LONG TERM CARE –
IN LIMBO or WORSE?

A report on seven public forums
during
February/March 2001
about the
FUTURE OF LONG-TERM CARE

Presented by a Group of Organizations
Concerned with the Future
of Long Term Care

May 2001

TABLE OF CONTENTS

FOREWORD

PENETRATING THE SILENCE

A recent poll [1] showing **80% of Ontario residents worried about long term care** came as no surprise, because the number of stakeholders in our long- term care system continues to grow. The sixty-five-plus generation, together with their adult children, the "Boomers", is becoming a larger and larger segment of the population. In a sense, the **"Boomers"** are **double stakeholders**. They will be forced to pick up the slack if the care for their ageing parents is inadequate**;** and they have reason to be worried about what care will be available for themselves in their own approaching old age.

Despite this widespread concern, the Ontario **government**, which unwillingly inherited the Long Term Care Act, Bill 173, from its predecessor, **continues to treat long-term care as a stepchild**. Community Care **Access Centres**, which now control in-home care as well as placement into long-term care facilities, were **established** in 1997 **without legislative authority** of any kind. As "creatures of government policy", they were given **directions** about priorities for care and eligibility criteria. They were given **fixed budgets**, which, year after year, have proved inadequate to the population's needs. And finally, in May 1999, they were given **limits on the hours of care** to be allowed monthly to each client.

It was only because they wanted to make their **limits on hours of care impossible to appeal** that the government finally proclaimed the Long Term Act, and wrote these limits into Regulation 386/99. At the same time, **in July 1999**, letters were sent to all the Access Centres, advising that they were **"approved agencies"** under the Act, **effective June 1997** [2].

Most provisions of the Act are completely at odds with the system of Community Care Access Centres. But the Act is still the only legislation on the books with respect to community-based long-term care. The writing of a new Act has been clearly indicated, and has been confirmed by the Health Minister in letters to all organizations that inquired, along with promises of public consultation on its contents. But the **introduction** of a new Act has been **postponed** again and again, and in the current session of the legislature there has been, once more, nothing to suggest that the new Act will be forthcoming. And, of course, there has been no sign of public consultation.

In the mean time, **long-term care**, which had been understood for years as in-home care to enable seniors to "age in place," **has been re-defined** by the reiteration of the new term for nursing homes and homes for the aged. They are now called "long-term care facilities" and we have been told that the contemplated new legislation will follow this new definition by combining, in one Act, facility care and in-home care.

[1] See Environics poll April 2001**.**

[2] All this ***ad-hocery*** was needed to avoid the possibility that clients might go to the Health Services Appeals Board and appeal successfully for the hours of service they actually needed**.** The first appeal was from a young man who had become paralyzed in an accident. He appealed for the hours of care needed to allow him to continue at Brock University, where he was an honour student. This appeal was settled out of court. It was when a second appeal came forward that the Government decided to put a legal limit on hours of care**.**

Deeply concerned about the future of long-term care, a group of community organizations, came together last Fall. Our first act was to ask the Health Ministry once again when the promised public consultations were to take place and when we could expect to see a draft of the new legislation or some form of consultation document. Receiving nothing but a vague acknowledgement to this inquiry, we concluded that we ourselves would have to undertake the needed public consultation.

Hence, we planned a series of public forums on the future of long-term care in seven centres throughout the province (Thunder Bay, Sault Ste.Marie, Windsor, Hamilton, Ottawa, Kingston and Toronto). Additional forums have since been held or are being planned in Oshawa, London, and Cornwall. Despite the inclement weather, a total of over 800 persons attended these forums. Without benefit of any consultation document defining the Government's intentions, we had to invite participants to address the question: **"What should be the essential elements in a new long-term care Act?"** The Opposition Health and Long Term Care Critics participated in each of the forums, which were held during February and March 2001. This Report highlights what was said at these forums, both by local organizations making written submissions and by individuals, telling their own experiences with long-term care, as well as their ideas about how to improve it.

We heard from:

- ✓ individual **staff members** working in long-term care facilities and in home care,
- ✓ **unions** representing these workers,
- ✓ individuals whose **parents**, spouses or siblings reside in long-term care **facilities** or are receiving **care in their own homes,**
- ✓ community **organizations** who focus on quality of care issues in **facilities** and in **home care**,
- ✓ community **organizations** that include this focus among other concerns for the well-being of **seniors** and the chronically ill,
- ✓ community **organizations** who include this focus among other concerns about our **health care** system,
- ✓ i**ndividuals** who are now or have in the past been **recipients of home care,**
- ✓ **individuals** with disabilities.

The Report contains the **problems** in **facility care**, in **home care** and in **other aspects** of long-term care, as seen by participants. It ends by summarizing their **recommendations** for improving the future of long term care.

EXECUTIVE SUMMARY

Speakers at all seven forums spoke about problems in long-term care facilities, in community care and in other aspects of long term care. While we have divided the report by subject and summarized the recommendations at the end, this executive summary combines the problems presented with the solutions recommended by participants in seven cities**.**

1. ENTITLEMENT TO CARE

All presenters agreed on the need for a clause in the new Long Term Bill declaring that **seniors, and others in need of long term care, are ENTITLED to the care they need,** whether they are residing in long term care facilities or in their own homes. There was strong reaction against the current qualifying of this entitlement with phrases like "in relation to available resources," since the availability of resources is always the choice of the government of the day. With long-term facility care and home care to be covered by the same legislation, Ontario residents must also have the right to choose to stay in their own homes and receive the supportive care they need. **No one must be forced into institutional care.**

2. RESTORATION OF STAFFING RATIOS IN NURSING HOMES

Individuals with relatives in long-term care facilities, front-line nurses, health care aides in facilites and the unions representing these workers, all deplored the deregulation of staffing ratios in nursing homes. They recommended that restored ratios should include the **round-the-clock presence of enough registered nurses** as well as a sufficient number of health care aides, to provide the hours of care **current** residents need**.** The former ratios (2.25 hours per day per resident plus one registered nurse) are not high enough to meet the needs of today's older and sicker residents.

3. ATTRACTION AND RETENTION OF NURSES, HEALTH CARE AIDES AND PERSONAL SUPPORT WORKERS/HOMEMAKERS

The presenters referred to above, as well as community care nurses, personal support workers and home care recipients were also unanimous in reporting **a serious human resources crisis** in both facility and in-home care. Nurses in long- term care facilities and in home care are paid less than nurses in hospitals, while health care aides providing in-home care earn less than they are qualified to earn as health care aides in facilities. Both facilities and Community Care Access Centres are already finding it difficult, sometimes impossible, to fill empty positions. It appeared essential, therefore, that **compensation, benefits and working conditions be equalized (for those with equal qualifications) across the entire health care system.**

4. INSPECTION OF LONG TERM CARE FACILITIES AND WHISTLEBLOWER PROTECTION

Presenters from all those involved in facility care noted that "The legislation must require **at least one surprise inspection per year**. Inspectors must **consult with frontline workers** and these inspections must be subject to appeal from any resident or employee if the report doesn't order the correction of all problems." Frontline staff must be assured that they can report candidly and safely if they see conditions that threaten the well being of their residents.

5. PRIVATIZATION

There was consensus among most presenters that the process of **privatization in the long-term care sector must stop**. Its harmful effects on care recipients are seen everywhere.

- ✓ The **track record of privately owned nursing homes**, now freed from regulation of their staffing ratios, inspires no confidence that they will ever consider the meeting of patients' needs more important than their "bottom line." There is, therefore, no reason to believe that the 80% of tenders for new beds that have been awarded to private corporations, will be any more adequately staffed than the facilities they are presently operating. We may well have new beds in which residents become incontinent because no one has time to answer their calls when they need to go the bathroom. Residents in the new beds may well continue to stay in their chairs all day because no one has time to get them up for a little exercise. And they may continue to be fed "pureed food, all mixed up, cooled with milk, served with heaping tablespoons" in the fifteen minutes that are allotted for feeding residents in Thunder Bay nursing homes.
- ✓ The **"managed competition"** process in the awarding of contracts for in-home service was intended, and has succeeded, in greatly **increasing the number of for-profit agencies** with contracts to provide home care. Meanwhile our traditional non-profit agencies have sometimes been forced into bankruptcy when they lose home care contracts they have been fulfilling faithfully for many years. For those receiving care in their homes, the effect has been to virtually **eliminate the chance that the same worker will come to their homes regularly.** Staff kept on casual status, calling in each day for the day's assignments is cost-effective for the provider and, therefore, has a much better effect on the "bottom line."
- ✓ Many presenters also voiced principled objection to seeing **tax dollars, "our money,"** going into the pockets of profit-making businesses. In the case of long-term care facilities, our money will not only continue to subsidize their operations, but will also **cover the cost of building the new facilities.**

6. GOVERNANCE AND PUBLIC ACCOUNTABILIY

New Long Term Care legislation must include **uniform rules for the governance** of Community Care Access Centres and make their operations open and accountable to the communities they serve. Wherever they live, Ontario residents should know how to become members of their local Access Centre and how to become members of its board of directors. Board meetings should be open to the public and the present **exemption** of Access Centres **from the Freedom of Information regulations** must be **ended.** Community members should be able to find out the details of all contracts awarded by the Centre**.**

7. COMPLAINTS PROCEDURES

In long term facilities, many presenters felt it essential that family councils be established, and recognized by the facilities operators, so that problems can be addressed effectively. It was also emphasized by seniors' organizations that seniors and others dependent on care to remain in their homes need to **feel completely safe** in reporting any violation of their rights, as well as unsatisfactory service..

8. REGULATION OF RETIREMENT HOMES

Inadequate home-care (including waiting lists for supportive care), and long waiting lists for regulated facilities, are, it was pointed out, forcing low-income seniors to seek the cheapest retirement homes they can find, when they can no longer manage with the amount of care they are receiving. New Long Term Care legislation must provide for **defining care homes, determining the standards of care required for licensing and the means for inspecting and enforcing these standards.**

9. IN-HOME RESPITE

Presenters from many areas spoke of inadequate support given to family care-givers. Access Centres have been instructed that any professional or non-professional going in to

the home is to be considered respite for the care-giver. But experience has shown that there is no effective respite unless the worker coming into the home is specially trained to care for medically complex or cognitively impaired patients. While such training is available, no incentives exist for personal support workers/health care aides to take this extra training. Differential rates of pay must be established for workers with specialized training**.**

10. FUNDING

While we all know that throwing money at a problem does not necessarily solve it, most of the problems revealed by presenters at the seven forums were clearly associated with inadequate funding**.**

- ✓ **The closing of acute care hospital beds** stands out as **the direct cause of the rationing and waiting lists for in-home care.** Despite the advice of the Health Services Restructuring Commission, the government **withdrew** $800 million dollars from the province's hospitals, **before** investing in the increased community resources, so clearly needed, to care for the patients being discharged sicker and quicker. The result has been that **Access Centre's have to use most of their still limited resources to care for sick post-hospital patients, leaving seniors who need supportive home care to go on waiting lists or into unregulated retirement homes**. Despite talk of increased funding to community care, the government's investment has yet to reach a level to meet population needs.
- ✓ **The closing of chronic care beds and the changed admission policies for chronic care hospitals** have created crisis conditions in long term care facilities. The crisis was exacerbated by the deregulating of staffing ratios. Nursing home operators saved money for their shareholders by not hiring additional staff, even though more staff were needed for their residents now needing heavier care. But we also heard over and over again that actual subsidies for long- term care facilities have failed to reflect the care levels of current residents.
- ✓ **The funding of long term care has been shifting more and more to the individuals** who depend on it or to their families. Families, to the best of their ability, pick up the slack when home care is inadequate and volunteer their time in nursing homes when there is not enough staff to give proper care to a relative residing there. But **family members**, most of them willing to help as much as they can, **can not always do it all**. If care recipients or their families have plenty of money, they can **purchase the needed extra care at home** or **hire an attendant** to stay with a facility resident and provide the care the staff has little time for. For seniors who have neither available family nor money, the luxury of purchased care is beyond their means. They can live at risk with inadequate care or look for an unregulated retirement home they can pay for with the total of their limited income

11. ACCOUNTABILITY

With the number of for-profit agencies now holding home care contracts, and the number of for-profit corporations awarded capital funding for the construction of new long-term care beds, many presenters felt **it is time for the Government to account to tax-payers for the amount of health care dollars going into private profits.**

SECTION I. THE PROBLEMS

A. IN FACILITY CARE

1. Reduction in Chronic Care Facility Beds

Presentations from the participants had varying points of view, but all agreed that residents in facilities today are older and sicker than they used to be and that staff are often too overburdened to give the quality of care they would like to give and the residents need. Many noted, as a clear sign of how critical the situation in facilities has become, the increasing number of paid attendants hired by residents' families to ensure their safety and comfort.

Many noted, as a clear sign of how critical the situation in facilities has become, the increasing number of paid attendants hired by residents' families to ensure their safety and comfort.

As pointed out by a number of presenters, the reduction in chronic care beds, and the refusal to admit any but the most medically complex patients into chronic care hospitals, is the direct cause of the **increasing number of heavy-care patients in nursing homes and homes for the aged**. One presenter, whose 90-year-old mother is a resident at Kipling Acres, had investigated a number of facilities in advance of her mother's need for placement. She found Kipling Acres, a municipal Home for the Aged in **TORONTO,** was far better than any of the private nursing homes she visited. Her observation, after her mother was admitted, was that **60% of the residents had Alzheimer's,** and usually a number of other chronic conditions. Her mother was not unusual in being legally blind, hearing impaired, with heart problems and diabetes in addition to her dementia.

A Registered Nurse, Sally Delaney who works in a nursing home in **KINCARDINE**, expressed grave concern about the funds available for HI-INTENSITY needs of nursing home residents. Sarah Delany told of an incident where a patient with several severe bed sores was transferred into her facility. What was required was an AirFlow mattress that would relieve the pressure and allow the sores to heal. **The red tape required to get approval for the expenditure of between $35 and $65 per day took over three weeks**, during which her wounds became so dangerous that she had to be sent to an acute care hospital. Only then was the AirFlow mattress supplied. Unfortunately the patient died a few days later. (We have since heard that this situation has been improved.)

"It is estimated that between 50% and 70% of residents in Long term Care facilities have dementia or cognitive impairment."

The **KINGSTON** Council on Ageing pointed out that "Over the past two decades, the **average age of long term care residents has increased from 73 to 86 years of age**. The typical resident today is not only older but also sicker when they enter a long term care facility."

”It is estimated that between 50% and 70% of residents in Long term Care facilities have dementia or cognitive impairment,” said James Dafoe, Executive Director Alzheimer’s Society, **WINDSOR-ESSEX,**

The Chronic Care/Long Term Care Committee of the Ontario Council of Hospital Unions observed that the changed admission policies in chronic care also increased the level of care needed by their hospital patients. They did a survey on the workload of staff in present and former chronic care hospitals. A random sample of 424 members was taken out of a total population of 2400 members in six hospitals and one nursing home, which had formerly been a chronic care hospital. A majority of those surveyed (54%) reported working before or after their paid hours, without pay. A similar number (57%) reported working during lunch breaks without pay. Almost half (47%) reported that they were working more unpaid overtime than four years earlier and 92% reported their workload is increasing. Among health care aides 96% thought that the increased load was affecting their own health.

At Perley-Rideau Veterans’ Health Care Centre, an LTC facility which used to be a chronic care hospital, 73% of workers surveyed reported working unpaid overtime and 100% reported an increased work load.

Particular attention was paid to the Perley Rideau Veterans’ Health Care Centre, a chronic care hospital in **OTTAWA** that was turned into a long term care facility, with a corresponding drop in its funding (from $200 per bed per day to $150 per bed per day). Workers there were clearly more liable to report unpaid overtime work (73% versus 53% for the survey of hospitals). The number reporting an increased workload was 100% (versus 90% for the hospitals).

In Windsor, CUPE Local 1132 urged “ the government to restore the number of chronic care beds to the 1993 level of 10,598 province-wide and that the funding be set at an adequate chronic care (complex continuing care) level.” CUPE Local 1132, Windsor-Essex.

2. THE RESCINDING OF REQUIRED STAFFING RATIOS

Each registered nurse in a long term care facility now looks after an average of 60 residents during a day shift and 100 resi - dents during a night shift.

Before the present government came into power, nursing homes were required to have sufficient staff to provide 2.25 daily hours of care for residents and a registered nurse on duty at all times. Both these requirements were rescinded at a time when chronic patients whose needs were not “medically complex” were already being directed to long term care facilities. The combination of unregulated staffing ratios with increased numbers of heavy care residents virtually guaranteed that understaffing would be chronic and sustained in for-profit nursing homes, while non-profit homes would be left struggling to maintain their higher standards.

On this issue, too, we heard from both individual staff members and individual concerned family members of residents, as well as from unions and community organizations. Olga Kremko, whose mother is now dying at Kipling Acres, observed that there was one health care aide for sixteen residents and one nurse for thirty-two residents at what she considered a superior facility. She noted that if one of the workers was ill, there was usually no temporary replacement; the rest of the staff, already overburdened, had to pick up the slack.

Residents are often becoming incontinent, just because no one has time to answer their calls when they need to go to the bathroom.

The Council on Aging in **KINGSTON** quoted the Ontario Association of Non Profit Homes and Services for Seniors as saying that "each registered nurse in a long term care facility now looks after an **average** of 60 residents during a day shift and 100 residents during a night shift."

The Ontario Coalition of Senior Citizens' Organizations pointed out that what happened most often after deregulation of staffing ratios was not so much layoffs but a failure to hire enough additional staff to care for the sicker residents they were now receiving.

A Registered Nurse from **BRAMPTON**, Deborah Brassard, told us that, from years of experience in long term care facilities, including six years on the Ministry's annual classification project, she has seen staff numbers remaining the same, while those entering the facility are older and sicker than ever before. "The bottom line", she said, was that "there is not enough money per resident to ensure adequate nursing care… those coming into homes now are physically and cognitively in need of a tremendous amount of support, requiring staff that are more skilled than ever." She pointed out that residents are often becoming incontinent, just because no one has time to answer their calls when they need to go to the bathroom.

Front-line workers in chronic care hospitals found that they often could not bathe their patients more than once a week and that they were lucky to be able to take a resident outdoors more than once a month. Even indoors many stayed in their wheel-chairs all day because no one had time to help them to their feet for a little exercise.

The Ontario Council of Hospital Unions' survey showed that their members in chronic care hospitals and in the converted nursing home often could not bathe their patients more than once a week and that they were lucky to be able to take a resident outdoors once a month. Even indoors many stayed in their wheelchairs all day, simply because nobody had time to help them to their feet for a little exercise. They also reported that five minutes a day was generally all the time they had to talk to a resident.

The Ontario Nurses' Association in **OTTAWA** also pointed to their members' reports of excessive caseloads and an inability to deliver sufficient patient care. They, too,

deplored the elimination of staffing ratios in the face of residents' increasingly acute care needs.

Marlene Tressler, a retired nurse, speaking for the Algoma Health Coalition told the forum in **SAULT STE.MARIE** that "Minimum 2.25 hours care per resident per day and a registered nurse on duty at all times must be restored in long term care facilities."

At the very least Long Term Care legislation should restore what the Harris government has removed: the minimum level of nursing and personal care at 2-1/4 hours per patient per day and at least one registered nurse at all times.

Patricia Jaggard, a Registered Nurse, told the **HAMILTON** forum "I care for the elderly, and I deal with increasingly complex cases that require more of my time. My residents require special care and attention daily, in order to meet their needs and their normal activities of daily living. Many residents have Alzheimer's disease, and are cognitively impaired. Some residents can be physically aggressive and very agitated. Some may require the use of special medical equipment."

"Family members sometimes find that staff does not appear to have time to feed residents or to take them to the bathroom when necessary." **THUNDER BAY** Patients' Rights Association.

Family Caregivers Action Network in **THUNDER BAY** stated to the forum: "The time-factors regarding nursing 'tasks' have become more important than the actual task – or time required, or taken, to care for a living person…. Food is pureed, all mixed up and cooled with milk, served with heaping tablespoons and approximately 15 minutes are allowed for the task….Staff do not have time to read charts, to get to know their residents: who is blind, a veteran, partially paralyzed, has Alzheimer's, or other special needs. There is no front-line nursing supervisor to guide them, to educate them, etc."

Food is pureed, all mixed up and cooled with milk, served with heaping table-spoons and approximately 15 minutes allotted for the task.

3. FUNDING

With approximately 56,000 Ontario residents, living in about 500 long term care facilities, presenters everywhere agreed that funding for long-term care facilities is not keeping up with care needs. Many argued that this is because the formula on which funding is based is a flawed one. The **KINGSTON** Council on Ageing quoted an estimate from the Ontario Association of Non Profit Homes and Services for Seniors that the shortfall is at least $230 million per year (now changed by OANHSS to $500 Million).

The Alzheimer's Society of **WINDSOR-ESSEX** County believes that the classification system has significant shortcomings: "It does not accurately capture the level of needs for people with Alzheimer's Disease or a related dementia. Nor does the tool accurately reflect the intensity of services needed or the degree of specialized expertise required for residents with limitations due to cognitive impairment and/or those who require behavioural interventions. It focuses on personal care needs and does not address the need for

specially trained staff, appropriate staffing levels or for mental health professionals such as psychologists, and does not provide any opportunity for the inclusion of stimulating and supportive activities." James A. Dafoe, Executive Director,

It is estimated by the Ontario Association of Non-profit Homes and Services for Seniors that the shortfall [in funding] is at least $500 million per year.

Deborah Brassard, the Registered Nurse from **BRAMPTON** described the funding system as "entirely paper-based. The amount of money each facility gets is totally based on its ability to adequately document each resident's nursing needs, i.e. how much assistance they need to dress, go to the bathroom, transfer etc. Ideally, as a person needs more nursing care, the facility should get more money. In reality, most facilities find their annual piece of the pie gets smaller, even though their residents' needs get greater and greater. Many facilities have had to cut staff to stay within budget….Others…may try cutting salaries or benefits or simply asking staff to work short when someone calls in sick."

The funding system is "entirely paper-based….As a person needs more care, the facility should get more money."

Wendy Pearson, an **OTTAWA** nurse working in an acute care hospital's Alternate Level of Care Ward, expressed great concern about how the shortened stays in acute care are impacting on the long term care sector. She said: "As a result of this quicker stay and sicker discharge, there is need for high assessment and clinical judgement in the health care providers in the long term care sector. Ultimately there needs to be a dramatic increase in the number of licensed, registered personnel to care for our frail elders."

The **THUNDER BAY** Patients' Rights Association stated in their presentation: "If funding level depends on assessment, then the tools used must be the best available. The Ministry should investigate the Resident Assessment Instrument (RAI-HIP) which is used in Ontario Chronic Care hospitals (including St. Joseph's Hospital in Thunder Bay), in U.S. nursing homes and in several other countries. It integrates assessment with the care planning process and, if staffs who use it are well trained, it has the potential to improve the quality of care."

"If funding level de-pends on assess- ment, then the tools used must be the best available."

4. ATTRACTION AND RETENTION OF LONG TERM CARE NURSES, HEALTH CARE AIDES AND PERSONAL SUPPORT WORKERS

> "[T]he biggest threat to our long term care and home care sectors – and indeed all health care sectors –is Ontario's nursing shortage…a shortage that grows with each passing day. We can't retain the nurses we have; many are within a few years of retiring, and many more are heading to greener pastures in the United States, where they are more appreciated, better compensated and are offered incentives for furthering their education." This appraisal of the human resource crisis, by an **OTTAWA** presenter from the Ontario Nurses Association, was echoed by a number of presenters.

Patricia Jaggard , a gerontological nurse from **HAMILTON** declared: "Funding must provide for adequate staffing and appropriate compensation and competitive wages for long term care nurses, because it is critical that gerontological nurses not be lost to [the attraction of higher salaries in] the acute care setting."

"Right across the board, from old to new nursing homes, there are multiple staff vacancies, both inhealth care aides and registered staff category."

Canadian Pensioners Concerned, stated at the **TORONTO** forum "There should be standard and adequate rates of pay and benefits for staff, equivalent to that paid in (acute care) hospitals."

Deborah Brassard also concludes that there are "not enough nurses out there to fill all the required positions, be it in hospitals or long term care facilities. Right across the board, from old to new nursing homes, there are multiple staff vacancies , both in the health care aide and registered staff category. But especially in the registered staff category. (When) the government slashed nurses in its downsizing and restructuring policies in recent years, many nurses left the field entirely."

At the Employment Insurance Board we see "many cases of voluntarily leaving of health care workers. Their duties have so increased in the past few years and they just can't handle it."

Bill Orr, a member of the Canadian Auto Workers National Pensioners, told the **TORONTO** forum that he sits "on an Employment Insurance Board and sees many "cases of **voluntary leaving of health care workers**. They are leaving because they can't handle the job any more…It's not for the money they are paid, which is disgraceful. But it is for the fact that **their duties have been so increased** in the past few years and they just can't handle it. They apply for Employment Insurance but they don't get it because they voluntarily left their jobs."

A presenter from the Dilico Ojibway Child and Family services in **THUNDER BAY** stated: "We would be able to attract more Aboriginal people to serve in their communities if we could offer full-time work."

5. INSPECTIONS AND ACCOUNTABILITY

"The same deficiencies appear in report after report for some facilities," stated Concerned Friends of Ontario Citizens in Care Facilities in **TORONTO.** They noted, in their annual Report Card for Ontario's Provincially Regulated Long Term Care Facilities (based on the Compliance Review System's report) that, [there were]recorded 414 violations of current standards in this review of 78 Compliance Reports. "In the past we have observed long term care facilities to be under enforcement for two years. In the meantime residents are living in sub-standard and often unsafe

conditions." Concerned Friends found that 39.6% of the violations were Nursing Service violations; 15.94% concerned environmental safety/hazard and security; 10.86% concerned environmental maintenance and 7.4% of the violations concerned medication. Included in these categories were such violations as "changes in weight were not evaluated and action not taken as required"; "resident did not receive medication and treatment as ordered by a physician"; "food and beverages not given to residents at a temperature and manner that promotes safety", "inadequate cooking temperatures", "residents not protected from hazardous products","residents call system and door alarm not working properly", "no organized program of infection control", "offensive odour build-up noted in resident's room and in dirty utility room".

In 78 Compliance Review reports, [of long-term care facilities]Concerned Friends found 414 violations, of which 39.6% were Nursing Service violations.

Speaking for the Ontario Nurses Association in **HAMILTON**, Joy Widawski said "[Increasing caseloads and complexity of care required] are the kinds of problems that should be exposed by inspections of long term care facilities by the Ministry of Health and Long term Care. However, we know that these inspections don't occur that frequently. And for the inspections that do occur, the Ministry doesn't require inspectors to consult with front-line care professionals or order the correction of any problems identified with the provision of care and accommodations. So, necessary changes may never be made. . . . The legislation must require that ministry inspectors conduct at least one surprise inspection of each long term facility in the province once a year. Inspectors must consult with front-line professionals, and reports from these inspections must be subject to appeal from any resident or employee of the home if the report doesn't order the correction of all problems."

"[Increasing case loads and the complexity of care required] are the kinds of problems yjay should be exposed by inspections of long-term care facilities….The Ministry does not require the inspectors to confer with front-line care professionals."

Canadian Pensioners Concerned stated in their **TORONTO** presentation: "Nursing Homes must have regular and unscheduled inspections and provincial standards of care must be enforced."

The Ontario Coalition of Senior Citizens Organizations stated that an important element in "guaranteeing adequate care for residents in facilities is that inspections of nursing homes, which are licensed, regulated and subsidized by the government, must become random and unannounced. The present system of making appointments for inspections has proved grossly inadequate in the maintaining of proper standards. The $1.2 billion dollars that is being invested in building new long term facility beds will not necessarily change this situation, especially since 80% of this investment is going to private, profit-making corporations."

Amani Oakley, speaking at the **TORONTO** forum on behalf of the Toronto Health Coalition and the Seniors' Alliance to Preserve Canada's Social Programs, pointed out how **difficult it is to hold nursing homes accountable for premature deaths of residents**.

When demanding medical records of a deceased resident, she has been told by managers that we "are not allowed to have the medical record of the person who died" nor is the next of kin."How do you kow that something has gone wrong in one of these facilities unless you have access to the medical records," she asked.

6. WHISTLEBLOWER PROTECTION

In addition to improved government inspection, an important source of information about standards of care in long term care facilities is the staff, some of whom attended our forums because they were so concerned about the conditions in their facility. A number of presenters pointed out that the government could hear a lot more about what is going on if staff knew they could safely report problems. The ONA presenters in both **HAMILTON** and **OTTAWA** made a point that inspectors do not presently meet with front-line staff, who could give a more detailed and explicit picture of care conditions.

The present system of making appointments for inspections has proved grossly inadequate in the maintaining of proper standards. The $1.2 billion dollars that is being invested in building new long term facility beds will not necessarily change this situation, especially since 80% of this investment is going to private, profit-making corporations."

7. PRIVATIZATION OF LONG TERM CARE FACILITIES

"Municipal Homes for the Aged provide higher standards of care for residents…. I request that legislation prohibit any reductions in the number of Long Term Care beds, facilities or the municipal funding for their operation," said Patricia Jaggard, RN at the **HAMILTON** forum.

"The RFP process and the criteria for awarding long-term care beds in the North is definitely unfair. There are cases of transferred seniors who have not seen their spouses for months, because of travel or financial difficulties."

The Council on Ageing in **KINGSTON** reported that "Concern was expressed at the committee over the funding of the proposed new 20,000 long term care beds. It is our understanding that both for-profit and not-for-profit nursing home operators may apply for a non-repayable government grant toward the cost of developing these additional beds. Certainly the additional long-term care beds are seriously needed. However, if the government is attempting to constrain health care spending, the question was raised why the government would choose to provide non-repayable grants to for-profit operators. The for-profit operators will own the long term care facility and reap the profit, not the taxpayers, who helped to finance the for-profit long term care facilities."

Two mayors of small towns in Northern Ontario expressed deep concern about the tendering process for new long-term care bed. Mayor Bob Krause of the **TOWNSHIP OF SCHREIBER** said: "In small communities, we have a serious problem. Our seniors requiring long term care want to remain close to their family and friends. .It is hard enough to convince a senior citizen to move into a long term care facility; it becomes even more difficult when the move involves long distances, sometimes hundreds of miles from their home. Schreiber Township Council feels that the provincial

government needs to change the criteria for long term care facilities in Northern Ontario; perhaps by allowing any small communities who wish to go into long term care,to be allotted the beds."

"It is hard enough to convince a senior to move into a long-term care facility; it becomes even more difficult when the move involves long distances, sometimes hundreds of miles from their homes."

Mayor Duncan Wilson of the **MUNICIPALITY OF RED LAKE** stated: "The RFP process and the criteria for awarding long term care beds in the North is definitely unfair as long as it is based on population and not on the needs of communities, the lack of transportation and the uniqueness of our area…. In the Municipality of Red Lake we currently have a waiting list of 40 people in need of long term care…. There is no bus or plane service to Dryden, and no direct plane service to Kenora. It is a three-and-a-half hour drive to Kenora, with only intermittent bus service. There are cases of transferred seniors who have not seen their spouses or loved ones for months because of travel or financial difficulties…It is very hard to understand why, in the announced 2001 bed allocations, the farthest northern community is Sudbury. Surely something must be done to rectify this situation."

Speaking for the Algoma Health Nurses of **SAULT STE.MARIE** and the Senior Health Advisory Committee, Jean Cauduro expressed the frustration they feel because the proposed Davey Home for long term care was turned down. "We have three hundred or more people in our city who need these beds now," she said.

There are [in Windsor-Essex between 400 and 500 persons with a persistent mental illness who live in private domiciliary hostels. They often live in crowded conditions (two to six per room) and are cared for by staff with little or no training…. Someone from outside the system should en sure that residents receive the care they deserve."

8. REGULATION OF RETIREMENT AND OTHER CARE HOMES

Retirement homes have become both a choice for some and a last resort for others who can not manage in their own homes with the assistance available to them from family and/or the public system. These homes are completely unlicensed, unregulated and unsubsidized by the provincial government, although a few municipalities (Hamilton and Windsor are examples)have by-laws defining licensing requirements. Ontario is the only province that has no form of licensing for retirement homes and, in consequence, no way to enforce standards of care. Organizations and individuals concerned about the future of long term care are disturbed about this matter because inadequate home care (including waiting lists for supportive care) and long waiting lists for regulated facilities are forcing low-income seniors to look for the cheapest retirement they can find. With their limited resources, these seniors may be forced to live in conditions that are appalling.

Frank Sheehan, President of the Schizophrenia Society, **WINDSOR-ESSEX** reported that: "There are between 400-500 persons with a persistent serious mental illness who live in private domiciliary hostels. They often live in crowded conditions (2-6 per room) and are cared for by staff with little or no training…. We are familiar

with the operation of the 20-25 domiciliary hostels in this area. Someone from outside of the system should ensure residents receive the care they deserve. As regards to the prevalence of the private sector, we do not believe anyone should make profit in caring for these vulnerable people. The 15-20% profits made by these for-profits should go into improving the quality of life for these people."

"Many people [with schizophrenia] are living in one room, in rundown hotels/motels, rooming houses, deteriorating basement rooms, on the street, in jails or with ageing parents."

Helen Shumacher of the **THUNDER BAY** Chapter of the Schizophrenia Society said that:"It is short sighted to assume that the advent of more efficient surgeries and improved medical discoveries will reduce the need for housing, supports and health care in the future. …Many people are living in one room, in rundown hotels/motels, rooming houses, deteriorating basement rooms, on the street, in jails or with aging parents….If young adults are going to be stabilized, live and work in the community, they must have decent housing, support services and job opportunities….Biochemical brain disorders require real medical diagnoses, treatment, and for many, ongoing lifetime care. Please include and address the needs of this needy population who will be in need of long term care."

The Council on Ageing –**OTTAWA-CARLETON** established a Task Force to study the regulation of retirement residences after a community forum on that subject in April 2000 issued a record of its proceedings. The Task Force proposed a definition of a retirement home as a "residential care home facility providing care services (beyond room and board) to three or more related adults 18 years of age or older and is not a Long Term Care Facility." They concluded that provincial licensing should be established and should include**:**

- ✓ a definition of retirement home defined by legislation
- ✓ criteria for licensing established
- ✓ the Province should set licensing requirements
- ✓ an independent third-party agency (composed of stakeholders and the public) be established to grant and revoke licenses based on provincial criteria
- ✓ the provincial criteria be based on public consultative process
- ✓ the process of licensing and enforcement of license conditions by the provincial agency should include a role for municipalitie

B. HOME CARE AND COMMUNITY SUPPORT SERVICES

1 ENTITLEMENT TO CARE/WAITING LISTS

At the **TORONTO** forum this was addressed by the Ontario Coalition of Seniors Citizens' Organizations. "The first essential element of a new Long Term Care Bill is that it proclaim the **right** of every Ontario resident **to receive the care he or she needs**, without the qualification so often insisted on by the present government, 'within available resources'. What resources are made available is always a choice of the government of the day, a choice based on what seems to them politically expedient at any given moment. Enshrining the **right** to care for the most vulnerable members of our society is the only way to remove this political element which, up to now, has left thousands on waiting lists for both home care and long term care facility beds."

"It is not acceptable to provide care according to available resources. Who decides what are available resources?"

A number of presenters in every area expressed similar ideas. Concerned Friends of Ontario Citizens in Care Facilities declared that "it is not acceptable to provide care according to 'available resources'. Who decides what are the available resources?"

Canadian Pensioners Concerned declared: "Our government must commit to providing adequate funding to fulfil the right of every citizen and every community to a good quality of health care, delivered with respect and dignity for the recipient."

New long-term care legislation must contain real staffing regu - lations that are linked to THE REAL CARE NEEDS of residents."

From CUPE Local 79 (workers in the Toronto Homes for the Aged Division) we heard that "the new long term care legislation must contain clear staffing regulations that are linked to the **real care needs** of the residents."

The **OTTAWA-CARLETON** Long Term Care Committee recommended that the new Act must "include a clause which states that people are entitled to have the care they <u>need</u> rather than a clause based on care that is <u>affordable."</u>

"When guidelines are drawn up for home care, consideration should be given not only to need but to locale. There is no public transportation for our rural seniors, and when they can no longer drive they become prisoners in their own homes."

"The rural senior becomes a prisoner in his own home while waiting. There is no public transportation for our rural senior citizens, and when they can no longer drive their own vehicle, they become isolated. Their children are not always available because either they live too far away or are very busy with their younger family. This leaves the senior to depend on a good neighbour or friend. These people, however well intentioned they are, are not professional caregivers. The rural, independent senior really does not like to impose. When guidelines are drawn up for home care, consideration should be given not only to need but to locale. Let's remember that there is a vast difference between the urban senior

and the rural senior. Distances, lack of services and isolation must be a consideration." Shirley Whartman, USCO.

"As a union, we try to negotiate agreements that provide a measure of protection against illness and indignity in old age. However, we realize that no matter how good our agreements, they are only good so long as the plant is in operation, which is largely out of our control, depending on over-all economic conditions such as exchange rates and urban planning decisions in cities far away from Thunder Bay. We do not believe that health care should be left to collective bargaining and the vagaries of the capitalist business cycle. **Health care should be a right of all Ontarians whether employed, unemployed, young or old**." CAW Local 1075, **THUNDER BAY.**

"Because of finite budgets and an increasing demand for services, people with chronic diseases like Alzheimer Disease are not able to get adequate services, or in some cases any services at all."

The **OTTAWA-CARLETON** Long Term Care Committee said that "the Act should not recommend a specific level of funding but should consider a purpose clause which **entitles people to the care they need."**

"A significant proportion of government funded community services are available only through Ontario's 43 Community Care Access Centres (CCACs). CCACs are increasingly expected to give priority to people who require acute care services as a result of discharge from hospital. Because of finite budgets and an increasing demand for services, people with chronic diseases like Alzheimer Disease are not able to get adequate services, or in some cases any services at all. Eligibility criteria place emphasis on clinical or personal care needs. Therefore, people with Alzheimer Disease, who require supportive services but not personal care are often ineligible or a lower priority for services." Alzheimer's Society, **THUNDER BAY.**

Presenters clearly felt that the only way to make the government accountable for providing needed care, instead of the present system of rationing care, is to enshrine an Entitlement clause in the new legislation.

Presenters clearly felt that the only way to make the government accountable for providing needed care, instead of the present system of rationing care, is to enshrine an Entitlement clause in the new legislation. With the reduction in lengths of stay in all acute care hospitals, experience everywhere was that most CCAC resources are being absorbed by post-hospital patients, whose need for home care is acute. In consequence, seniors and others needing supportive care to be able to remain in their own homes are at the bottom of the priority list**.**

2. STAFFING/COMPENSATION PARITY

Presenters from all parts of the province agreed that we face a human resources crisis in the community care sector, due, at least in part, to inequity of pay in comparison to pay in institutions. The **WINDSOR-ESSEX** speaker from the Ontario Nurses' Association told the following story. "On the Friday immediately preceding

Christmas day, the Chief Nursing Officer at Hotel Dieu General Hospital received a call from management at the CCAC that they could not add any more patients on their caseworkers as there were not enough nurses available to provide the care. As a consequence the onus was put on the hospital to either extend unnecessary and expensive lengths of stay or discharge and somehow provide the care themselves. An "outpatient clinic" was quickly put in place on an acute med-surgical unit and the services were provided by the nurses on that unit. By doing this the hospital was able to discharge patients in an expeditious manner…. Needless to say, this was a much more costly means of doing business. It certainly defeats the purpose of the benefits of providing home care services."

"On the Friday immediately preceding Christmas day, the Chief Nursing Officer at Hotel Dieu General Hospital received a call from management at the CCAC that they could not add any more patients on their case workers as there were not enough nurses available to provide the care."

"Detailing the working conditions for home care workers in their area, two Personal Support Workers from **BURLINGTON**, speaking at the Hamilton forum gave the following recommendations: " Travel allowance compensation should be given when personal vehicles are used to get from one client to the next. We need to have a standard of salary for Personal Support Workers after attaining a college diploma. We need to institute stipulations regarding pensions upon retirement for the home care worker; we need to institute sick days with pay; home care workers need a voice in the political arena. Quality care is the goal of the home care worker, and as such should be treated equally. As a result, we need working laws to protect the home care worker." Glenda Fraser and Holly Greene

"One of my workers, my nurses actually, was ill and unable to come to work one day. The first available person, because of the shortage, was at 2 o'clock in the after- noon. . I was left in my bed without medi - cation, without my bowel routine and a lot of other very private embarrassing things."

A home care recipient, Dinah Cotter, had this to say to the forum in **KINGSTON**: "One of my workers, my nurses actually, sorry, she was ill and unable to come to work one day. Well, instead of having a replacement at 8:30 am which is usually when they come, the first available person, because of the shortage, was at 2 o'clock in the afternoon. I was left in my bed without medication, without my bowel routine and a lot of other very private embarrassing things, sorry, she was ill and unable to come to work one day. Well, instead of having a replacement at 8:30 am which is usually when they come, the first available person, because of the shortage, was at 2 o'clock in the afternoon. I was left in my bed without medication, without my bowel routine and a lot of other very private embarrassing things. And it wasn't because the company so much failed, but the company didn't have anything to work with and that's because the nurses aren't here, because thanks to Mr. Harris, they've gone south, they've gone elsewhere or they're just not going into this practice**."**

Speaking to the **OTTAWA** forum, Marcia Taylor of the Ontario Nurses Association said:"nurses in the long term care and home care sectors are substantially less than what nurses receive in hospitals, making it harder to attract nurses in these sectors."

"When positions open up in the hospital sector, that is where the majority of available nurses are going. …Who wouldn't go where the money is better, when you are trying to pay off a mortgage and support a family?"

The **OTTAWA** Long Term Care Committee stated that the Province must "equalize the compensation and working conditions of workers with similar training and responsibilities across the entire health care system, to stabilize the work force, prevent further attrition of trained workers and attract new, qualified workers."

"If there is to be adequate service to people in their own homes, it is essential that rates of pay for professional and non-professional home care workers be equalized with rates paid in hospitals.…Equalization of pay rates is of first importance to community care workers, but it is also highly important to those receiving care. We can't expect to get quality care from workers who are underpaid, kept on casual status and paying for their own travelling time." said the Ontario Coalition of Senior Citizens' Organizations**.**

Deborah Brassard, from **BRANTFORD,** said "When positions open up in the hospital sector, that is where the majority of available nurses are going….Who wouldn't go where the money is better, when you are trying to pay off a mortgage and support a family?"

3. CASUALIZATION AND CONTINUITY OF CARE

Casual status for home care workers was seen by most presenters as a very unfavourable working condition that contributed to the difficulty of retaining sufficient professional and non-professional staff in the home care sector. It was also pointed out that, for those receiving care, casual staffing policies are virtually destroying the most important element of quality care – continuity – having the same worker coming in most of the time.

"Each day a different caregiver arrived to provide the post-operative care I received at home following a mastectomy. On the fourth day, the caregiver said 'I'm not qualified to do this procedure'."

"Our nurses tell me that they are very concerned about the lack of continuity of patient care under the RFP system. Patients may see a different nurse every time a contract is up. That's just not good for them, and is a very troubling concept for nurses who so desperately want to provide quality care," said Joy Widawski, RN, speaking for the Ontario Nurses Association at the **HAMILTON** forum.

"Where a person with dementia receives services from a CCAC, there often is insufficient consistency in the staff assigned to provide services to an individual client. Many clients receive the same service from several different workers. This can negatively impact the well-being of the client: constant change can add to confusion, can make it difficult to care when a care provider lacks the essential knowledge and medical history of the client." James A. Dafoe, ED, Alzheimer Society, **WINDSOR-ESSEX.**

Dolores Dickey, Canadian Liver Foundation and **THUNDER BAY** Breast Cancer Support Group, told the forum: "Each day a different caregiver arrived to provide the post-operative care I received at home following a mastectomy. On the fourth day the caregiver said, 'I'm not qualified to do this procedure. I'll have to call the office and get someone else to come'– the 4th day – when the type of care I needed was clearly established in the system. Each nurse had to read the notes left by the previous nurses before starting work. When there is no continuity it is more difficult to note an adverse change in a patient's condition. Finally, when the 6th new person arrived, I commented that I thought the system left a lot to be desired. The answer I received was that Community Care would soon be receiving new software that should improve the scheduling."

Many clients receive the same service from several different workers. This can negatively impact the well-being of the [Alzheimer] client. Constant change can add to con fusion, can make it difficult to care when a care provider lacks the essential knowledge and medical history of the client.

In **TORONTO**, the Ontario Coalition of Senior Citizens' Organizations said: "For anyone receiving care, having the same person come all or most of the time is the first requirement of good care. It allows for the care provider to get to know the needs and wishes of the care recipient, to get to know her or him as a person, to develop a relationship that often deepens into a friendship gratifying to both parties. Such continuity is fast disappearing because the most-effective way to deploy home care workers is to keep them on casual status, having them phone in each day for the day's assignments."

4. MANAGED COMPETITION

The **WINDSOR** Health Coalition stated that they considered "Managed Competition" in community care to be causing increased privatization of the health care system. "An excellent example of this approach is the Community Care Access Centres established in Ontario, to act as workers – awarding contracts to providers by means of a Request for Proposal process. The end result is: care "as funding allows," rationing of services, loss of experienced, highly trained providers, lack of continuity, added stress and anxiety for patients waiting for care and family members who now have to contribute as caregivers. Caregivers – who once had job security, good wages, good benefits and decent working conditions – are now paid low wages and benefits, have no security, no pension provisions and lack (in some cases) good working conditions."

"Managed competition" tends to create a competitive environment, promoting the business interests of the organization rather than the needs of the client in the deployment of staff.

"It is unknown whether health professionals in rural areas will decide to continue working in the home care sector, or whether they will be willing to travel to our rural communities. We do not want to jeopardize the trust that our clients have developed in these services by disruptions in continuity of care resulting from terminated service contracts and further reductions of health

professionals in the home care sector," said the presenter from the Dilico Ojibway Child and Family Services in **THUNDER BAY.**

The Ontario Dental Hygienists' Association in **HAMILTON** told the forum there: "It costs provider organizations more than $30,000 to prepare each proposal submitted thus limiting the number of providers to those who can absorb this expense. This expense will eliminate many volunteer-based, not for profit providers who offered competitive care and used volunteers based in the community to provide enhanced services such as Meals on Wheels, friendly visiting and so on. The RFP process has not allowed for innovation in use of healthcare providers, such as dental hygienists, who can offer not only needed oral care but assessments in nutritional aspects, self-care and so on. …All seniors need daily oral care to ensure that they have a good nutritious diet, ability to speak properly and no loss of self esteem due to bad mouth odour or missing teeth."

"This community [Windsor-Essex] has learned first hand what this RFP has done, lack of nurses – while on many occasions, hos pitals could not dis-charge patients from the hospital, for the agencies did not have the nursing staff.

"Most CCACs do not provide services directly, but enter into contracts with service provider organizations, on the basis of a request for proposal process. This "managed competition" tends to create a competitive environment, promoting the business interests of the organization rather than the needs of the client in the deployment of staff. Contracts are awarded to 1 – 3 years and the competition can result in a change in the organizations under contract. When an organization loses its contract, the front-line staff does not automatically move to the new service provider organization. This can result in a high turnover of staff, and makes it difficult for an agency to ensure that a client will receive services from the same worker. Managed competition also turns expertise into a competitive advantage. Provider organizations and their staff are reluctant to share best practices or to support each other in caring for a client with highly specialized needs, like dementia." James A. Dafoe, ED, Alzheimer Society, **WINDSOR-ESSEX**.

CUPE Local 1132, **WINDSOR-ESSEX**. stated that: "This community has learned first hand what this RFP has done, lack of nurses – while on many occasions, hospitals could not discharge patients from the hospital, for the agencies did not have the nursing staff. This is not the health care system that we in Windsor-Essex envision for our community.… CUPE believes that funding should be spent on care and not profit, therefore, we are calling for an end to the RFP process and the immediate implementation of a publicly-funded, publicly administered and publicly delivered community care system, with meaningful community control and adequate provincial standards that ensure quality care. The non-profit public provision of home/community care services is essential."

According to **THE KINGSTON** and District Labour Council. "The not-for-profit public provision of home care and community care services is essential. The public administration of Medicare has saved Canadians billions of dollars. The practice of "de-insuring" health services by eliminating them from Medicare coverage, forcing people to pay privately for care, has created a two tier health care system where private insurance companies profit. There is no room for profit and inequity in health care**."**

The **OTTAWA**-Carleton Long Term Care Committee called for an independent, impartial review of the managed competition model to evaluate the changes in home care delivery as a result of the competition process.'

In **TORONTO**, Canadian Pensioners Concerned said simply that "the Request for Proposal process should be ended."

According to the Ontario Coalition of Senior Citizens' Organizations:"The announced purpose of the competitive model was to create a 'level playing field for profit-making agencies…The theory behind this was that profit-making agencies are more efficient and cost-effective than non-profit organizations. In the opinion of the present government, the 'bottom line' is a better motivator to give good service than the idealism and the culture of service which has energized our traditional non profit services for so many years… Casual status and the fact that workers are not paid for their travelling time between assignments present strong incentives to home care workers to do the chores and get out as quickly as possible. Some Access Centres even have schedules allotting 15 minutes for a bath, an hour for laundry, etc….Another huge disadvantage of the competitive process is the amount of staff time that both Access Centres and provider agencies are forced to devote to the Request for Proposal process…At the same time, the competitive atmosphere has put an end to the formerly co-operative relationships among provider agencies."

At the **TORONTO** forum Pat Noon read a letter from a personal support worker who could not attend because she was in the community caring for a senior. Her letter said: "I am from the Phillipines. I came to Canada thirteen years ago. For three years I have been working in a non-profit organization as a personal support worker. I have been working full time with enormous faith that I have chosen the right profession. I did not know then that agencies are required to bid for a contract – profit or non-profitable should race for it. Our agency lost the contract. And so I and my co-workers will lose our jobs. If we are lucky to get hired by those agencies that got the contract, I am sure that none of them will hire us full time and we have to start at the beginning again with no benefits and low wages."

"I am from the Phillipines. I came to Canada thirteen years ago. For three years I have been working in a non-profit organization as a personal support worker. I have been working full time with enormous faith that I have chosen the right profession. . Our agency lost the contract. And so I and my co-workers will lose our jobs."

5. GOVERNANCE OF COMMUNITY CARE ACCESS CENTRES

"The CCACs must have open membership for everyone living in their catchment area", said Canadian Pensioners Concerned at the **TORONTO** forum.

"The CCACs must have open membership for everyone living in their catchment area. By-laws for elections to the Board of Directors must be public documents, easily accessible."

"A uniform process for becoming a member or Board member of any Community Care Access Centre should be mandated. ++By-laws for elections to the Board of Directors must be public documents, easily accessible. Only non-union representatives of companies that have contractual relationships with the CCAC, as well as non-unionized people working for the provincial government, should be prohibited from holding a position on the Board." CUPE Local 1132, **WINDSOR-ESSEX**.

"At present," said the presentation of the Ontario Coalition of Senior Citizens Organizations in **TORONTO**, "each of the forty-three Access Centres is free to make its own rules about how it will relate to its community, how community members can join the Centre, be elected to its Board of Governors, attend and participate in Board meetings. The variety of approaches is striking. One Centre limits the number of community members who can join. Another requires a curriculum vitae and approves or disapproves of the applicant based on how they respond to what the applicant has done with his or her life. Some Centres have open board meetings; others allow citizens to apply to make a ten-minute presentation."

"Each of the forty-three Access Centres is free to make its own rules. The variety of approaches is striking."

6. CULTURAL SENSITIVITY

Several presenters emphasizes the need for cultural sensitivity throughout the long term care system. Speaking to the forum in **THUNDER BAY**, the Anishnawbe Mushkiki & Thunder Bay Indian Friendship Centre stated: "In Northwestern Ontario, it is recognized that there is a chronic shortage of long term care facilities for Aboriginal seniors. A majority of Aboriginal communities must send their seniors to long term care facilities located far away from their home communities. Many of these institutions do not have Aboriginal specific services, and the Aboriginal senior must face a range of issues that negatively impact on their ability to access services, to have an active voice in their care, and therefore affects their quality of life….Most Aboriginal seniors require client advocacy and support due to their limited English vocabulary… The greatest need among seniors is for culturally appropriate services that help them cope with chronic conditions and functional disabilities and enable them to stay in their own homes."

"A majority of Aboriginal communities must send their seniors to long term care facilities located far away from their home communities. Many of these institutions do not have Aboriginal specific services."

"Consultation with Aboriginal communities is essential in order to ensure that certain sections in the Act with respect to Aboriginal communities are maintained, at minimum. Any new Long Term Care Act must safeguard the rights of First Nations and Aboriginal communities to establish priorities, plan programs, and deliver services that link with other main components of the health care system while appropriately addressing unique needs with respect to language, culture, geographics and demographics." **DILICO OJIBWAY** Child and Family Services.

In **OTTAWA**, Councillor Clive Doucet said that "Over fifteen percent of the population of Ottawa states that their mother language is French. Language is critically important when you grow old. There must be services in French for francophone seniors so that their health concerns are well understood and they are comfortable when in hospital or long term care facility."

The new long term care legislation must establish policies that assure services [in their own lan-- guages] to franco phone seniors and the multi-ethnic communities in Ottawa and elsewhere in Ontario."

Three **OTTAWA** Community Health Centres, in a joint presentation, said that "the new long term care legislation must "establish policies that assure services [in their own languages] to francophone seniors, the multi-ethnic communities in Ottawa and elsewhere in Ontario."

Judith Matheson, who co-ordinates the United Church pastoral care team at the **OTTAWA** Hospital, made a strong recommendation that quality home care must include emotional/spiritual care. "There is a lot of stress when someone is losing their health. There is a tremendous amount of health care dollars saved in the healing process if we look after the emotional/spiritual needs" of people being cared for, by family or by the public system.

III. OTHER PROBLEMS IN LONG TERM CARE

A. The problem of elderly couples when one mate is in a long term care facility was raised by Joy Caghill of the **HAMILTON** Older Women's Network. "Please think about a person entering a nursing home, think about that person having a pension income, and then think about the spouse that is left at home who is unemployed and under the age of 60. What does that person live on? The pension must go with the spouse in the nursing home to pay the resident's portion of the bill. Think of how the spouse at home is grieving for the loss of the way of life and the loss of a loved one, no one to talk to , to hold and to love. Now that spouse applies for welfare, but under the provincial income assistance legislation the family income is the deciding factor regardless of where the income-producing spouse is living and regardless of the expenses incurred in being in a nursing home. The grieving spouse in ineligible for welfare… unless this couple declares themselves involuntarily separated. Sure the wording is clear, but to this couple, it means something much more sinister…legal separation from the one I love. Following this the at-home spouse can apply for a grant not to exceed $152 from the pension of the spouse in the nursing home. Could we not have pieces of legislation that actually work together instead of in opposition? Could we make life easier rather than harder for people who are already deep into the tragedies of this life? Those who are drafting legislation for long term care should consult with those who are drafting legislation for provincial income assistance. We cannot continue to pit one Ministry's legislation against another**."**

"Please think about a person entering a nursing home, think about that person having a pension in come, and then think about the spouse that is left at home who is unemployed and under the age of 60. The grieving spouse in ineligible for welfare."

B. Eleanor Divine, President of the Family and Friends of the **Mentally Handicapped** in **WINDSOR** presented some of the problems with obtaining the needed long term care. "While we recognize there will be times in the lives of the developmentally challenged when they will require health care, as do we all, however, their mental condition (formally known as mental retardation) is not an illness but is a condition. The medical model of support is inappropriate for them…. Adequate funding, from the Ministry of Community Social Services, to keep the develop-mentally challenged in familiar surroundings as long as is possible, is the preferred long term plan for our sons and daughters. Care under the Ministry of Health, in our opinion, should only be considered when nursing care is required." Eleanor Divine, President, Family and Friends of the Mentally Handicapped, Windsor.

The mental condition (formerly known as mental retardation) is not an illness but is a condition. The medical model of support is inappropriate for them. Adequate funding, from the Ministry of Community Social Services to keep the developmentally challenged in familiar surroundings as long as is

C. Marilyn Warf, Regional Director, Persons United for Self-Help in Northwestern Ontario, spoke at **THUNDER BAY** to the problems of **parents of disabled children.** "Huge gaps remain in services

for caregivers of children with disabilities….Current planning and implementation does not create seamless delivery. Persons with disabilities and families with disabled members report that too much time and energy is required to access supports and services…We strongly encourage the planners of long term care to look at the full perspective relating to health and the delivery of supports and services for the benefit of those that rely on its delivery for many aspects of their wellness."

D. The Council on Aging of **KINGSTON** addressed the problem of **long waiting lists** for seniors who cannot pay the rates for preferred accommodation in long term care facilities. "Under the current legislation, each long term care facility must set aside 40% of the beds for subsidized patients. The balance – or 60% of the beds – may be held for full pay patients. This results in a longer wait for placement in a long term care facility based on ability to pay rather than on need. Lower income seniors are further penalized since they cannot afford to purchase private home care services to augment the maximum of 60 hours per month of home care provided through the local Community Care Access Centre; an option available to the higher income seniors. … There should be an amendment to the provincial legislation removing the 60/40 ratio of full pay residents to subsidized residents. Placement should be based on need rather than on financial status of the patient."

"Under current legislation, each long term care facility must set aside 40% of the beds for subsidized patients. The balance, or 60% of the beds, may be held for full pay patients. This results in a longer wait for placement in a long term care facility based on ability to pay rather than on need."

E The Ontario Coalition of Senior Citizens' Organizations in **TORONTO** stressed the need for an **independent complaints procedure for persons receiving care in their homes**. They said: "Seniors and others dependent on care need to feel completely safe in reporting any violation of their rights, as well as unsatisfactory service. Experience has shown that no matter how well designed an Access Centre's own complaints procedure, it can never hope to hear from most care recipients with serious complaints. This is because vulnerable people, who desperately need service if they are to be able to 'age in place', are afraid to complain to the organization that controls their service for fear of losing what service they have.".

Seniors and others dependent on care need to feel completely safe in reporting any violation of their rights, as well as unsatis-- factory service

F. The **financial problems of family care givers and individuals living on disability support** were emphasized by several presenters. In **TORONTO,** Lois Bedard pointed out that "I retired at fifty-one to care for my sister who was cognitively impaired. I received no compensation for my lost earnings at a time when my salary as a teacher was peaking." B.H.Shannon submitted to the Toronto forum a letter he had sent to Health Minister Tony Clement pointing out that, for an elderly spouse caring for an age-disabled mate, **present tax regulations make it impossible to use retirement savings withdrawals to pay for**

needed help. Another Toronto speaker, who is trying to live on Disability Benefits, told the forum that the **$930 per month she receives is impossible to live on in Toronto,** but if she manages to earn some supplementary income, most of it is deducted from her disability cheque. Her monthly cheque was reduced to $883.50 when she earned $1600 marking English exams. She has suffered some serious health problems, as well as the death of her son and drained her energy resources substantially to earn this money

"I retired at fifty-one to care for my sister who was cognitively impaired. I received no compensation for my lost earnings at a time when my salary as a teacher was peaking."

G. Presenters from many areas spoke of **inadequate support given to family care givers.** Access Centres have been instructed that any professional or non-professional going in to the home is to be considered respite for the care giver. But experience has shown that there is no effective respite unless the worker coming into the home is specially trained to care for medically complex or cognitively impaired patients. While such training is available, no incentives exist for personal support workers/health care aides to take this extra training. Differential rates of pay must be established for workers with specialized training.

A speaker trying to live on Disability Benefits, told the forum that the $930 per month she receives is impossible to live on in Toronto but if she manages to earn some supplementary income, most of it is deducted from her disability cheque.

Speaking to the **TORONTO** forum, Linda Davis Bonar, herself disabled, said "I have survived many health crises (including falling off an operating table while still under anaesthetic). I am here to speak for those who can not. Respite and relief assistance have been fully recognized as a necessity. Many do not realize until they are burnt out that they need a time and space of their own. [We] run the risk of losing our caregivers and also the decline of our own personal health without adequate and preventative interventions."

Janet Partanen is a Registered Nurse, who had looked after her 90-year-old, sometimes confused father for four years, until his worsening arthritis and incontinence necessitated finding a supportive retirement home. She told the **TORONTO** forum that "during that four years I desperately wanted to have a vacation. The only way I could have had any respite was to put him into care. I couldn't even be away for one evening." To get some respite, she applied to her Access Centre and was given a pile of forms two inches thick and was required to get physiotherapists and doctors to fill them out. Those, she said, "who take a person to look after, are really jeopardizing the rest of their life because a holiday may be out of the question."

"Respite and relief assis-tance have been fully recognized as a neces -sity. Many do not realize until they are burnt out that they need a time and space of their own. [We] run the risk of losing our caregivers."

SECTION II SUMMARY OF RECOMMENDATIONS

Following are the major recommendations made by presenters at the forums to be essential elements of new long-term care legislation:

1. Seniors and others in need of long term care are **entitled to receive the care they NEED**, in their homes as long as possible, or in facilities when necessary

.

2. **Staffing ratios** in long-term care facilities must be **regulated** and must be **high enough** to meet the current needs of residents.

3 **Compensation, benefits and working conditions must be equalized** (for those with equal qualifications**) across the health care system.**

4. **Surprise inspections and consultation with front-line workers** are essential to enforcing standards of care in long-term care **facilities.**

5. **Privatization,** in the awarding of construction grants for the operators of private facilities and in home care contracts**, must stop.**

6. There must be **uniform rules** for the governance of **Community Care Access Centres** and **information** about their contracts with provider agencies must be made **public.**

7. An arm's-length**, ombuds-like agency** must be established so that care recipients will feel safe in reporting **complaints** about violations of their rights, as well as unsatisfactory service.

8. New long-term care legislation must provide for **licensing,** standards of care and enforcement of standards in **retirement and care homes.**

9. **In-home respite,** with **higher pay** for **trained** respite workers, must be provided through the Access Centres.

10. **Funding** for all elements of long term care must meet the **population's needs,** with sensitivity to the needs of our **diverse society**

11. The government must **account to taxpayers** for the number of health care **dollars going into private profit**.

APPENDIX "A"

Long Term Care Forums in Ontario

THUNDER BAY ***Attendance over 100***
Monday, February 5th - 7:00-9:00 PM
Thunder Bay Labour Centre
929 Fort William Road
Contact person: Evalina Pan (807) 473-8100 epan@baytel.net

SAULT STE. MARIE ***Attendance 55***
Tuesday, February 6th – 7:00-9:00 PM
United Steelworkers Hall
681 Dennis St.
Contact person Elsa Morehouse (705) 949-6235 elsam@onlink.net

HAMILTON ***Attendance 88***
Tuesday, February 13th – 7:00-9:00 PM
Hamilton Public Library, Central Branch
55 York Blvd.
Contact person Fran Borsellino (905) 516-5690

WINDSOR ***Attendance 70-80***
Thursday, February 15th – 7:00-9:00 PM
CAW Local 200/444 Hall
`855 Turner Rd.
Contact person Andy Schmidt (519) 977-1058

OTTAWA ***Attendance Over 100***
Wednesday, February 21st -- 4:00-6:00 PM
Sandy Hill Community Health Centre
221 Nelson Street at Rideau
Contact person Abe Rosenfeld (613) 244-2817 arosenfeld@sandyhillchc.on.ca

KINGSTON ***Attendance 70-80***
Thursday, February 22nd --6:30-9:00 PM
Kingston Public Library – Central Branch
130 Johnston ST. at Bagot
Contact person Ross Sutherland (613) 374-5211 ebe@web.net

TORONTO ***Attendance over 350***
Tuesday, March 6th 1:00-4:00 PM
Ontario Legislature
Queen's Park
Contact Care Watch Toronto (416) 590-0455

APPENDIX "B"

ORGANIZATIONS RESPONSIBLE FOR THE FORUMS

Alliance of Seniors to Protect Canada's Social Programs
530 Wilson Ave., 3rd floor
Toronto, ON M3H 1T6
(416) 544-8253

Canadian Pensioners Concerned
10 Trinity Square
Toronto, ON M5G 1B1
Phone: (416) 368-5222

Care Watch Toronto
140 Merton Street, 2nd floor
Toronto, ON M4S 1A1
Phone: (416) 590-0455

Concerned Friends of Ontario Citizens in Care Facilities
140 Merton Street, 2nd floor
Toronto, ON M4S 1A1
Phone: (416) 489-0146

Congress of Union Retirees of Canada
15 Gervais Dr. Suite 305
Toronto, ON M3C 1Y8
Phone: (416) 654-0210

Older Women's Network
115 The Esplanade
Toronto, ON M5E 1Y7
Phone: (416) 214-1518

Ontario Coalition of Senior Citizens' Organizations
3101 Bathurst St. Suite 500
Toronto, ON M6A 2A6
Phone: (416) 785-8570

Ontario Health Coalition
15 Gervais Drive, Suite 305
Toronto, ON M3C 1Y8
Phone: (416) 441-2502

Ontario Nurses Association
85 Grenville St., Suite 400
Toronto, ON M5S 3A2
Phone: (416) 964-8833