The Independence of the Elderly and Issues of Long-Term Care and Institutionalization

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I represent the Ontario Coalition of Senior Citizens Organizations and I am privileged to address this Conference from the perspective of the Canadian senior consumer. I will be considering on the topic of seniors' independence and the issue of long-term care and institutionalization.

I. A PROFILE OF CANADIAN SENIORS TODAY

It might be well at this point to give a picture of Canada's current seniors. Today's generation of Canadian seniors is unique in history. They have experienced more changes and at a more accelerated rate in social, economic, cultural and technological life than any generation before them. They have lived through the devastation of two world wars and they remember life pre-automobile, radio, television and airplane. They have seen the advent and diffusion of the computer, aero-space programs and atomic energy development and even the ultimate technology with the capability to end all development — the atomic bomb. Today's Canadian seniors are more sophisticated, more articulate, more vocal, better educated and healthier and wealthier than their parents were, and their children will be more so.

While the younger generations were born into, and are accustomed to, a rapidly changing environment and social milieu, these tremendous changes have created unprecedented challenges to seniors to adapt or cope. Victor Marshall,[1] one of Canada's leading social gerontologists, suggests that the major gerontological problem is the ability of the aging individual to adapt to changing society. Marshall maintains there is a lack of fit between demands of society and the needs of the older individual and that this lack of fit could be remedied by either adapting the society to the needs of the individual or by adapting the older individual to the new form of modern society. Marshall questions: "How can we explain the reasons why some older people are better adjusted than others to society?" He answers: "three major determinants of adaptation of the older individual are: health, wealth and social support."

Marshall argues that older Canadians do not form a major poverty group per se, but as a sub-group, those seniors in the lowest income quintile can expect to live 6.3 fewer years for males and 2.8 fewer years for females. Also, men in this group can expect to live free from disability 14.5 fewer years and women 7.5 fewer years than those in higher income groups. Poverty, then, leads to profound inequities in health and life for Canadians.

As for the factor of social support in the realm of adapting and coping, it is well known that 75 to 80% of care-giving services to community-dwelling elderly comes from the informal sector — volunteers of family and friends who, as care-givers provide health-care services of daily living activities which allow older persons to remain in their own home and live independently. Informal social support for ethnic elderly is particularly stronger when care-givers are from their own ethnic community, in a familiar environment of language, tradition and culture.

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1. V. W. Marshall, "Aging into the 21st Century" (Plenary Address to Congress, Ottawa, April 1980).

Canada is facing rapid demographic changes in its elderly population. Those 65 years of age and older are increasing at the rate of 3% per year compared to an increase of 1% per year for the total population. The elderly will increase from 2.6 million or 12% to 5.8 million or 16% by 2021 (in 1965 it was only 8%). By the year 2031 Canada's elderly will have increased to over 25% of the population and one out of three adults will be a senior. The fastest growing segment of the senior population is those 85 years of age and older, most of whom are single women. It is glaringly evident that the "old" old are the most vulnerable to chronic ailments — the group which requires the most intensive care.

Another consideration is the increasing dependency ratio of the elderly population to the working-age population, due to the continuing low birth-rate. The social support base for our future elderly will be changing. This dramatic social change forebodes new and threatening problems for Canada's future seniors. Two workers will be required to support one senior.

Turning to the other side of change or adaptation mentioned — the adaptation of society to the aging individual — Marshall concludes:

> *If we are to produce a society that is good for and to the older people* [...] *we can't wait* [...] *Conditions of the future are produced by the actions we take now.* [...] *We cannot continue to make policy decisions which ignore the reality of our aging society.* [...] *The ability of the aged themselves to cope with the adversities and uncertainties of the future is strong. The aged are, on the whole, competent. With the assistance of family and community based support, they and all of us have the opportunity to put into place a social system which will help us all to age in dignity.*

Some further demographic statistics to consider — as recently as 1986, 91% of Canada's 2.7 million elderly lived in private households. Of seniors 65 to 74, only 3% lived in nursing homes or other institutions (in 1981 this figure was 3.4%). However, for those 75 years and over, 17% lived in institutions (in 1981 this figure was over 19%). Twenty-five percent of the elderly lived alone (this proportion was only 12% 25 years ago).

The foregoing statistics lead to the question of seniors' independence. During the 1980s a number of studies focussed on the needs of Canadian seniors. These studies were in response to increasing government and public awareness of seniors' issues. Nearly all these studies emphasized and pointed to one conclusion: *seniors wanted to live in their own home and in their own community as long as possible.*

II. SENIORS' INDEPENDENCE

In 1988, the federal government department Health and Welfare Canada, in recognition of the importance of seniors' independence, launched the Seniors' Independence Program.[2] This initiative provides funds aimed at improving the quality of life and independence for Canadian seniors. As part of this program, a major study was conducted by the National Advisory Council on Aging (NACA).[3] A mail-in questionnaire survey entitled "Independent Living — What are the Barriers?" was sent to seniors and seniors organizations throughout Canada.

The questionnaire addressed the nature and scope of the barriers encountered by seniors in maintaining an independent life-style in their communities. The data from the questionnaire/survey resulted in two reports: *Understanding Seniors' Independence, Report No. 1: The Barriers and Suggestions for Action* and *Understanding Seniors' Independence, Report No. 2: Coping Strategies*. The conclusions in these reports are summarized below.

A. Report No. 1: The Barriers and Suggestions for Action[4]

Independence is possible for seniors, if they can rely on a network or supportive interpersonal relationships and have access to the resources and services they need. Potential barriers identified most frequently as being problematic included, in order of importance, the following:

a) *Physical health: sensory loss, impairment, musculoskeletal and joint disorders, pain, incontinence and problems related to the improper use of medications.*

b) *Emotional/mental health: loneliness, anxiety or fear, depression and dementia.*

c) *Transportation and mobility: lack of transportation, hazardous conditions, special problems of handicapped seniors and special problems of rural seniors.*

d) *Community-based support services: inadequate quantity of services and organization of services, and problems related to service providers.*

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2. Health and Welfare Canada, News release, "Federal government to Support Independence for Seniors" (8 February 1988).

3. National Advisory Council on Aging, "Independent Living — What are the Barriers" in *Expression* (Ottawa: NACA, Spring 1988).

4. National Advisory Council on Aging, *Understanding Seniors' Independence*, *Report No. 1: The Barriers and Suggestions for Action* (Ottawa: NACA, May 1989) at 81.

e) Safety and security: anxiety and fear and lack of knowledge about safety measures and devices.

f) Housing: housing that is not adapted to seniors' needs, the high cost of housing and home maintenance and the lack of innovative choices in residential arrangements

g) Communications and information: the lack of information about how to get needed services and communication barriers due to language, culture and physical disabilities.

B. Report No. 2: Coping Strategies[5]

The coping strategies reported were classified: self-reliance (actions without explicit help of others); informal network; formal services; and cannot cope. In the problems with both physical health and emotional/mental health self-reliant strategies were most often reported.

Of the remaining problem areas, transportation, community-based services, and communications and information the informal network of family and friends was frequently mentioned as coping support. However, housing and safety problems were reported as almost exclusively dependant on formal services for coping strategies.

In addition to informal network of family and friends, frequently, with intense care-giving demands formal services will be required, including: income replacement, social support services, respite care for care-giver, nursing and medical care. Where the burden of care-giving cannot safely be provided in the home, based on professional assessment and consent of the patient and family, the alternative of institutional care (chronic care, nursing home or home for the aged) must be considered.

Let us now move to the areas of long-term care for seniors with reference to institutionalization and alternatives based on community-based services and home support services. Although delivery of health care is a mandate of the provinces, the processes of delivery and administration of long-term care varies from province to province. For the purposes of this discussion, only the Province of Ontario will be considered.

The concerns about Ontario's extended care program were expressed in The New Agenda:

> *A perception that many elderly persons who are in extended care facilities could be maintained in their homes if appropriate services were available* [...] *and* [...] *that there is lack of consistency in the extended care program three different types of providers operate under different legislation, funding mechanisms,*

5. National Advisory Council on Aging, *Understanding Seniors' Independence, Report No. 2: Coping Strategies* (Ottawa: NACA, May 1990) at 4.

staffing requirements, standards of care and inspection procedures. Two ministries are involved in the funding and direction of extended care — the Ministry of Health and the Ministry of Social and Community Services. Further:

[...] *The central theme of our proposal is to improve the health and functional status of the elderly through enhanced community care services, and, thereby reduce preventable and inappropriate institutionalization.*[6]

That was in 1986 and to date the government is still conducting studies on this issue.

III. INSTITUTIONALIZATION

Canada has the highest rate of institutionalization of the elderly in the world at 9.5% and Ontario has the highest rate in Canada at over 12%, compared to Australia at 6.0%, the United States at 5.3%, and the United Kingdom at 5%. Institutional care for Ontario's seniors provides a sheltered environment for those unable to remain within the community and includes: chronic care hospitals, nursing homes for those requiring at least 1-1\2 hours per day of nursing care, and residential and/or nursing care in homes for the aged.[7]

IV. CHRONIC CARE HOSPITALS

The long-term chronic care program is described:

when a person requires care as an in-patient for a chronic disorder for a long period of time and the care includes the need for regular frequent care by skilled professionals. After 60 days the patient contributes for room and board (based on OAS/GIS income). Health care costs are paid by the government under OHIP.[8]

Ontario's chronic hospital care is the most expensive per capita health cost. In the fiscal year 1986/87, over 10,000 elderly patients were admitted to chronic care hospitals for a total government expense of about $425 million, at an average cost of over $40,000 per patient.[9]

There is an argument for increased chronic care and extended-care that is supported by sensational media headlines: "Shortage of Beds Nearing Crisis"; "Bed-Blockers Blamed

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6. Ministry for Senior Citizens' Affairs, *A New Agenda*: Health and Social Services Strategies for Ontario's Seniors (Toronto, 1986) at 16.
7. Secretariat for Social Development, *The Elderly in Ontario: An Agenda for the 90s* (Toronto, 1981) at 14.
8. Ministry for Senior Citizens' Affairs, *Guide for Senior Citizens, Services and Programs in Ontario* (Toronto, 1987) at 29.
9. Ontario Ministry of Health Annual Report 1986/87 (Toronto, September 1987).

for Emergency Ward Crunch"; "Patients Wait in Line for a Bed at Metro's Crowded Hospitals". These are horror stories about critically-ill patients waiting in over-crowded halls for acute-care treatment and even surgery while beds are occupied by elderly patients awaiting discharge to more intensive and long-term care.[10] It is estimated that 13.9% of acute care hospital beds in Toronto are occupied by patients waiting for long-term placement.[11]

V. NURSING HOMES

The *Nursing Homes Act of 1972* and legislated amendments of 1987[12] regulate the standards of Ontario nursing homes operated under license by the Ministry of Health. They are for people who require at least 1-1/2 hours per day of direct nursing care, but whose condition does not warrant hospitalization. Licensed nursing homes must provide at least 75% of their nursing beds for extended-care (Levels III and IV care). Residents pay for their accommodations, the same as chronic-care hospital patients.[13]

The amendments to the *Nursing Homes Act* obviously resulted from demands for reform. Generally, the public perception of nursing homes was negative. Many nursing home "horror" stories have encouraged these negative reactions: "Elderly Under Care, Abused, Neglected"; "Residents of Nursing Homes May Get Rights Bill"; "Ontario Takes the Bleak Homes to Task".[14] One nursing home spent only $1.90 per day for each resident on food and only $400 for the entire year on recreation.

In 1987 approximately 30,000 people resided in 333 nursing homes in Ontario entailing a total government expense of about $347 million. Over 90% of these homes, all privately operated, were "for profit", with 28 homes under the auspices of "non-profit" charitable or service organizations.

VI. HOMES FOR THE AGED

These homes are for seniors who cannot live on their own because they need some daily care. They are operated either by municipalities or by non-profit charitable organizations, funded by the Ministry of Community and Social Services. Most of the homes are approved for extended care and payment for residence is on a co-payment basis similar to that of nursing homes. In the fiscal year 1986/87 there were over 28,000 beds in 182 homes at a total government expense of approximately $281 million.

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10. "Special Report", *The Toronto Star* (April 4, 1988), A1.
11. Aronson, Marshall and Sulman, "Patients Awaiting Discharge from Hospital", (1987) Aging in Canada, at 539-540.
12. *Nursing Homes Act, 1972*, S.O. 1972, c. 11, *Nursing Homes Amendment Act, 1987*, S.O. 1987, c. 20.
13. *Supra* note 6 at 1-2.
14. *The Toronto Star* (November 4, 1986) (February 13, 1988).

The process of institutionalization is such that it discourages independence and creates an environment of increased dependency. Residents soon lose all motivation for individual expression or choice of actions for their own lives. Institutions by their very nature tend to promote autocracy and subjugate individuality.

Of course, statistics can be manipulated to favour certain positions or be self serving, but consider this: the annual report of the Ministry of Health for the year 1988/89 showed that of a total health care budget of $12.5 billion, over 52% or $6.5 billion was spent on institutional care, while 4% or $534 million was spent on community health programs (in 1986/87 these figures were $1.16 billion and $183 million). According to 1987/88 budget estimates, expenditures for long-term care totalled $2 billion, of which $750 million was spent for 58,000 nursing homes and homes for the aged beds, and $773 million for 12,000 chronic care beds and $451 million for in-home/community services. This is in addition to services committed by individuals, families, volunteers and charitable organizations.

This now brings us back to community-based support services.

VII. COMMUNITY-BASED SUPPORT SERVICES

> *Community support services are based on the concept that people, regardless of age or ability, should be able to maintain the maximum degree of independence in their lives. That people differ from one another and these differences need to be taken into account when services are provided* [...].[15]

Community support services in Ontario include: homemakers and nurses services, home support, integrated homemakers, home care, elderly persons' centres, and senior citizens housing.

We have already discussed some aspects of community support services and the contribution of these services to the independence and coping support for seniors. As always, the problem of cost-effectiveness and the need for expansion of these services in the coming decades to provide for the rapidly increasing senior population must be faced.

> *The propriety of community support services is generally agreed in that it is cost effective — you get value for the money. Timely services prevent or delay the need for more expensive services such as hospitals or other institutions.*[16]

The debate of expanded community services versus institutionalization has been going on for over a decade, and continues today. In 1982, National Health and Welfare reported:

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15. National Advisory Council on Aging, *Towards a Community Support Policy for Canadians* (Ottawa: NACA, 1986) at 7.

16. *Ibid.* at 23.

> *Viewing community services as an alternative support system to institutional care* [...] *involves the allocation of resources to the different systems and the delivery of services on an integrated basis. If community care of the aged is to become the preferred support, the imbalance between expenditures related to homes for special care and home and support services will require redress. Governments, non-governmental agencies, and society in general will be grappling with this issue for some time.*[17]

Further considerations regarding the issue of institutionalization and home support services are offered. In a brief to government ministries, Concerned Friends said:

> *Nursing homes and homes for the aged, as well as chronic care hospitals have been grossly over-utilized in Ontario as a convenient way to deal with social problems presented by aging and disability. With the highest rate of institutionalization in the world, we have a responsibility to examine other options.* [...] *Assistance with activities of daily living which can best be provided in a person's own home* [...].[18]

Cope Schwenger, in his critique of health care says:

> *So much is being spent on hospital care and rapidly increasing medical technology that alternatives to hospitals* [...] *are starved for funds.* [...] *Lip service is given to so-called "home support services"* [...] *It is not generally recognized by many that programs such as Meals on Wheels, friendly visiting and visiting homemakers are keeping older people out of institutions and that they may be even more cost effective* [...] *there is said to be too little support at all government levels for care outside of institutions and still too little interest in alternatives* [...].[19]

In 1986, a joint study by the Ministry of Health and the Ministry of Community and Social Services found that 50% of all residents in nursing homes required less than 1-1/2 hours of daily care. This was confirmed by a recent study commissioned by the Ministry for Senior Citizens' Affairs. The study findings show:

> *More than half the residents were 85 or over; almost 74% were women; there is no statistically significant difference between nursing homes and homes for the aged in the average amount of direct care required; 17% of the total sample of residents required at least 3 hours of direct care per day, 55% of the residents required less than 90 minutes of care per day; the remaining 28% required between 90 minutes and 3 hours of care per day.*[20]

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17. Health and Welfare Canada, *Canadian Governmental Report on Aging,* (Ottawa: Public Affairs Directorate, 1982) at 104.

18. Concerned Friends, *Brief on Omnibus Extended Care Act* (December 1987) at 10-11.

19. C. Schwenger in *Aging in Canada* at 512.

20. Price Waterhouse — Medicus, *Report on Direct Nursing Requirements of Extended Care Residents in Ontario* (Ministry for Senior Citizens' Affairs, March 1988).

Current policies in both areas of institutional care and community support services are in need of change and improvement to adequately meet the needs of Ontario's aging society. The issue appears to be whether to choose between limited community support services and institutional services. The question remains: "Are institutions the destiny of Ontario's seniors?"

This discussion of the issues of Ontario's seniors' health care needs, institutionalization and long-term care is appropriately timely. On May 12th 1990, the late Ontario Liberal government published *Strategies for Change — Comprehensive Reform of Ontario's Long-term Care Services*. This publication followed the legislative announcement of December 6, 1989 by the Honourable Charles Beer, former Minister of Community and Social Services, after nearly two years of studies by a planning task force of the Ministries of Health, Community and Social Services, Senior Citizens' Affairs, and for Disabled People.

In *Strategies for Change* the government committed itself to:

a) Create service access agencies to facilitate the process of admittance to long-term care and appropriate home support services.

b) Create new funding systems for nursing homes and homes for the aged according to level of care.

c) Create a single inter-Ministry to manage long-term care system — A Community Health and Support Services Division under a Deputy Minister jointly responsible to Ministries of Health and Community and Social Services.

d) Integrate and consolidate in-home services.

e) Enhance community support services.

f) Enhance support for informal care-givers.

The principles of reform are stated to reflect the value upon which the reform of long-term care and support services would be based, as follows:

a) Individualization: the belief that the dignity and uniqueness of each individual must be recognized and respected.

b) Independence in Choice: independence involves the individual's freedom to make life-style decisions. Services should be designed in ways that maximize the independence and choice of consumers.

c) Community Living: provide services and options that will assist people to live in their own homes and communities whenever possible.

d) Service Accessability: access should be simplified and integrated in order to be responsive to individual needs.

e) *Support for Informal Care-Givers: to recognize the important role that family members, friends, neighbours and volunteers perform in providing assistance to the elderly individual.*

f) *Affordability: the cost of services should be shared fairly among levels of government and consumers.*

The government committed itself to $2 billion new funding over the next six years for long-term care reform — $52 million for the current year, rising to $640 million annually in year 1996-97. A co-payment system (not including costs of health or personal service) for services provided (housekeeping, board, lodging, and chargeable community support services). People whose income is less than $20,000 will not be required to pay.

The report *Strategies for Change* points out many of the inadequacies and weaknesses of the present long-term care system and offers many suggestions for improvement and design of new in-home services programs to ensure that the objectives of greater flexibility and responsiveness to individual needs are achieved. It envisions a fully-developed, integrated and co-ordinated service system, built upon a base of existing programs and services.

VIII. RESPONSES BY ORGANIZATIONS OF SERVICE TO SENIORS AND DISABLED PEOPLE

There has been a deluge of responses from concerned senior citizens' organizations and advocacy groups on behalf of the elderly and the disabled. Three of these responses are considered below:

The Advocacy Centre for the Elderly (ACE) wrote:

Although the changes in the services will take many years to complete, the government is intending to start action on the reforms in the immediate future. Some changes have already been introduced, such as the development of the community and health services division. Other reforms will require legislative change. Although many of the reforms appear to be positive changes to the confusing and complex social service system, and the principles of reform as expressed are welcomed by consumers, many questions need to be asked about the details [...]. *How will the agency to act as the Service Access Organization (SAO) be chosen? Will consumers be required to access the services only through the local SOA or will they be able to obtain access to a single service such as Meals on Wheels by contacting that service directly? What if the consumer disagrees with the assessment or the service plan by SAO? What mechanisms will be established to ensure that consumers may have plans or assessments reviewed if they disagree? Will consumers be required to take the first available bed in an institution, or will they be able to exercise their right of choice of facility? Will the payment scheme take into account financial*

problems faced by spouses when one enters an institution but the other remains in their own home?[21]

The Ontario Coalition of Senior Citizens Organizations (OCSCO) believes that universal, no-cost access to in-home services is a basic right. It believes that the proposed policy of co-payment would strain the few resources of many consumers of long-term care services and prevent many from obtaining the services they need. They recommend a voluntary board of directors from the community, with consumer representation, to ensure that the SAO is accountable to public interests. An independent appeal process must be openly available in the process so that consumers have an avenue to challenge assessments of their needs and the amount of services made available. Assessments should be conducted by a multi-disciplinary approach to appraise an individual's social support network and coping strengths.

OCSCO supports a change of funding based on an individual's care needs as they change over time. Rehabilitative programs and a continuum of care which supports discharge into the community or supportive housing options is strongly suggested by OCSCO. OCSCO appreciates the goal and intent of *Strategies for Changes* and recommends the enhancing of these concepts to make a more humane long-term care system for consumers so that their quality of living and dying is improved.

The Ontario Coalition of Non-profit Organizations Working with Seniors recommended that the Ministers appoint an advisory committee on legislation governing long-term care services with representation from consumers, care providers, and representatives of hospital and public health associations; that the ministers establish policies that clarify the respective roles of not-for-profit agencies and the commercial companies involved in long-term care; that the government develop mechanisms to fund existing human resource shortages by improving training, recruitment and retention of personnel required by the long-term care reform program; that they institute a policy whereby service access organizations be administered by community boards with balanced representation from consumers, providers and municipal and provincial appointees; that they establish and fund an advisory committee to establish a process for insuring quality of service delivery in the long-term care system; that they implement recommendations of the Report of the Inter-Ministerial Committee on Visiting Homemakers' Services to provide training for homemakers, to set homemaker wages at $11.50 per hour as soon as possible in order for agencies to comply with the province's pay equity legislation, and to examine the option of tax incentives to support family care-givers.

The government's long-term care reform budget will increase by $460 million by the year 1996 and in the current fiscal year the government would provide an additional $52 million dollars. It is certainly a significant increase in funding for the $2 billion a year long-term care system. However, according to calculations, our conservative estimate is that it would cost at least $850 million over the next four years to comply with the above factors. Yet the government's commitment is for only $460 million over the next 7 years. We do welcome *Strategies for Change* as an excellent starting point for dialogue with the partners of long-term care delivery.

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21. Advocacy Centre for the Elderly, Newsletter (Summer 1990).

At the risk of being criticized by the medical profession, I feel the urge to express my shock at the lack of knowledge and consideration some physicians have shown with respect to the needs of residents in long-term care facilities, and older people in general. I am referring to the tendency of some physicians to rush and inadequately explain care and treatment to older people. Furthermore, a number of physicians have large numbers of residents in one or more long-term care facilities and as a result, we conclude that these physicians are unable to provide proper individualized care and treatment. Professionals, particularly the medical profession, are often not aware of services for seniors or seniors' needs, yet their approval may be required to access services. Negative attitudes towards older people and aging are often held by professionals, para-professionals, and even seniors themselves. It irks us sometimes to hear a doctor say, when he is faced by a medical complaint from an elderly person, "What do you expect at your age?"

CONCLUSION

Overall, we must enable older adults *to retain their independence*; to maintain control over their own lives through greater involvement in decisions about and for themselves and their environment through increased knowledge and information; to have better access to a broad range of community-based services and resources. For as long as possible, the elderly must be kept out of institutions, not only to reduce costs, but, more importantly, to enhance their quality of life. When institutional care is required, the appropriate level of care, with emphasis on the quality of life, must be ensured for all senior Canadians.[22]

As senior activists, we have continually advanced the cause of long-term care with focus on in-home support services. In spite of many studies, planning task forces and consultations by governmental bodies, institutionalization still flourishes in Ontario. Although government has repeatedly expressed support for community and home support services, and in particular, their cost-effectiveness, it appears that this was only lip service. There have been forces against any legislation or implementation of home support programs as alternatives to institutionalization. Ontario retains the dubious distinction of having the highest rate of institutionalization in the world.

Now, for the first time, a study has been presented by a governmental body recommending and endorsing many of the policies we have been lobbying for. Ontario and Canada have a historical opportunity of establishing the world model for long-term care for their elderly, to enable them to live out their living and dying in dignity. We are all on this body as law-makers and life-giving care providers to advance the causes of independence for your elders. Now, with the possible change in attitude by our government and with the installation of the new NDP provincial government, maybe, maybe, perhaps our vision will materialize.

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22. Institute for Health Care Facilities of the Future, *Future Health Care Delivery, Aging* (Ottawa, 1988) at xi.