed by Dr. Gallagher. A wide range of opinions and comments were obtained from the seniors who participated in these initiatives. These consultations were essentially an exploration of the views of seniors. However, the frequency with which the same themes emerged suggests that the findings provide a good reflection of seniors' and caregivers' values and expectations. The consistency of findings also indicates that there may be merit in replicating these initiatives using a more scientifically rigorous methodology. The findings from the interviews and focus groups are presented in this section.

3.4.2 Overview of Issues of Importance to Seniors

In regard to the two initiatives noted above, it was not possible to obtain comparative rankings for all of the issues of importance for seniors. Therefore, all responses, or response categories, are included in the analysis in this section. Table 6 presents an overview of the topic areas identified in the NACA interviews and the consultations. It should be noted that although similar themes were identified by seniors and caregivers in the NACA interviews and the consultations (e.g., service continuity and predictability) the themes, and responses, were not exactly the same for each group.

In regard to the NACA interviews, the issues of importance to seniors are grouped into three main areas, i.e., services, service providers, and the health care system. These three areas are characterized by the "expectations" held by seniors. The NACA interviews were conducted with 10 seniors and with eight informal caregivers. The two consultations consisted of eight and four seniors, respectively. The quoted material in the following section comes from both the NACA interviews and the consultations.[15, 16]

3.4.3 Overview of Seniors' Comments

While it is possible to group the main themes and values expressed by seniors, for analytical purposes, doing so does not present an adequate sense of how seniors feel about their health care system. Therefore, this section will provide a real world context and, hopefully, will allow the reader to better understand the care issues with which seniors with disabilities are engaged on a daily basis.

Seniors evaluate the effectiveness of **services** by asking whether the intervention worked and whether the symptoms went away. Seniors were clear about what constituted sufficient services. They did not want more done to them than was necessary. Examples were also given of what constituted ineffective services from the perspective of seniors, i.e., things that did not work well.

> "From the beginning, a nurse came a few times to see how I'm going to have a bath. She didn't help very much. Just, watch, watch, watch."

TABLE 6: Issues of Importance to Seniors in Regard to their Health Care

1. NACA INTERVIEWS

A. Issues of Importance to Seniors

1. Expectations Related to Services
   - A1.1 Effective
   - A1.2 Sufficient
   - A1.3 Available
   - A1.4 Continuous, predictable
   - A1.5 Acceptable
   - A1.6 Flexible, adaptable
   - A1.7 Affordable
   - A1.8 Accessible
   - A1.9 Timely

2. Expectations Related to Service Providers
   - A2.1 Clear communication
   - A2.2 Caring
   - A2.3 Goes the extra mile
   - A2.4 Anticipated future needs

3. Expectations Related to the Health Care System
   - A3.1 Coordination
   - A3.2 Changes observed from Health Care reform
   - A3.3 Concerns about medications

B. Issues of Importance to Informal Caregivers

1. Expectations Related to Services
   - B1.1 Continuous, predictable
   - B1.2 Family centered
   - B1.3 Acceptable
   - B1.4 Timely
   - B1.5 Affordable
   - B1.6 If affordable, available

2. Expectations Related to Service Providers
   - B2.1 Clear communication
   - B2.2 Competent
   - B2.3 Well trained
   - B2.4 Shows interest
   - B2.5 Makes enough time
   - B2.6 Caring and respectful
   - B2.7 Goes the extra mile
   - B2.8 Anticipates future needs

3. Expectations Related to the Health Care System
   - B3.1 Coordination and monitoring
   - B3.2 Available range of services
   - B3.3 Appropriate settings for care
   - B3.4 Opportunities for self-managed care

2. CONSULTATIONS

1. Major Themes
   - C1.1 Communication
   - C1.2 Caring, respect and dignity
   - C1.3 Control and choice
   - C1.4 Coordination
   - C1.5 Personal responsibility for health
   - C1.6 Competence and training
   - C1.7 Continuity and predictability

1. Major Themes (Cont'd)
   - C1.8 Cost, entitlements and willingness to pay
   - C1.9 Time and timeliness
   - C1.10 Transportation
   - C1.11 Appropriate settings
   - C1.12 Staffing issues
   - C1.13 Expanded roles for volunteers
   - C1.14 Issues regarding medications

Seniors were clear that it was important for them to know that services were available when needed. They also noted that there was inadequate monitoring after a serious illness.

> "I have not received any services since a month after my discharge from hospital. Since then I have not seen anyone. No visit, no telephone call .... In case of complications I have to go to the emergency at the hospital."

Seniors expressed a need for continuity and predictability in service provision. It is particularly important for seniors to have the same Home Care worker. One respondent who had the same worker expressed satisfaction when asked about the importance of having the same person over time.

> "It's important to me because if I have one that has to come in unexpectedly, I find it hard because I have to tell her where everything is and you know explain things, what has to be done and where we do them, and so I think it helps to have the same one."

Some services are not acceptable to older people. This may be because of cultural or other basic values. Seniors also emphasized the importance of matters such as food.

> "I don't make fancy meals, I have a good healthy meal. They [Meals-on-Wheels] bring me stuff they bring for other people. But I don't like that. They don't bring my food."

Seniors noted that flexibility and adaptability in service provision were important to them. They also expressed concern over the costs of some services, particularly medications, and some indicated that they simply did not have the means to pay for needed medications.

Seniors noted that services should be accessible in the sense that health professionals should come to their home to care for them, that they should not have to wait to see their doctor, and that service providers should be in close physical proximity. They also noted that there should be an appropriate coordination and timing of services.

> "The workers are all very good. But it's the times and the changing all the time ... the time they come now is terrible. Eleven to twelve. You see I have to get these feet done before I put my shoes on. If they don't come before twelve o'clock, I can't wear my shoes ... that means I can't walk or anything in the morning."

> "I'd just come home from the hospital. I knew I didn't want them to come at 1:00 p.m. Once I get dressed I'd probably have to get undressed for those people to come. It's too hard on me getting changed.

Seniors and their informal caregivers had certain values pertaining to **service providers**. They felt that communication should be clear and honest. They appreciated phone calls about the results of tests. Timeliness of communication was also important. Seniors noted the need for better communication in emergency wards where people may be left unattended for some time.

> "[left] for two or more hours with no one saying anything about what is going on. If they would just tell you, when they have a more life-threatening situation to deal with, you would understand and relax a bit."

It is important for seniors to be looked after in a caring climate. It is also important for seniors to be heard, and to be believed. Seniors can tell when they are not being treated in a caring way.

> "They wanted the money and that's all there was to it. They didn't give a damn about the care of the clients."

Seniors gave examples of what it means to be treated with caring and respect.

> "Calling me by my name, asking me for feedback like if something they are doing feels painful, taking me seriously or listening carefully when I tell him (the doctor) about my symptoms, having homemakers and others recognize and respect my values."

Seniors valued care staff "going the extra mile," i.e., providing service which is above the expected or normal level, such as extra teaching, extra provision of supplies, home visits from doctors or just extra time. Seniors thought it was important for care providers to assess seniors' future needs and

plan for them in advance. They also felt that they should have some control and choice over these plans. Seniors placed a high value on the competence and training of staff.

In terms of values related to the **health care system,** seniors thought that there should be good coordination between the various components of the health care system. For example, one senior claimed that three or four people she knew had been sent home from the hospital with no coordination with Home Care in the past week alone. She noted that Home Care coordination is particularly important after day surgery as "older people may be too drowsy to understand instructions."

Seniors were asked directly about the impact of health reforms. Some had faith that the changes would be for the best but others were less optimistic. Seniors noted that they felt it was harder to see their doctor and that it was harder to get a bed in a hospital.

> "Yes, for the last seven years things have changed a lot .... Now the change doesn't make sense neither for people in hospital or at home. Medication is too expensive."
>
> "There have been many changes and I am not pleased with them. They make me angry."
>
> "I was spoiled the old way. That was perfect. The new system is not good in my opinion."

Seniors also expressed concerns about their medications and the way they had been affected by recent changes.

> "I had trouble when the government changed one of my pills, the ("brand name"), they changed it to a generic one and I had terrible diarrhea all night long and everything for two weeks."

As noted earlier there were some seniors who supported reform and blamed the media for raising fears among the public.

> "There is some fear among the public; coming from the media. The media often scare senior citizens ... we must give a chance to what is going on right now in medicine .... They do a lot that they couldn't do years ago."

While many of the concerns expressed by informal caregivers mirror those of seniors themselves, there were some unique areas of concern for this group as well. One area caregivers felt was important was that care should be family centered.

> "Maybe another dimension is it's not just me in a jam with my wife, it's our children as well."

Caregivers noted that they may have to get actively involved in the care of their loved one even if they are in the formal care system.

> "Then I got going over there quite frequently, because I found she wasn't getting enough nourishment. She was getting thin. And I was taking in supplements, food supplements for her."

In terms of values related to service provision, informal care providers placed a high value on the competence and training of the staff in the formal care system. A high value was also placed on care providers who showed an interest in improving the family member's quality of life.

> "So that's what you want is people who are interested in the case and want to do continual caregiving for older patients. Not this idea of put them on something to keep them quiet and keep them controlled but give them some quality of life, that's what you want."

Caregivers appreciated staff who had enough time to properly attend and care for their loved ones.

> "When the homemakers take him out shopping they stop for a coffee and talk to him real thoughtfully, like he's a person."

In terms of values related to the health care system, caregivers were concerned about the lack of coordination between services. They also noted that services should be flexible and adaptable, that there should be an adequate range of services and that there should not be service gaps. They also thought there should be a full range of back up services to support informal caregivers.

> "It would be money down the drain for everybody (if I'd had to put her in a home sooner). And we'll be finishing off, truncating a person's life prematurely and unnecessarily. You're dealing with a person's life here. Every day I keep her at home, I feel I am giving her another day of normal life.

3.5 Discussion

A number of important lessons were learned in comparing the goals of reforms to the expectations of seniors and of caregivers. Perhaps the most important and critical finding was the degree of disjuncture between the apparent goals of reform and the goals of seniors. The difference was manifested at several different levels. While the reform process has focused on structure and process variables, in the belief that improvements in these areas will lead to improved outcomes, seniors have focused on health outcomes directly. Even when there are similarities in goals, one may need to go through a process of analysis to establish the logic chain which reconciles two related but different goals. An example of reconciling different goals can be seen using the reform goal of greater democratization and seniors' expectations about the outcomes of care. The logic chain linking greater democratization and better care would be something like this: local boards are established ☞ seniors will have an opportunity to be represented on these decision making bodies, ☞ seniors will be able to influence board decisions to meet their goals ☞ these decisions will be acted upon by local administrators ☞ the decisions will be appropriately implemented at the front lines of health care to the benefit of seniors.

In addition to differences in goals there are also differences in perspective. These differences lead to differences in the methods one may use to evaluate reforms. Reforms have been primarily established from a structural and administrative perspective. This means that there is a focus on larger groups, on equity across groups and individuals, on formal policies, and so on, i.e., a focus

on the general or the collectivity. This perspective is likely to be congruent with a more quantitative methodological approach to analysis. While the above matters may also be of interest to seniors, their focus seems to be more individualistic and particularistic. Seniors' primary concerns are with the care provided at the front lines, and with the experiential meaning of that care. Thus, to evaluate the issues of concern to seniors, one may need to adopt a combination of both quantitative and qualitative approaches to analysis. For example, qualitative analysis could be used to study the following issues: the extent of "caring" provided by staff; the degree to which seniors' dignity is maintained in the process of receiving care; the extent to which care providers listen to, and respect, the input of seniors into their care; and the perceptions of seniors, based on their own experience, of how care has changed in conjunction with the implementation of reforms.

FOOTNOTES

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