

# The Care We Need

Ontarians speak out on  
the state of home care  
&  
A proposal for reforming  
home care in the public  
interest



**MARCH 10, 2015**

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*Canadian society has a collective responsibility to ensure universal entitlement to public care throughout life. Such care must be provided without discrimination as to gender, ability, age, physical location, sexual orientation, socio-economic and family status or ethnocultural origin. The right to care is a fundamental human right.*

**Statement from Charlottetown Declaration on the Right to Care, 2001**



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# EXECUTIVE SUMMARY

## a principled approach to home care reform and a democratic process to hear from those most affected

Medicare was established when hospitals cared for the ill and homecare for the frail. This has changed dramatically over the last thirty years, with much more clinical care provided at home as well as a growing number of frail elderly and the disabled requiring support at home. At the same time, the commitment of Canadians to the right to health care based on need rather than income has not declined. Indeed, support for this value has grown. To modernize the system we need to recognize the principles of the Canada Health Act and apply them to the full range of services that people need.

For more than two decades, Ontario governments have pursued policies centred on cutting hospitals. At the same time, governments have failed to create and enforce clear standards for accessible home care as patients are moved to the community. In effect, the continual failure to establish a clear right to access medically necessary home care amounts to an erosion in the scope of our public health coverage. Today, the patients find their ability to access publicly-funded care in community settings to be severely rationed, poorly organized and subject to user fees.

Ontario's home care system is struggling; unable to meet the burden of the downloaded patients from hospitals with ever more complex needs for post-acute care and rehabilitation, and, at the same time, provide a wider array of services to support longer-term care at home for the elderly and persons with disabilities and chronic illnesses. Within the home care system there is a highly-skilled workforce of nurses, health

professionals and support workers whose dedication to community care is invaluable. But the system itself is fragmented, under-resourced, and inadequately designed to meet the changes occurring both within the health care system and the demography of Ontario's population.

Home care reform is needed. But in reforming home care we need to take care to build upon the strengths that we have, and avoid the pitfalls of further fragmentation and privatization.

The Ontario Health Coalition has undertaken to build consensus for a principled approach to home care reform: one that is grounded in the deeply-held values of equity and fairness that underlie our health system; that supports democratic governance and processes; that enables persons with disabilities and chronic

illnesses and the aging to live at home for as long as possible; that engages the existing resources in the nurses, health professionals and support workers who are committed to providing community care, and; that builds upon and reforms the home care governance structures that already exist, while addressing the shortfalls in the system.

We are proposing a vision of progressive reform founded upon our fundamental shared values and existing resources within our CCACs. Ontario has an existing province-wide

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infrastructure of Community Care Access Centres with local offices and organizational structures, some of which already directly provide services such as rehabilitation, rapid response teams, mental health services in the school system, and palliative care nurse practitioners. Furthermore, we already have a strong foundation of thousands of dedicated nurses, health professionals and support workers who work in our existing home care system and are committed to community care. We believe that these existing resources provide a sound basis that can be built upon to better provide a comprehensive system of home care.

But we are not advocating the status quo. We are calling for a fundamental cultural change in home care – and the required changes to provincial policy – to reflect the values of public health care, embrace clear provincial standards to improve access to care and establish safe ways of assessing quality of care, and establish locally-led democratic governance in the CCACs who would become the reformed direct provider of public non-profit home care. We are calling for a change in leadership, firm requirements for accountability to the communities served, and a system to more effectively measure and meet population need for care. We are proposing an integrated public and non-profit model that would vastly improve coordination and streamline resources while stabilizing the workforce. This will, in turn, reduce turnover and improve opportunities for continuity of care and ameliorated training. We have also protected a role for locally-based non-profit community agencies that are strongly supported by their communities.

This proposal addresses the structural problems of fragmentation and duplication and establishes an integrated governance body for home and community care that can grow and adapt to changing needs and modalities of care while streamlining resources to provide better access to care. This proposal can and will

improve home care in the public interest.

We took a draft version of our principles and proposals for home care reform out across Ontario to consult with a broad array of people impacted by changes in home care. We held 10 cross-Ontario round table meetings, attended by 95 representatives from seniors' organizations, disability groups and community care agencies, as well as discharge planners, care coordinators, nurse practitioners, nurses, health professionals, personal support workers, unions, students, community health centre staff and clinicians, health coalition members, academics, municipal politicians and other stakeholders. Consultations were held in Hamilton, Niagara, Kitchener-Waterloo, London, Sarnia, Thunder Bay, Sudbury, Peterborough, Ajax and Toronto. We then followed up with individual interviews with participants in January and February 2015. The results of the round table consultations and the individual interviews are included in this report.

While there is not total consensus on everything, there is a truly remarkable level of agreement both about the state of home care and the priorities for reform. In our consultations, all across Ontario participants expressed their deep frustration with what they experience as an unresponsive, inadequate, inequitable, fragmented and overly bureaucratic home care system. While everyone expressed the need to improve continuity of care, there was no attachment to the current system of home care. In fact, participants everywhere expressed a desire for profound reform and significant, demonstrable change. Ontarians' core values about our

collective responsibility to care for each other with compassion are being disregarded, and in every consultation participants shared stories of people in need who have been left without care in sometimes horrifying circumstances. Participants in every part

*Home care reform is needed. But in reforming home care we need to take care to build upon the strengths that we have, and avoid the pitfalls of further fragmentation and privatization.*



of Ontario from every walk of life expressed passionately that they want to stop the suffering of people in need of home care.

- When we asked participants to describe the state of home care in their regions, in every consultation, participants described severe problems with access to care. There was total consensus that many people are not getting home care that they need and are suffering as a result.
- Participants also reported, with total consensus, that home care is overly bureaucratic, top-heavy, fragmented, and participants believe that many resources are not making their way to improving actual care. This consensus has fed the openness shared by a remarkable range of participants from all kinds of different interest groups that there must be both fundamental structural reform and a profound change in culture in home care.
- There was total consensus that home care should be more accountable and responsive to Ontarians. In virtually every round table, multiple participants reported that there is nowhere for complaints to be heard and no meaningful redress. In every round table meeting, participants wanted us to raise accountability as a priority in our home care reform proposal.
- Everywhere, participants described with frustration arbitrary and inequitable decisions regarding public home care access or denial of access.
- All participants expressed concerns or gave accounts of inadequate training, particularly for PSWs, while home care patients' needs are becoming more complex. Note: in every consultation, participants who were not from unions and were not care workers themselves,

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expressed concerns about poor wages and working conditions for PSWs, often noting that these have resulted in shortages, high-turnover, inadequate training, missed visits, poor continuity of care and poor quality of care. The leadership of non-profit community, social service and health care agencies in particular noted the increases of wages at the top levels of the CCACs and the precariousness of work for direct care workers.

- The need for standardization was also frequently raised in the context of complaints about inadequate responsiveness of CCACs to complaints from patients and families, inadequate responsiveness to calls from other health professionals, differing definitions of care needs among different parts of the health care system (ie. a family doctor refers to a patient as palliative but the CCAC has a different definition of palliative and refuses to provide care the doctor says is needed), differing requirements to provide care etc. Participants wanted higher standards across the board for management of access to care, continuity of care, and easier navigation of community care.
- There was total consensus that patients needing home care require advocacy and assistance in navigating a complex system of community agencies, CCAC services, LHIN services, and CCAC-contracted provider companies.
- There was total consensus that home care is too fragmented, disorganized, and poorly coordinated. Many of the criticisms of home care from family members, patients, and care providers alike focused

on poor communication between care providers of all different levels, inadequate information and poorly-informed consent.

- In addition, there was total consensus that the array of private interests and structural interests that exist in home care are inhibiting access to care, flexibility for care workers to meet the holistic needs of patients, and acting against the public interest. While some of the direct care provider agencies wanted money devolved directly to them and CCAC roles to be reduced or eliminated, virtually all of the patient advocates (seniors, families, academics, lawyers, community advocacy agencies) expressed concerns about profiteering at the expense of patients, conflicts-of-interest with for-profit companies (particularly those home care companies that also own retirement homes and get care services from CCACs) and greed. Further, in most of the consultations, most participants expressed that non-profit provision of care is a core value.
- A number of issues that were commonly cited by provider agencies include: inequities between wages for community care and service agencies and those for the CCAC staff; onerous application processes to the LHINs and CCACs and onerous billing arrangements with the LHINs; inability to provide best clinical practices and needed care because there is so little flexibility allowed, and; processes that are seen a political or inequitable in CCAC dealings with provider companies.
- Total consensus was also expressed about patients being discharged too quickly from

**Principles for Home Care**

- Universal, comprehensive, accessible
- Public and not-for-profit
- Democratic & flexible with local community governance
- Responsive & transparent
- Integrated into a continuum of care
- Equitable, incorporating a full awareness of diversity
- Standards-based & enforceable
- Respectful
- Accountable to the communities served
- Compassionate

hospitals. In almost every consultation health professionals, seniors and advocates as well as community care providers felt that early discharges are resulting in high rates of readmission to hospital, suffering for patients, and poorer health outcomes. In many consultations, participants described coercion used to force patients out of hospital too quickly and without adequate care.

- Participants evinced a deep level of agreement that care needs to be more holistic, that assessments are not properly capturing need and needs are not met. In southern Ontario, many participants were concerned with the lack of culturally appropriate care for diverse populations. In the north, many were concerned with the lack of care for people in remote communities and extremely poor access to care.

- Home making services were raised as vital by seniors' organizations, family groups and community service agency leaders. They described a home care system that is indifferent to the real needs of people, in particular seniors with home making care needs. Most participants noted that these care needs are crucial for prevention.

Overall, participants in our consultations all across Ontario participants described a home care system that is lacking compassion. In virtually every consultation participants wanted compassion included in the core principles for reform. In fact, in our consultations there was almost total consensus on the

principles that should underlie public homecare.

Charting a course for home care reform will be difficult, and, no matter which course there will be entrenched interests who do not get what they want, but what it clear is that Ontarians will support a principled approach that means real change. Ontarians want our government to focus on improving access to care and providing compassionate care to meet the needs of our communities while embracing social justice and safety for the vital home care workforce. If policy makers allow themselves to be led by these principles and values that should guide reform, for which we have found a deep consensus, we have confidence that the public interest will be served.



# PRINCIPLES for home care reform

Medicare was established when hospitals cared for the ill and homecare for the frail. This has changed dramatically over the last thirty years, with much more clinical care provided at home as well as a growing number of frail elderly and the disabled requiring support at home. At the same time, the commitment of Canadians to the right to care based on need rather than income has not declined. Indeed, support for this value has grown. To modernize the system we need to recognize the principles of the Canada Health Act and apply them to home care.

In applying the principles of the CHA to homecare, we need:

- to allocate public services on the basis of health needs, regularly reassessing the particularly vulnerable
- to include the full range of homecare services, especially therapy, nursing, homemaking, rehabilitation, respite, palliative, and assistance with the activities of daily living
- to recognize that homecare is an essential part of universal health care
- to do adequate capacity planning across the continuum of care
- to accommodate differences among locations, communities and individuals, including cultural differences
- to ensure both decent working conditions and appropriate training for care providers in order maintain the necessary labour force
- to ensure continuity of employment and care provision
- to recognize the determinants of health, which include appropriate food, clean and safe housing environments, and social contacts

## Homecare principles

- Universal, comprehensive, accessible
- Public and not-for-profit
- Democratic & flexible with local community governance
- Responsive & transparent
- Integrated into a continuum of care
- Equitable, incorporating a full awareness of diversity
- Standards-based & enforceable
- Respectful
- Accountable to the communities served
- Compassionate



# **SUMMARY** cross-Ontario round table consultations

In June 2013, the Ontario Health Coalition toured Ontario holding round table consultations on home care reform. We invited seniors' organizations, disability groups, community care agencies, discharge planners, care coordinators, nurse practitioners, nurses, health professionals, personal support workers, unions, students, community health centre staff and clinicians, health coalition members, academics, municipal politicians and other stakeholders to participate. In total, we held 10 round-table consultations attended by 95 people. Consultations were held in Hamilton, Niagara, Kitchener-Waterloo, London, Sarnia, Thunder Bay, Sudbury, Peterborough, Ajax and Toronto.

The notes from each of the round table consultations are included in this report. This feedback, from the almost 100 participants, creates a disturbing picture of how home care in Ontario is experienced by a broad array of those most impacted by home care and their health care professionals, community service agencies and advocates.

In January and February 2015, we followed up with the participants from the round table consultations and conducted individual interviews to see what had changed in the interim. We contacted all the participants that we could find and asked them whether home care had improved, stayed the same or worsened. All but one person said that it had stayed the same or worsened. A summary of these interviews is also included in this report.

Our process was to engage participants in a general discussion on the state of home care services in their area, review a proposal for home care reform developed by the Ontario Health Coalition and get feedback from participants about our ideas for reform. Our goals were threefold:

- to develop a clear picture of what is happening in home care in order to assess the trends across the province and any unique regional differences that participants might identify, and;
- to see whether it is possible to generate consensus for structural reform of Ontario's home care system, and;
- to conduct a democratic process for assessing our policy proposals and modifying them based on the feedback received.

We are sincerely grateful for the time and commitment of all the participants in our consultations.<sup>1</sup>

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<sup>1</sup> Many participants expressed fear that they, their family members who need home care or their agencies would be penalized if they were in any way identified as being part of this project so we have not listed them in this report.





# THE STATE OF HOME CARE ACROSS ONTARIO

While there is not total consensus on everything, there is a truly remarkable level of agreement both about the state of home care and the priorities for reform. In our consultations, all across Ontario participants expressed their deep frustration with what they experience as an unresponsive, inadequate, inequitable, fragmented and overly bureaucratic home care system. While everyone expressed the need to improve continuity of care, there was no attachment to the current system of home care. In fact, participants everywhere expressed a desire for profound reform and significant, demonstrable change.

Ontarians' core values about our collective responsibility to care for each other with compassion are being disregarded, and in every consultation participants shared stories of people in need who have been left without care in sometimes horrifying circumstances. Participants in every part of Ontario from every walk of life expressed passionately that they want to stop the suffering of people in need of home care.

## Access to Care is Paramount

When we asked participants to describe the state of home care in their regions, in every consultation, participants described severe problems with access to care. There was total consensus that many people are not getting home care that they need and are suffering as a result. Many participants shared stories of family members and friends, clients and patients who were deemed ineligible for care despite need, or were subjected to long waits, or simply were not given the option of needed care. Participants conveyed their shock, anger and indignation at this. This was the most common theme running through the descriptions of the state of home care in every region. Everywhere, people who have need for care are not receiving it and everywhere their suffering was a cause of deep upset. It was clear that the inadequacy of home care is a violation of core values shared by participants from every region, every type of interest group, and every age.

## A Need for Fundamental Reform

Participants also reported, with total consensus, that home care is overly bureaucratic, top-heavy, fragmented, and participants believe that many resources are not making their way to improving actual care. This consensus has fed the openness shared by a remarkable range of participants from all kinds of different interest groups that there must be both fundamental structural reform and a profound change in culture in home care.

## Improved Accountability & Responsiveness

There was total consensus that home care should be more accountable and responsive to Ontarians. In virtually every round table, multiple participants reported that there is nowhere for complaints to be heard and no meaningful redress. In every round table meeting, participants wanted us to raise accountability as a priority in our home care reform proposal. This accountability was not seen as the

Results of consultations with 95 seniors, advocates, community service agencies, home care providers, home care workers and professionals, and primary health care professionals

Ministry of Health might define it. People were not calling for more reporting to the LHIN or the Ministry of Health, but rather a process by which complaints would be received and addressed in a timely fashion, and a home care system that meets the values and priorities of Ontarians, with vastly improved responsiveness to the public, to patients and families, and to our communities.

## **Clear Standards**

In an apparent contradiction, many participants also wanted clearer standards, more standardization, more enforcement and other changes that might indicate a desire for more centralization. In fact, the desire for community accountability and responsiveness and standardization should not be seen as contrary. It was clear in the discussions that participants wanted standardization regarding several aspects of home care in particular. These are not incompatible with public accountability and responsiveness to community need. The need for standardization was most often referred to in the context of the following:

- **The right to access care/eligibility for home care**

Everywhere, participants described with frustration arbitrary and inequitable decisions regarding public home care access or denial of access. The inequities described are not only between regions – participants gave examples of cities that have unequal access and many cited poorer access in rural areas – but also between individual clients in the same region wherein clients with lesser needs seem to get more care than clients with higher needs, and also arbitrary cut-offs or disapprovals because of inadequate funding.

- **Quality of care and improved training**

All participants expressed concerns and gave accounts of inadequate training, particularly for PSWs, while home care patients' needs are becoming more complex. Note: in every consultation, participants who were not from unions and were not care workers themselves, expressed concerns about poor wages and working conditions for PSWs, often noting that these have resulted in shortages, high-turnover, inadequate training, missed visits, poor continuity of care and poor quality of care. The leadership of non-profit community, social service and health care agencies in particular noted the increases of wages at the top levels of the CCACs and the precariousness of work for direct care workers. They raised these issues both in the context of social justice and also as a strategic issue in health care reform. Many participants noted that quality of care and complexity of care required changes in the treatment of the workforce to ensure continuity, better training, broader skill sets, stability and professionalism. There were very few individual stories that involved complaints about a particular care worker. These concerns were overwhelmingly raised as a systemic problem.

- **Improved management of care/coordination**

The need for standardization was also frequently raised in the context of complaints about inadequate responsiveness of CCACs to complaints from patients and families, inadequate responsiveness to calls from other health professionals, differing definitions of care needs among different parts of the health care system (ie. a family doctor refers to a patient as palliative but the CCAC has a different definition of palliative and refuses to provide care the doctor says is needed), differing requirements to provide care etc. Participants wanted higher standards across the board for management of access to care, continuity of care, and easier navigation of community care.

## **Patient Advocacy**

There was total consensus that patients needing home care require advocacy and assistance in navigating a complex system of community agencies, CCAC services, LHIN services, and CCAC-contracted provider companies. People had various recommendations about this. Virtually all participants seemed to agree that patient advocates are needed. In addition, some called for an ombudsman-type structure.

## **Integration & Improved Communication/Coordination**

There was total consensus that home care is too fragmented, disorganized, and poorly coordinated. Many of the criticisms of home care from family members, patients, and care providers alike, and focused on poor communication between care providers of all different levels, inadequate information and poorly-informed consent. Primary care providers report that they cannot get information from CCACs, cannot reach care coordinators and do not get their phone calls answered or returned. Community service agencies, advocates, and family members reported poor communication and extremely inadequate or non-existent coordination. In Toronto where home care clients often must cross CCAC boundaries, there were repeated reports of people falling through the cracks. From poor or no communication during assessments, to false information given on hospital discharge, to poorly trained care workers who are not fully informed of care needs or do not adequately inform clients and families of their choices, to woefully inadequate communication and sharing of information among providers, the picture we were given was one of a home care system that is in disarray.

## **Public and Non-Profit Care**

In addition, there was total consensus that the array of private interests and structural interests that exist in home care are inhibiting access to care, flexibility for care workers to meet the holistic needs of patients, and acting against the public interest. While some of the direct care provider agencies wanted money devolved directly to them and CCAC roles to be reduced or eliminated, virtually all of the patient advocates (seniors, families, academics, lawyers, community advocacy agencies) expressed concerns about profiteering at the expense of patients, conflicts-of-interest with for-profit companies (particularly those home care companies that also own retirement homes and get care services from CCACs) and greed. Further, in most of the consultations, most participants expressed that non-profit provision of care is a core value. Most said that they strongly opposed profit-taking from the frail, disabled, ill and elderly. Most wanted reform to eliminate for-profit home care or at least strongly contain the for-profits and stop the poor-practices and conflicts of interest that people are witnessing, including pushing patients to pay for extra out-of-pocket care services, providing inadequate care in retirement homes and bringing in publicly-funded home care to supplement it (sometimes with the same companies benefitting from profits in both the retirement homes sector and the home care sector). Interestingly, the direct care provider agency staff who participated in the discussions were open to ideas other than total devolution, but were frustrated at current practices.

## **Concerns of Provider Agencies**

A number of issues that were commonly cited by provider agencies) include: inequities between wages for community care and service agencies and those for the CCAC staff; onerous application processes to the LHINs and CCACs and onerous billing arrangements with the LHINs; inability to

provide best clinical practices and needed care because there is so little flexibility allowed, and; processes that are seen a political or inequitable in CCAC dealings with provider companies.

### **Early Discharges and Hospital Readmissions**

Total consensus was also expressed about patients being discharged too quickly from hospitals. In almost every consultation health professionals, seniors and advocates as well as community care providers felt that early discharges are resulting in high rates of readmission to hospital, suffering for patients, and poorer health outcomes. In many consultations, participants described coercion used to force patients out of hospital too quickly and without adequate care.

### **The Need for Holistic Care and Culturally Appropriate Care**

Participants evinced a deep level of agreement that care needs to be more holistic, that assessments are not properly capturing need and needs are not met. In southern Ontario, many participants were concerned with the lack of culturally appropriate care for diverse populations. In the north, many were concerned with the lack of care for people in remote communities and extremely poor access to care. The uniqueness of the north is not properly recognized, participants felt. Everywhere, people described regional inequities, noting that care is less accessible in rural areas.

### **Recognizing Home Making as a Vital Service**

Home making services were raised as vital by seniors' organizations, family groups and community service agency leaders. They described a home care system that is indifferent to the real needs of people, in particular seniors with home making care needs. Most participants noted that these care needs are crucial for prevention. In general, participants decried the inflexibility of home care with regards to the provision of home making services. Most felt that these services must be included in the basket of services provided by publicly-funded home care.

### **Restoring Compassion**

Overall, participants described a home care system that is lacking compassion. In virtually every consultation participants wanted compassion included in the core principles for reform. In fact, in our consultations there was almost total consensus on the principles that should underlie public homecare.

### **The Opportunity to Build the Widest Consensus Possible**

While charting a course for home care reform will be difficult and, no matter which course, there will be entrenched interests who do not get what they want, but what it clear is that Ontarians will support a principled approach that means real change with a focus on improving access to care and compassionate care to meet the needs of our communities while embracing social justice and safety for the vital home care workforce. If policy makers allow themselves to be led by the principles and values that should guide reform, for which we have found a deep consensus, we have confidence that the public interest will be served.

# ONTARIO'S HOME CARE SYSTEM

## Issues & Proposals for Reform

Ontario's home care system has been strained by two major policy shifts in recent decades. First is the movement of thousands of sicker and more complex patients out of hospitals to home care, which has been seen by policy makers as a less expensive alternative to hospital-based care. At the same time there has been dramatic reform of the structures governing and managing home care. Compounding these policy shifts are demographic factors including a growing and aging population and a strong desire for people to be supported in living at home for as long as possible when aging.

For more than two decades, Ontario governments have pursued policies centred on cutting hospitals. At the same time, governments have failed to create and enforce clear standards for accessible quality home care as patients are moved to the community. In effect, the continual failure to establish a clear right to access medically necessary home care amounts to an erosion in the scope of our public health coverage. Today, the patients find their ability to access publicly-funded care in community settings to be severely rationed, poorly organized and subject to user fees.

While these changes have not worked for post-acute patients, they are not working for the aging and those with chronic illnesses and disabilities either. The vision of a comprehensive strategy for long-term care, enabling Ontarians to stay at home as we age or experience illness and disability has been largely abandoned.

The result is a home care system that is struggling; unable to meet the burden of a burgeoning client load with increasing acuity for shorter-term care and rehabilitation, and, at the same time, provide a wider array of services to support longer-term care at home for persons with disabilities and chronic illnesses and the aging population. Within the home care system there is a highly-skilled workforce of nurses, health professionals and support workers whose dedication to community care is invaluable. But the system itself is fragmented, under-resourced, and inadequately designed to meet the changes occurring both within the health care system and the demography of Ontario's population.

Home care reform is needed. But in reforming home care we need to take care to build upon the strengths that we have, and avoid the pitfalls of further fragmentation and privatization. The Ontario Health Coalition has undertaken to build consensus for a principled approach to home care reform: one that builds on the deeply-held values of equity and fairness that underlie our health system; that supports democratic governance and processes; that enables persons with disabilities and chronic illnesses and the aging to live at home for as long as possible; that engages the existing resources in the nurses, health professionals and support workers who are committed to providing community care; and that builds upon and reforms the home care governance structures that already exist while addressing the shortfalls in the system.

# Insufficient Funding

Despite repeated announcements about improved home care funding, in fact, home care funding has not kept pace with the offloading of hospital patients and the demographic factors of population growth and aging. Furthermore, CCACs are reporting that they are serving much more acute (medically complex) clients whose care needs require more intensive resources.

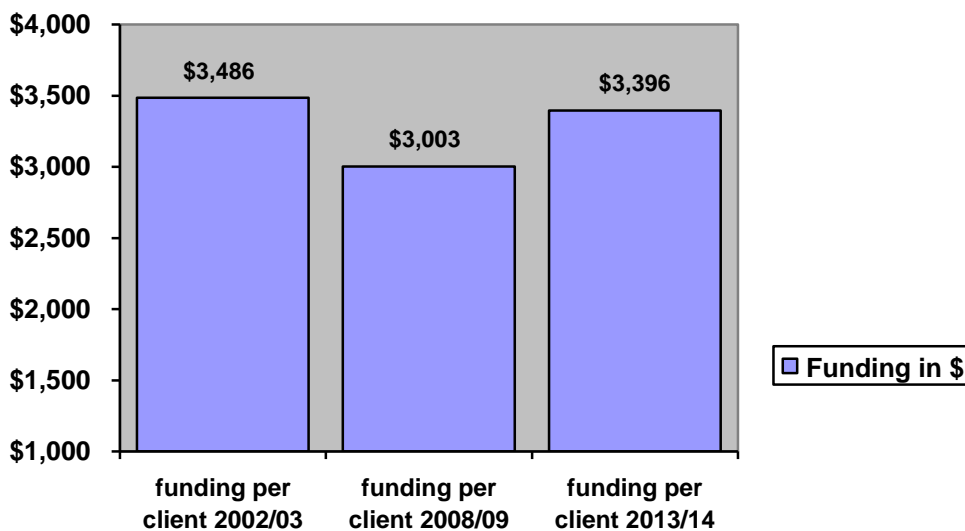
In 2010, Ontario's Auditor General reported that funding per home care client had declined between 2002 and 2009. Following that audit, over the last three years, the provincial government has announced significant improvements in overall funding for home care. But funding increases have not kept pace with hospital offloading and funding per client is still less today than it was in 2002, despite higher acuity.

From the 2004 audit to the 2010 audit, total expenditures for home care increased from \$1.22 billion to \$1.76 billion. In the same period, the total number of clients increased from 350,000 to 586,000.<sup>2</sup> This means that while the number of clients increased by more than 66%, funding increased by just over 40%. Based on the auditor's figures, average per person funding for home care clients was \$3,486 per client in 2002/3 and declined to \$3,003 per client in 2008/9.

By 2013/14, according to Ministry of Health data, the number of clients had increased to 699,020.<sup>3</sup> According to Ontario's Public Accounts, total CCAC operational funding had increased to \$2.37 billion. Based on these figures, by 2013/14, funding per client had increased from the low point of 2009, but is still below the level of funding per client in 2002/03. By 2013/14 funding per client was \$3,396.

Thus, funding per CCAC client is still approximately 3% lower than it was in 2002/03, while acuity (complexity of care needs) for clients has increased significantly.

**Ontario Home Care Funding Per Client is 3% Less Than in 2002/03**



<sup>2</sup> Ontario Auditor General, 2010, pp. 113.

<sup>3</sup> Home Care Ontario, Facts and Figures – Publicly Funded Home Care. Accessed February 26, 2015 at: <http://www.homecareontario.ca/home-care-services/facts-figures/publiclyfundedhomecare>

## Inadequate Access to Care

Though the right to access publicly-funded hospital and physician care across Canada is clearly established in the Canada Health Act, as patients have been moved out of hospitals they find an array of ad hoc and inadequate care in home care, community services and long term care facilities. Often patients are forced to pay out-of-pocket for needed care. Every report since the late 1990s has found home care to be rationed and insufficient. The result is wait times that are chronic and pervasive across Ontario. According to the provincial auditors' reports and Ministry data, home care wait lists have numbered more than 10,000 people consistently since 1998. Wait list figures, however, do not capture the whole picture. The unmet need for care is currently not measured. Wait lists are not tracked in consistent manner across Ontario's CCACs and in many cases there is simply no access to care. For over 15 years of home care reform, the Ontario government has failed to set clear standards establishing the right to access needed care.

Despite marginal reforms, home care services remain ad hoc and uneven across the province. The institution of service caps – a system of strictly rationing the amount of care available to home care clients – started formally in 1999 when the Ministry of Health issued service guidelines and later a regulation strictly limiting access to care.<sup>4</sup> Formally-sanctioned rationing and poor access to care have persisted ever since.

In 2008, the government announced a change in the regulations rationing care available to clients:

- Caps were entirely eliminated for people waiting for a long term care bed.
- For all other home care clients, caps were raised from 80 to 120 hours of service per month for the first 30 days and 60 to 90 hours of service per month after the first 30 days.

The government provided targeted funding increases to facilitate early discharge from hospital for patients waiting for hip and knee surgeries by providing in-home rehabilitation and support services. In addition, the government increased funding to increase the hours of personal support and homemaking in tandem with the increases in the hours permitted under the service caps.

Despite the changes since 2007, chronic home care underfunding, increased demand and poor organization of the sector mean that care continues to be severely rationed and inadequate. Today, entire categories of patients – those deemed to have “moderate” needs or less – are simply denied home care eligibility and/or are cut off. Eligibility can vary from CCAC to CCAC and, within CCACs from one month to the next, depending on arbitrary budget levels. Policy is not centred on measuring and trying to meet community need for care. In fact, need for care is not measured. Continued downloading of hospital patients caused by closure of hospital outpatient rehabilitation across Ontario and the continuing closure of hospital beds means that funding increases have not translated to increased amounts of care for those on home care caseloads. In reality, funding per client has gone down.<sup>5</sup> The number of people trying to access care and failing is not measured. Moreover, inadequate measuring and restructuring of home care has resulted in an inability to assess whether the targeted funding accomplished its goals.<sup>6</sup> As CCACs face deficits or funding shortfalls, they routinely re-assess clients and cut care in a formally-sanctioned system of care rationing leaving many with assessed need without access to publicly-funded home care.

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<sup>4</sup> Regulation #386/99 passed by the Harris cabinet. This meant home care was not to be provided based on need, but according to strict service caps.

<sup>5</sup> See the previous section for calculations.

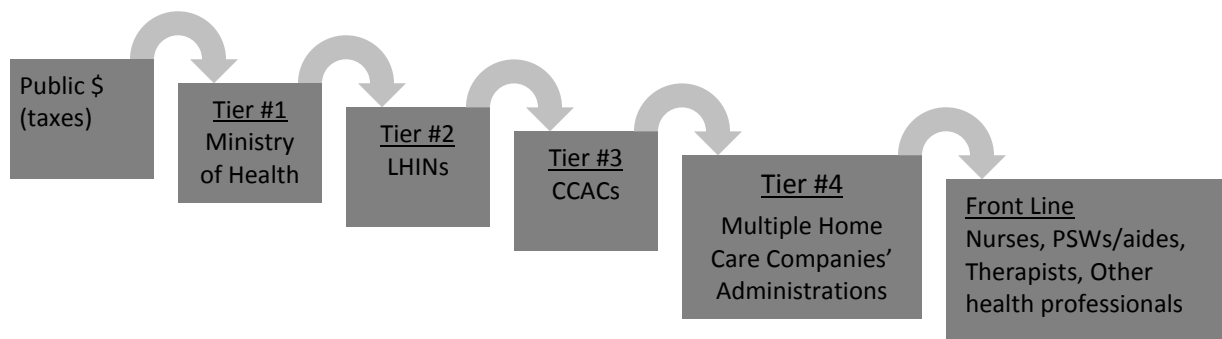
<sup>6</sup> Ontario Auditor General, page 118.

# We Are Still Suffering the Costs and Consequences of Competitive Bidding

Competitive bidding has not existed for nursing or support contracts since 2003 but we are still living with the costs and consequences of it. This system pulled attention and resources away from care provision and improving access, and ushered in an array of provider companies – the majority of which are for-profit – whose interests have dominated the sector. Today Ontario’s home care is provided in majority by for-profit companies and case management and care functions are split between the purchasers of service (CCACs) and hundreds of providers (a mixture of for- and non-profit companies).

As a result, in Ontario’s current home care system vast resources and attention are spent on maintaining an array of providers and rationing care. For more than a decade, setting standards for accessing care, measuring need, and assessing real hands-on quality have taken a back seat. The priorities in system reform have been skewed by private interests and the profit- and expansion-prerogatives of provider companies to the detriment of patients.

The costs of competitive bidding have not been properly assessed by the provincial government. Each of hundreds of contracted agencies has a mark-up in their pricing for services that covers their own administrative costs and profit-taking. The cumulative additional cost of maintaining a vast array of duplicate provider companies has never been measured fully. In fact, in Ontario’s home care system, public funds are transferred through four separate levels of administration before any money reaches the front-lines of care.



**Figure 4. Public funds for home care are transferred through 4 tiers of administration before they reach the front lines**

Since the beginning of competitive bidding in home care, successive governments have claimed that the system design is dedicated to improving quality of care rather than simply cutting costs and facilitating privatization. Instead, more than 15 years after the inception of competitive bidding, the same problems of inadequate and rationed services, poor and inequitable access to care, ineffective or non-existent measurement of community need for service, high administrative costs, staffing shortages, privatization and ineffective measurement of quality and service delivery continue to plague Ontario’s home care system.



# GOVERNMENT ACTIONS

## required to reform home care in the public interest

Home care should be reformed to be provided through restructured public non-profit home care centres, based on the resources of the current CCACs, and organized to respond to local needs. These restructured CCACs would directly hire care providers, although some small, community-based effective non-profit organizations may be contracted to provide some services. The objectives of these agencies would reflect a fundamental change in the culture of service delivery and effective, equitable and safe ways of assessing quality and improving access to care. In the transition

from structures and agencies currently providing home care, workers must be guaranteed successor rights.

In calculating expenditures, we need:

- to recognize the cost of not providing care and of inadequate care
- the costs of the current system of competitive bidding, including the costs of failing to ensure an adequately prepared labour force and of turnover.

## Reform the CCACs & build a public non-profit integrated home care system

The Community Care Access Centres (CCACs) were initially created as regional home care service providers with community-based Boards of Directors and community memberships. They provided direct care services along with non-profit community providers. They were subsequently directed by the Ministry of Health to divest all direct service provision and run contracting systems for all care (competitive bidding).

The structures required by competitive bidding have diverted tremendous resources from care into marketing, administration, profit-taking and redundancy. As a result of the instability created by competitive bidding and massive public opposition, bidding for nursing and support contracts has been stopped since 2003. But the costs and structures set up to facilitate bidding, create a “market” and privatize home care have been left in place.

Home care must be reformed to focus on providing access to care, providing improved integration and coordination, delivering quality based on sound standards, and responding to the values and priorities of our communities. To do this the provincial government must:

- Reform the CCACs to regional home care centres that directly provide care, reducing the duplicate layers of administration and costs involved in maintaining approximately 1,000 separate companies contracted to provide home care. Repeal directives requiring the CCACs to divest direct care and allow the restructured Access Centres to hire direct care staff.
- Provide leadership to change the culture of home care from bureaucratic and unresponsive to equitable, responsive and democratic. Change the executive leadership of the CCACs and ensure that their mandate reflects a

fundamental change in the culture of service delivery, fosters democratic local governance, and support for equity and social justice. Make the leadership accountable for the delivery of home care in the public interest. The reformed local agencies would be charged with providing effective and equitable care, and practicing safe ways of assessing quality and improving access to care.

- The reformed Access Centres should provide case management as well as direct care provision integrated in one organization with the goal of improving accessible, effective, equitable, comprehensive, and high quality care.
- Reverse the private for-profit delivery of homecare by focusing resources on

building quality, local community-controlled, integrated non-profit delivery. Thirteen years of expanded for-profit care has brought no evidence of better care outcomes, but has created instability and removed resources from caregiving.

- Establish a granting fund for non-profit agency pilot projects providing for innovation and identification of specific local community needs that:
  - improve access and equitable services for ethno-cultural and marginalized communities
  - fill service gaps and emerging needs
  - promote health and prevent unnecessary hospitalization or institutionalization

## Fund homecare to meet population need for services

- Establish an enforceable, standards-based continuum of care provided on a universal and equitable basis, without presumption of unpaid caregiving. Every applicant for home care has the right to an assessment of his or her care needs. Every applicant who is assessed as having a need for home care services must be enrolled for home care services. Wait lists should not be used as an excuse to refuse enrollment or ration care. If everyone assessed as needing home care is enrolled, it becomes possible to properly measure waitlists and unmet care needs to improve planning.
- This continuum must include acute homecare services, rehabilitation and other therapies, mental health services, supportive care, palliative care and respite.
- Supportive homecare – based on need - must be re-established to allow seniors to age in place and persons with disabilities or chronic illnesses to live in the community, and in-home respite for family caregivers.
  - Further discussion is required about how to establish need for home support. Publicly-funded services should be based on assessed need, including supportive care that provides a vital preventive and health promotional role.
- Ensure supportive housing is affordable and those who cannot afford it are subsidized.
- Ensure that culturally sensitive services are accessible on an equitable basis.

## Plan to build needed capacity across the continuum of care

Building a better home care system cannot be seen in competition with providing an effective acute care system. Ontarians need both, and sound health care planning must address the needs across the health care continuum.

- Capacity planning across the health care system has not been undertaken for almost two decades. Population need for health care services from emergency and acute care to home care must be undertaken. Planning for infrastructure and resources to meet those needs must be the cornerstone of health care policy.
- The range of community supports that enable people with chronic illnesses,

disabilities and the frail elderly to live independently need to be supported. Most significantly, the need for public non-profit supportive housing must be addressed as a priority. Community agencies that provide day services and supportive care services should not be required to charge user fees (as some LHINs require) and these services should be integrated wherever possible with the public home care system to reduce complexity, improve access and prevention, and assist people in maintaining their health and independence.

## Establish terms of employment with a goal of achieving equality with other health sectors

- Respectful working conditions must include fair, equitable and comparable wages and benefits, pay equity, paid sick leave, pension benefits, employment security and guaranteed hours of work. Improve labour force conditions to make them comparable to the institutional health care sectors. Competitive bidding has contributed to staff shortages and incentives for workers to leave the sector for better working conditions. Turnover is too high

and wastes precious resources as well as destabilizing continuity of care. Continuity of care and quality of care rely upon a stable workforce, which, in turn, depends upon respectful and just employment conditions.

- Establish clear and enforceable whistleblower protection for staff and care recipients.

## Improve democratic governance and community control

- Repeal Bill 130 and restore democratic community governance of homecare services under reformed local home care agencies (as described above) based on CCAC resources.
- Establish clear protection of public access to information. Everyone must

have unimpeded access to information relating to decisions about their care. The public must have access to information that is necessary for meaningful public engagement in policy issues.

- Establish a culture of democratic engagement in home care governance and policy. Such engagement is vital to sound decision-making and should be embraced. A constructive flow of information between policy makers, service providers and communities is the best way to ensure the best possible organization of service provision and appropriate public accountability.
- Establish a clear complaints system and a pro-active and transparent evaluation system for homecare.
- Government should see patient advocates as a vital partner in ensuring a responsive and effective health care system. Fund patient advocates as part of the home care system both to advocate on an individual level and at a systems-level.

# **CONCLUSION** a principled approach to reform

Medicare was established when hospitals cared for the ill and homecare for the frail. This has changed dramatically over the last thirty years, with much more clinical care provided at home as well as a growing number of frail elderly and the disabled requiring support at home. At the same time, the commitment of Canadians to the right to care based on need rather than income has not declined. Indeed, support for this value has grown. To modernize the system we need to recognize the principles of the Canada Health Act and apply them to the full range of services including palliative, long-term residential care, respite care, public health and home care.

There is a widely-held consensus among Ontarians that home care should be a full and equal part of our health care system, embracing the fundamental values of equity and fairness that we hold dear. Our approach to home care reform builds upon those values. In addition, we recognize that Ontario has an existing province-wide infrastructure of Community Care Access Centres with local offices and organizational structures, some of which already directly provide services such as rehabilitation, rapid response teams, mental health services in the school system, and palliative care nurse practitioners. Furthermore, we already have a strong foundation of thousands of dedicated nurses, health professionals and support workers who work in our existing home care system and are committed to community care. We believe that these existing resources provide a sound basis that can be built upon to better provide a comprehensive system of palliative, long-term residential care, respite care, public health and home care.

We have proposed a vision of progressive reform building on our fundamental shared values and existing resources within our CCACs. We are calling for a fundamental cultural change in home care – and the required changes to provincial policy – to reflect the values of public health care, embrace clear provincial standards to improve access and establish safe ways of assessing quality of care, and establish locally-led democratic governance in the CCACs who would become the reformed direct provider of public non-profit home care. We have also protected a role for locally-based non-profit community agencies that are strongly supported by their stakeholders. This proactive proposal addresses the structural problems of fragmentation and duplication while establishing a strong integrated governance body for home and community care that can grow and adapt to changing needs and modalities of care while streamlining resources to provide better access to care. This proposal can and will improve home care in the public interest.



# Hamilton Home Care Round Table Meeting

June 5, 2013

## General Discussion on the State of Home Care in Hamilton

One participant has a brother with brain cancer. He receives publicly-funded home care two times per week for a few hours. His wife and children are working. The amount of publicly-funded home care he receives is totally inadequate.

One participant has a friend who is 94 years old. She gets home care twice a week for bathing. Home care is supposed to come in the morning. They might show up at 2 p.m. or at 6 p.m. The staff are poorly trained and change often. There is no continuity of care. She often has to cancel her outings to wait for care. People are afraid to complain.

This participant does income tax as a volunteer for seniors. Many just need some home support because they cannot maintain their living spaces. "It breaks my heart."

One participant's husband had a stroke. She provides most of his care. She said, "Thank goodness I'm retired otherwise I'd have to give up work." She wonders what will happen when she can't continue to do everything. She has received no respite. The CCAC never talked with her about it. She struggles with home making because she has no help: laundry, garbage etc. They are on fixed incomes and had to pay for his physio (only 20 sessions or 16 weeks are publicly-funded). The Chedoke Rehab Facility has a wait list of 6 months so he ended up at private physiotherapy. Several clinics said they do not have stroke training. They were going to physio four times per week. Private insurance paid 75% and they paid the rest. There was no home care physio offered or it was not available. She did not complain. She said, "Once you question what the discharge plan is, you're toast: they're not referring you to anybody and if you don't get referred you're toast."

One participant noted that testing for eligibility is not culturally appropriate.

One participant noted that if the CCAC thinks that there is a family member with even a little bit of time, they walk away.

One participant has a friend who had surgery. This friend has mobility impairment and uses a wheelchair and could get from the chair to the bathroom. They had no family in the area. The CCAC told this friend it would take a week to assess her after the surgery. Her daughter, who lives out of town, was unable to take vacation days. This person was left without help while waiting for assessment.

This participant said, "The CCAC are beyond being gatekeepers. You have to have strong negotiating skills or you don't get care."

Participants agreed that home care should be based on compassion.

One participant noted that differences in outcomes are so inequitable because some people have strong advocates and some do not. Home care works well for those who have a strong support system.

Some people heal better at home or get infections in hospitals. While home, for some, is a healing place, for others it is not.

This participant noted that in hospitals you see the experts. Once you are discharged to home care it is a whole other world and when people get discharged they have a whole different world to navigate. It is hard for them to get the care they need.

One participant noted that nobody cared for her when her husband had a stroke.

One participant reported that ethnic and cultural support is not available.

## Feedback on the overarching policy statement (Charlottetown Declaration on the Right to Care pp. 2)

People agreed with the sentiment but worried that the word "entitlement" is now seen as a negative.

The last sentence captures it.

Feedback on Principles:

There should be a right to appeal, oversight, accountability.

Change wording from “to accommodate differences” to “to accommodate diversity”.

Insert compassion as a principle.

Feedback on Proposal:

Powers of ombudsman must be established.

Who is monitoring standards of training?

Look at the Manitoba model.

People need to have a way to complain that is taken seriously.

Toughen up language on training.

“Quality” should be more important: “They are not looking at quality. They are only looking at numbers.”

Lots of risk for home care workers, lots of abuse [of workers].

Beef up accountability.

Support for the standards section and the precariousness of employment section.

No one should profit from illness or vulnerability. Participants repeatedly mentioned conflicts of interest as a problem.

Access to drugs and supplies for home care recipients is an issue.



# Niagara Home Care Round Table Meeting

June 5, 2013

## General Discussion on the State of Home Care in Niagara

One participant knows a severely depressed woman who is being given ½ hour every three days to get her to bed. This is not adequate and it is not helping to get her better.

One participant noted that elderly people are not getting enough hours of care: “Six hours a week: what is that? Maybe a couple of baths.”

One participant reported that there are not many palliative care hours available for those waiting for hospice. She knows a person who is dying. The nurse went in and the whole house was filthy. This person needed the full range of services, from housekeeping to nursing.

Participants talked about the high cost of private care. One person reported that home care is \$27 - \$30 per hour from one of the local providers. Participants noted that the home care provider company makes that money, not the workers. While people are dying and not getting proper care, people felt that profit taking was wrong.

Participants talked about continuity of care as a big problem that they see and hear about.

One participant reported that when you call the CCAC all you get is voice mail. It is hard to get ahold of anyone. You have to wait for them to call back. They don't call back.

One participant's landlady is a home care worker. She works with three high-needs people with disabilities. Her pay is about \$15 per hour. The company she works for tells her to use fewer supplies (she was using double-gloves with clients who were incontinent). She is over 60 years old, has a bad back. Home care work is hard physical work.

One participant reported that she has talked to home care workers who lose money because they are not reimbursed for their costs.

One participant reported that a local company does not provide adequate mileage to reimburse staff for their costs of driving to clients.

One participant reported that a woman she knows was discharged from hospital without any home care at all despite having high needs. Another participant verified this account.

One participant reported that many patients from Niagara go to Hamilton for hospital care. When they are discharged care is poorly coordinated across the region. She gave an example of a woman who was discharged from Hamilton. The discharge planner planned her care but the Niagara service providers did not actually provide it. The woman was bounced back and forth when she tried to get the care between the discharge planner in Hamilton and the service provider in Niagara.

Participants noted that people do not know how to advocate and they are scared to lose care.

One participant said that she and her sister were bullied into accepting the first long-term care placement for their father even though it was not good. They made a complaint because they felt so bullied. She thinks this happens a lot. Her aunt was bullied into paying for respite care from a private company by a CCAC representative.

Others concurred that they felt “pushed around”.

One participant noted that if you pay for it, you get home care right away. She gave an example of a person who paid for care and got it within a day on the weekend.

One participant reported that they are pushing people into retirement homes.

Feedback on overarching policy statement  
(Charlottetown Declaration on the Right to Care pp.  
2):

Don't like the word "entitlement" it lends itself to abuse.

Add "quality".

Didn't know what "universal" means.

In general, participants like it.

Feedback on Principles:

Positive.

Add "cultural" to diversity.

Ageism is a problem.

Include compassion as a principle.

Provide public education/support to learn how to access and navigate home care.

It is hard for people to find the CCAC, no one has heard of it.

Feedback on Proposal:

We need to standardize care.

Need to ensure appropriate compensation for care workers.

Need to stabilize the workforce.

# Kitchener Home Care Roundtable Meeting

June 6, 2013

## General Discussion on State of Home Care in Kitchener Waterloo

One participant noted that the assessments are inadequate. Some are done by phone. For his grandmother, they came to the house and looked at the house but never even spoke to his grandmother.

One participant reported that the CCAC said that they put her mother-in-law on the wait list but when they checked later she was not on the list.

One care worker noted that they are only given one hour to give care. Social needs are not being met: "They are not viewed by the government as important."

Another care worker reported that most visits are in one hour chunks. But now, care units can be as short as 15 minutes. She recently went into a retirement home where she was told she had 15 minutes each for 6 clients to "do their armpits and privates".

One participant reported that his neighbours could not get into a long-term care home. They (and he) were shocked at the cost.

One participant reported that PSWs have low wages, inadequate hours, and poor supervision. There is not enough long-term care and so many more heavy-care patients. The long-term care homes are unsanitary and safety is an issue. Not enough care is available to meet need.

One participant reported that he knows home care workers who have to use public transit to get from home to home.

One care worker reported that patients are getting more obese and are heavier than they used to be. She is sent alone to peoples' houses and has to use a mechanical lift. By the rules the lifts need two people. So she has to ask a client's 86-year old husband to help with the mechanical lift. It is not safe.

A participant said it should be peoples' right to choose whether to be in hospital.

Participants felt that care used to be better and is more severely rationed now.

The group felt strongly that care should be not-for-profit.

One participant called for a PSW strategy and respite for family caregivers.

Participants believe in a home care system with values.

One care worker reported that care is inequitable without any seeming reason. One client is blind and on their own. Has one hour of care five days per week. Another client with family who is better off has care 7 days per week. She does not understand the assessment.

## Feedback on overarching home care statement (Charlottetown Declaration on the Right to Care pp. 2):

The last sentence says it all.

We have a collective responsibility to provide care for each other. It isn't just that we want more money, we have a social/collective responsibility.

Change "entitlement" to "access".

## Feedback on Principles/Policy:

Add in "compassion".

Participants want a way to be heard/complaints/ombudsman.

Beef up accountability.

The CCAC is very arbitrary.

Informed choice/consent should be added.



# London Home Care Round Table Meeting

June 6, 2013

## General Discussion on the State of Home Care in London

One participant reported that she sees too many layers of assessment and a system that is too bureaucratic. There is the provincial assessment (CCAC) and then the private companies'. For clients it ends up a shell game between the two and no one is accountable. The assessments are poorly done: cultural needs are not included and there is no investment in educating the family and ensuring that the family understands the issues. Prevention like this would avoid hospital readmissions. There is also a lack of standardization and training. Very low standards of payment for home care wages. It is not a career, it is a stepping stone.

Other participants agreed with this description.

One participant noted that it is more difficult for the rural population to access care, more hesitancy and lack of knowledge about care options. This participant felt that there is a lot of money in the CCAC not going to care.

One participant reported that her mother is receiving private home care from 4 – 7:30 p.m. every day. It costs \$23,000 per year. She can only get publicly-funded care for ½ hour each morning and noon, not evening. Virtually every day they send in a different worker. Her mother is upset because the workers do not know what to do and she has to train them over and over again. It is \$21 per hour for private care.

One participant reported that the top pay rate for workers in one agency is \$15.02 per hour (PSW wage).

One participant reported that her friend could not get enough home care and had to sell her farm to pay for private care by a private provider company.

One participant reported that they were formerly on the CCAC board for many years. Their experience was that it was so top-heavy and complex that by the time care and support is given it is too dissipated to be appropriate for peoples' needs. There is nowhere for people to complain: "Even with my ability to advocate I was pulling my hair

out." It is disorganized, with poor flow of information, very little accountability. People who speak Arabic get care workers who speak Spanish, for example.

All participants reported that home care visits are often missed by workers. Often the workers never come at all, leaving clients waiting for care.

One home care worker reported that they work "short" [short staffed]. There are not enough staff. Also care work is more complex. They used to do shopping, cleaning etc. Now it is medicine reminders, physiotherapy exercises, more nursing home clients.

One participant responded that the whole system is about acuity. Home care has not been modified in terms of training and compensation for the higher acuity.

Another participant noted that there is poor training particularly regarding cultural issues. Workers do not know how to do meals appropriate for the culture of the clients.

One participant said that the bidding system is not open and fair, "It is very political".

## Feedback on overarching home care statement (Charlottetown Declaration on the Right to Care pp. 2):

Agree with the principle. People in the home are vulnerable. This should be recognized in the statement.

The inadequacy of home care is a form of elder abuse.

State the danger of not doing care.

Include the care provider point of view.

## Feedback on the Principles:

Accountability to the community that is being served is important.

Add compassion as a principle.

Safety is important.

There are quality committees in hospital but not in the community.

Advocacy needs to be built in.

People need somewhere meaningful to complain.

Feedback on the Proposal:

Home care needs to be standardized.

Money should follow the patient.

Training needs to be standardized.

Safe conditions must be ensured (for clients and care workers).

You cannot standardize care without people who are making poor wages.

# Sarnia Home Care Round Table Meeting

June 8, 2013

## General Discussion on State of Home Care in Sarnia

One participant reported that CCAC is supposed to move to “outcomes-based funding”. They are not currently doing it here. Each CCAC makes a decision about what is on the formulary.

One participant described a patient with dehiscence of a surgical wound. This person had been going for daily dressing changes at a CCAC clinic. This is not a best practice. It took the primary health care provider a week to get in touch with the CCAC case manager (the phone was always on voice mail). The primary care provider tried a proposal that is not on the CCAC formulary. The patient has to pay for this dressing out of her own pocket.

The CCAC only allows 2 negative pressure wound dressing units in the community at this time. The only way patients get what they need is if they have extended insurance or pay themselves.

“It takes so long to get ahold of the case managers to consult.”

See the recommendations of the ONTWG wound group.

One participant added: people have to drive to the “home care” wound clinic which is private. Who is making the money from them not having to drive the services to peoples’ homes? It is far to drive and far away from the hospital. The clinic is near Chatham, while wound care in the hospital is in Sarnia. So patients have to shuttle between the two at their own cost and they have to find transportation. They also have to pick up their own dressings.

One participant responded saying, “even more basically, people don’t know who the CCAC is and how to reach them”. There should be one phone number. People don’t know what the service offers. When you are on the phone, you get forwarded on and on and on.

This participant reported that their concern is so many layers of bureaucracy. When you get a CCAC contract you are responsible to the Ministry, the LHIN, and the CCAC. This person’s agency had a contract with the CCAC and gave it up because it was “too crazy”.

This participant reported that need has increased. Their agency’s community services have tripled from 13,000 one-way trips 5 years ago to 37,000 today. But resources are going into the upper layers. Staff is suffering. Their staff has seen no increase.

One participant reported that the Wallaceburg hospital has been cut but services were never put in place before the cuts. Complex continuing care beds have been cut while the local long-term care home has been trying to get 4 restorative care beds for 2 years.

Another participant responded that there is lots of long-term care shuffling going on. Lots of long-term care homes are vying for the restorative beds. In January there was a big change from government in high-intensity needs funding: \$0.62 per day/resident. [This is for people with complex wounds, tube feeding, respirators etc.]

One participant reported that her father needs physiotherapy. He lives in a long-term care home. He has been waiting for three weeks because he has been referred all over the place.

Another participant noted that the decision-making regarding long-term care and housing is divorced from the reality of peoples’ needs.

A participant said that patients are being discharged from hospital and sent home without care to wait for care.

Another participant confirmed this and said that, “often before they get their home care they are back in the emergency department.” This participant gave an example of a patient who was discharged before a weekend after having their blood pressure medications changed. The participant phoned repeatedly to follow up with the

CCAC to make sure this patient was being monitored. It was a weekend, "God forbid that you get discharged on a weekend," so no one answered the phone.

Another participant said that the CCAC is a Monday to Friday organization.

One participant noted that discharge planners limit the alternatives that they give to patients. I.e. they won't tell people that they have a choice between home care wait list, long-term care and hospital.

One participant noted that if you do not need help bathing, you cannot get home care.

Another participant reported that the assessments are not accurately assessing need.

One participant reported that there is not adequate training and not adequate accountability. This participant described a patient who was receiving PSW home care three times per day. The patient smelled of urine, had not been changed. Her lips were dry and cracked and there was a thick skin all over her mouth. Clearly she had not received mouth care and was dehydrated. Nobody had checked her mouth. She estimates that the patient had gone 2-3 days without eating or drinking.

This participant reported that post-op patients are prioritized.

One participant reported costs for meals on wheels \$6.95/hour and home making \$16/hour.

One participant noted that there is a need for more home making and preventive care because there are so many seniors in the community. She

suggests increases of types of services such as seniors' "day spas" to get their foot care etc.

Feedback on overall home care statement (Charlottetown Declaration on the Right to Care pp. 2):

We should be clearer that we are anti-privatization.

General agreement with the statement.

Feedback on Principles:

The system needs to be understood by the users/public.

Spell out what public and non-profit means.

Add interprofessional/interdisciplinary team.

Add in patient advocate. If you know the system you can get through it but not so if you do not.

Need ombudsman.

Feedback on Proposal:

The CCACs need fundamental reform. They are too bureaucratic and they don't provide care.

There is certainly room for integration. Build a new system that is integrated.

Concern that if you restructure the same people will be on top. There needs to be a cultural change.

They sent no feedback on the clients they receive. Their policy is not to give you a discharge summary.

Need to beef up accountability.



# Thunder Bay Home Care Round Table Meeting

June 10, 2014

## General Discussion on State of Home Care in Thunder Bay

One participant reported that home care in Thunder Bay is “awful”. The staff are not adequately trained for clients’ needs. Often home care visits are missed and staff do not show up. Increased resources are not improving things.

One participant reported that a large part of the local client population has responsive behaviours and there is not adequate training and consistency of care. It is difficult for clients to adjust to “umpteen people within a day or week”. Many of the First Nations people we serve are stranded here from remote communities where there are no services. Therefore a high-needs population congregates here in Thunder Bay. The bureaucracy involved in getting money from the Aging at Home program [through the LHIN] does not make sense. We have to bill them every week. Why not just transfer the money to us?

One participant reported that their mother-in-law is on home care. Workers change all the time. It is not consistent. Often workers do not show up for scheduled visits.

One participant noted that they started their career as a PSW/aide. They understand how challenging it is when you are in an environment when you have to do a certain list of things within a certain time it is difficult. This participant said she is mindful that the people providing care are marginalized themselves. It is a gendered workforce and their work is undervalued. It is a competitive situation. Graduates want permanent full-time jobs but the reality is casual not full-time staff. It is a woman-workforce trying to piece together a living working for a number of companies at the same time. Often they are working ridiculous shifts, exhausted, burnt out, not resourced properly. This does not make for a happy worker and good care. It means that if they are working in home care for an agency and in a long-term care home, both part-time, if the long-term care home pays \$2 more an hour and they get called in, they will cancel their home care shift.

One participant reported that in Thunder Bay, they are in a region the size of France. It is unique and

has unique needs. Health care providers lack information about aging and the elderly. There is a lot of hospitalization of the elderly due to poor prescribing practices and poor information on medications. Lack of health care provider education is vital.

This participant said that the drive for cuts is increasing “managerialism” and wasting health care dollars. There is a lack of comprehensive care and continuity of care. There has been a medicalization of care in the community: “We were told when care went into the community it was supposed to be responsive to people and meet their needs. Instead it has become myopic and medicalized.”

The system is very trendy and reactive. Some people may have some care today and it is gone tomorrow.

One participant reported “we have a multi-tiered system”. For ALC patients, to get someone out of hospital bumps back everyone else on the wait list.

This participant noted that families are not equipped and educated to understand their choices. Families need to have a serious discussion about what they want and do not want in terms of intervention.

Another participant noted that family caregivers are not listened to by CCAC. If they have been providing care for a long time and say they cannot do it anymore they should be heeded. Hospital planning should take this into account as well. Respite and home support are not available, they are not listening.

Families are not viewed as being credible. Some people have been on the wait list for Assisted Living for 15 years. ALC takes priority and some people just keep getting bumped back.

Another participant noted that Thunder Bay hospital is in code “gridlock” virtually all the time.

Another participant reiterated that even when a person is given home care many of the scheduled visits are missed.

Feedback on the overarching home care statement:

General support.

Situate home care within the types of care people can get. What is the function of home care?

Change “diversity” to “heterogeneity and diversity of Canadians and their lived conditions”.

Feedback on the Principles:

Bump up standards-based and enforceable.

Add compassion.

Bump up accountability and responsiveness.

Add in “person-centred care”.

Spell out geographic locations – the important point here is that in outlying areas there is no care at all.

Could go more deeply into the social determinants of health.

Should be responsive to the “holistic needs” of the individual.

Feedback on Proposal:

Pleased to see mental health status included.

Where is the LHIN? This should be targeted also. It is overly bureaucratic, “reactionary”, disorganized.

The LHIN forces community agencies to take away our focus from the actual work to do things like their “system integration” and administrative trends.

The LHIN is a buffer for the government.

Need to clarify what is under the LHIN and what is not.

Community participation should be a big part of governance.

Restructuring of the CCACs is already happening. Not sure how to get profit out of the mix at this point.

There needs to be a fundamental culture change at the CCACs. Not sure how that can be done.

Concerns about the uniqueness of the Northwest being recognized.

- Small communities in outlying areas cannot fly to meetings, participate. Feel not a part of it. Far less services.
- No long-term care beds available, Lakehead psychogeriatric unit closing, worsening bed shortage.
- Shortage of staff. Staff training. Both big issues.
- Geographic area of Northwest 80% of province area, 10% of population.
- Very little creativity in how to address needs. How to connect smaller towns with oral care program in Thunder Bay, for instance.
- Aboriginal communities are having a hard time establishing memoranda of understanding with CCAC for example.
- Problems accessing services in appropriate languages.
- Not enough hostel beds for people flying in for surgeries.
- No upstream services being put in place.
- Lots of readmissions in hospitals – people being discharged too early.
- Fragmented discharge planning.

# Sudbury Home Care Round Table Meeting

June 12, 2013

## General Discussion on State of Home Care in Sudbury Region

One participant reported that this area is different from the south because of the great distances between places. Competitive bidding has made home care top-heavy. This participant worries about the poor working conditions of the workforce. The top rates for seniors employees [PSWs] are \$14.50 - \$15 per hour. Starting rate is \$12 per hour.

There is not enough care across the continuum. 728 beds were closed in the three old hospitals. There are supposed to be 560 in the new hospital. There are not even 500 at this point.

This participant expressed that he wants his care to be under his control from home to hospice.

Another participant stated that a lot of people would agree with that.

This participant reported that CCAC criteria are very strict. This participant's mother needed home making to age at home. She didn't qualify for CCAC care even though she could not provide this for herself.

For many in the older generation, women did not work outside the home. Therefore they only have public pensions to rely on. On average, their incomes are \$14- \$15,000 per year. A secure place to live in Sudbury costs \$12,000 per year. For a person who has an ostomy, for example, the supplies cost \$3,000 per year. Home care will pay for incontinence supplies [ie.diapers] but they won't pay for the bags.

The Alzheimers Society has a co-pay program to top up CCAC home care. 1/3 of their clients cannot afford it.

Community RNs are paid half of what CCAC RNs are paid. They need comparable funding to provide comparable services.

40% of people who access emergency departments have dementia. Need strategies to

support families and workers who are caregivers for people with dementia.

Private costs for a PSW are \$25 - \$32 per hour. Agencies are competing for money.

To navigate through the community care system, patients need help. Seniors find all these agencies hard to understand.

One participant gave two examples of people who could not get adequate home care. A brother-in-law had an ostomy and had a bag. His sister was told she had to change it. She had no idea how to do it. This was a very onerous requirement for her. A friend had an amputation and similarly was not able to get care.

Another participant reported that they see PSWs trying to squeeze two hours of care into an hour. The system relies on the PSW modifying the care plan because they are not funded to provide the care.

One participant noted that there is poor recruitment, inadequate training for PSWs.

Another participant said, "if you complain, workers won't show up".

Another participant added, "If home care really is the health care of the future, you can't be advertising for workers in the paper saying "No experience needed"."

Another participant added: "It is a sad situation when retirement homes and long-term care home residents have to hire in PSWs."

There is not enough supportive housing.

One participant reported: The CCAC has a lot on its plate. It has always been treatment-focused. The health promotion piece isn't there. Physical activity is desperately needed. Community service agencies are doing a lot of the grunt work and are not resourced or recognized. The CCAC was mandated to do admissions to day programs. They only did two admissions in six months.

There are lots of complaints with the LHINS/CCACs.

Equalize pay between the community sector and CCACs.

Feedback on overarching home care statement (Charlottetown Declaration on the Right to Care pp. 2):

Agree with it.

Yes, it is a human right.

Feedback on Principles:

Add in linguistic needs.

As much as possible home care should meet the needs of people.

Add in something about empowering people to manage their own care.

Training is so important.

The Long-Term Care Homes Act recognizes abuse and neglect. There is no such thing in legislation for CCACs.

Public education is needed.

Seniors themselves should be included in decision-making.

Feedback on Proposal:

Bump up supportive housing.

Some participants strongly wanted to remove for-profit companies.

# Toronto Home Care Round Table Meeting

June 14, 2013

## General Discussion on the State of Home Care in Toronto

One participant reported that home care is intensely bureaucratic and underfunded. Their goal is to have a missed visit rate of <1 in 2,000 visits. RPNs and RNs are given a group of clients, paid per visit not hourly.

Another participant reported that home care workers suffer a significant rate of back injuries and are poorly paid. Some of the patients have complex care requirements and psychiatric needs. Heavy care work is being downloaded to PSWs. PSWs have to cobble together multiple jobs to make ends meet. This participant's hairdresser is a PSW.

One participant reported that in the Toronto region a discharge from a hospital may cross CCAC boundaries. In these cases there is poor communication and higher chance of the client being dropped from the assessment list. She gave an example of a patient discharged from hospital with an infection, not visited, had a fall. She is concerned about care workers not being professionals, not understanding doctors' orders and care plans. More and more care is downloaded to families. Schedulers are not well trained. Travel time for the workers is not realistic and care time is not adequate. No time is given for human contact: this is needed to assess the client properly. There are serious communication problems between all the service providers.

She reported that CCACs are assigning care workers to do additional support in retirement homes. Workers are doing Hoyer lifts alone because they cannot get anyone in the retirement home to help them. This is not safe.

The lack of integration and coordination is costly.

Another participant joined in. She said retirement homes are not providing the care that people are paying for. There is a lot of confusion. People fundamentally do not know their rights in retirement homes. In these homes the assessment

might be done by a PR person. When advocates challenge the assessments the costs go down.

Another participant noted that there is constant restructuring in home care. RAI assessment is the standard. If you just need bathing and are under 8 on the RAI you are not going to get home care. There are user fees and means-testing for home support services. There is an ombudsman in the Toronto CCAC. There is no wait list in the Central Toronto CCAC.

Another participant said that right across the road [Victoria Park] there is a wait list.

Another participant noted "it's not a system, it's a mess."

One participant told her story. She was in hospital and tried to get home care for her discharge. She said "it is confusing and I'm not dumb." Even if a person's rights are known, if they can't speak up they don't get them. She has a friend on home care who is afraid to go away on holiday because she is afraid to lose her services.

One participant told of three clients she is advocating for. They all have Alzheimers. They all had to go to long-term care homes because they could not get publicly-funded home care. Their families work full-time. In one case, the daughter works and couldn't leave her mother in the emergency department because there wasn't enough staff to watch her. Her mother was on a gurney in the hallway and kept trying to get off the gurney. The daughter was in trouble at work because she couldn't go to work. In the second case, the daughter who works full-time was caring for her father with Alzheimers. Her mother had passed away. Her Portuguese father needed more care than she could give and they could not get home care so she had to pay to put him in a retirement home. This participant noted that there is a 6-year wait list for Chinese-speaking long-term care homes.

Among the participants there were many complaints about retirement homes getting rich,

patients paying a lot for retirement homes, inadequate care in retirement homes.

One participant who used to be a retirement home operator reported that the net profit for these homes is in the mid-30% range. On health care costs, the homes can charge up to whatever level they want — 118% profit, for example. She reports that she receives complaints about “pushy” discharges from hospital, patients told that they have to take a placement whether it is a bad one or not.

Participants talked about the cost for privately-paid home care. One participant reported that it costs \$60,000 per year for live-in help in Toronto. Another reported that \$26 per hour is the low end.

One participant noted that many home care companies also own retirement homes. They get subsidized by the CCAC hiring in their companies to supplement inadequate care in their retirement homes.

Participants were concerned about profit-taking from frail and vulnerable people. Participants concerned about conflicts of interest, pushing clients to pay for private care, “chasing of money” at the expense of equity and patient care.

One participant reported that they had clients for whom they advocate that were palliative. Because they didn’t die fast enough they were cut off of home care.

Feedback on overarching home care statement (Charlottetown Declaration on the Right to Care pp. 2):

Participants agreed with the statement.

Feedback on the Principles:

General agreement on what is there.

Add in timeliness.

Note: specialized geriatric training needed, training needs to be appropriate for client population.

There needs to be some set of clear standards.

Bump up accountability.

Must meet the unique needs of the client/client-centred.

Clear standards for eligibility.

Under equitable, add fair and appropriate.

Integrate promotion and prevention wherever possible.

Somehow address the over-bureaucracy.

Address the problem of navigating the system.

Stop for-profit home care.

Feedback on Proposal:

Define some of the items more clearly. Define supportive housing.

Make principle “nutritional” food.

Include health and safety of workers.

Include that there is a higher level of risk in home care that must be recognized and mitigated.

Participants discussed whether or not full home making should be an entitlement. Some felt that it should not be an entitlement while others noted that just because, for example, my sister can come and bathe me doesn’t mean she is going to do it. Others were concerned about the “slippery slope” of means-testing. Agreed there needs to be a more holistic understanding of need. Assessments need to be improved. Eligibility criteria need to be improved. It needs to be equitable and reasonable.

# Ajax Home Care Round Table Meeting

June 15, 2013

## General Discussion on State of Home Care in Ajax/Durham

One participant reported that there are many adult with disabilities and younger people (eg. MS, ALS, MD etc.) living in long-term care homes because there is not enough home care. Evaluations are not good. Community agencies have to raise money through fundraising and it is more competitive and poorer economy means declining returns. The MS Society funds equipment and supports (wheelchairs, house cleaning, PSWs etc.). It used to have up to \$1,200 per client per year, now has had to reduce this to \$900/client/year.

One participant reported that it costs \$35 per hour for private home care.

Another participant said the workers are making \$15 per hour.

A participant reported that 5% of people in long-term care homes in Durham are under age 65.

One participant reported that her friend just got into supportive housing after an 8-year wait. Very tight criteria to get into supportive housing: no dementia for example.

One participant reported that her mother-in-law (who passed away recently) was assessed for home care. The assessment was done on computer, didn't capture her real needs. The assessment assumed the family would be doing the work. She was assessed for 1 hour every 3 days. Then she had a fall and was reassessed. Then two different companies are coming in. Workers turn over very quickly. In the last week of her life she had eight different people in her home. In some cases the workers didn't know why they were there or what they were supposed to do. There was not continuity of care. The workers said people kept quitting, that's why there was so much turnover. Her mother-in-law didn't like so many people seeing her body. The turnover is high because of poor wages, workers losing money, transportation issues. These are serious because they are affecting the way service is given. This

participant is from Port Perry and noted that it is worse in rural areas. Schedulers need training.

This participant talked about the heavy burden of care on her. Her mother-in-law's care was complex and heavy. Her mother-in-law had a shunt in her belly to receive drugs. She had to administer the drugs through the shunt. She was afraid to do it and uncomfortable keeping narcotics in the house. She was afraid of the side-effects of the drugs. She started having stress-related health care issues. The assessment deemed the family did not need respite. They didn't get respite until three weeks before her mother-in-law died. In order to get that respite she had to go to both her own doctor and her mother-in-law's doctor with her health problems. She was told by her mother-in-law's doctor that her mother-in-law was palliative and the home care situation would improve. She was told by the CCAC case manager that the doctor's definition of palliative and the CCAC's definition of palliative were different. She had to buy a hospital bed for her mother-in-law because she kept trying to get out of bed and she was afraid she was going to fall. They needed a special mattress and didn't get it until 1 ½ weeks before she died.

Another participant told of a worker who didn't have enough money for bus fare.

Another participant told of her daughter sent home and told to do her own needle with no training.

Another participant told of a friend who had a lung removed. He was sent home with no one. The discharge planner tried to get this participant (a friend) to say he would give the care.

One participant who is a home care worker told of being given 15 minutes now to do a home care visit. (Used to be an hour or a half-hour.)

Feedback on overarching home care statement (Charlottetown Declaration on the Right to Care pp. 2):

Participants agreed with it.

Feedback on Principles:

Note inequity across regions of Ontario.

Note extraordinary long waits. Some patients waiting up to 300 days for home care.

Add in fair wages and benefits.

Add in proper training, bump up accountability.

Add in “holistic”.

Feedback on Proposal:

Home support needed for younger people with disabilities and chronic illnesses who want to live independently.

There should be a national home care plan.



# Peterborough Home Care Round Table Meeting

June 17, 2013

## General Discussion on State of Home Care in Peterborough Region

Participants reported that people are being discharged from hospital without care in place.

One participant told of a friend who was sent home twice after a heart attack. She has diabetes and is an amputee. The expectation was that her friend would take care of her. She returned to hospital in a diabetic coma. Another man she knows was sent home. An agency came in and left him six frozen dinners but his fridge was not working.

One participant noted that there is not enough funding to serve the population. More ODSP recipients are being moved onto the health care budget. There are 8 rural townships in this region. Access and transportation are a big problem. User fees for home making are \$15 per hour.

Another participant reported that the area has a large seniors population and a large population living under the poverty line.

One participant reported that wait lists in the community are long. "If you don't arrange for home care from the hospital you can wait quite some time." Patients require advocates to get the care they need.

One participant said that it feels like there is nowhere to complain. Patients need help navigating through the system.

One participant added that she is from an advocacy organization and is not aware of any individual client-based place to make complaints.

Another participant noted that there is wide variety and skill sets of people going into the home. There is huge pressure on the hospital to discharge but it is a false economy as patients end up readmitted. Better skills are needed to assess home care recipients as their needs change and to prevent unnecessary hospitalizations. Care workers are being put into situations that are beyond their depth. There is a need for care workers to broaden their skill sets. This won't happen with such a big

wage differential between home care and hospitals.

One participant reported that the community "is not sexy for nurses". New grads like to go to emergency or the ICU. In home care nurses need skills to look at the whole client. More money is needed in community care. The CCAC can be a barrier to clients getting the care they need.

Another participant said that the curriculum should be changed to reflect chronic care needs and agencies need more money for training. Pay differentials are a deterrent particularly when new grads have student loans to pay off.

This participant reported that waits are longer for people trying to access home care from the community because hospital discharges are priority. Care is rationed because there isn't enough funding. There is competition between regions. This region is competing against Scarborough for resources and services.

One participant expressed concern about the lack of power for families and patients. People work now and don't have the ability to stay home to be caregivers. They don't have a say in how much care is needed: "It is taken out of your hands by the LHIN and CCAC". This participant said that the LHIN and CCAC should be working together. He also advocated for better PSW training and noted how vulnerable home care clients are.

Another participant noted that there is a lot of inconsistency in care workers. Lots of turnover. Training is key. Poor pay and long travel requirements mean that care workers lose money. Different care workers have different skill sets and will only do certain things. For example, some care workers will do some light housekeeping and some won't. Patients are not given full disclosure with the Home First program. Some may get care after discharge from hospital but for only one or two weeks.

A participant said that there is a need to capture the metrics associated with hospital readmissions.

Several participants talked about inadequate home care for people and long waits for care.

Feedback on overarching home care statement (Charlottetown Declaration on the Right to Care pp. 2):

General feedback – participants like it.

Right to care is accessing care. Need to be clear that people can't access care. Need to be clear about the purpose of the statement.

Feedback on Principles:

Enforceable by whom? Currently they are not responsive to complaints.

Citizens should have real input. Lots of support for democracy, non-profit, universal.

Add in supportive housing, food and nutrition, activities under 6<sup>th</sup> bullet.

Advocates are very important. Add them in.

Care worker compensation is important.

Feedback on Proposals:

Lots of concern expressed by participants about the amount of bureaucracy/top-heaviness/too few resources going to care. Participants also did not see the value of the LHIN.

Support for a multiservice agency. Some participants were highly critical of CCACs. Agencies want power devolved to them. Several felt that there cannot be real change unless the leadership of the CCACs is changed. Just restructuring and leaving the current leadership in place will not create the needed cultural change. Others felt that there is not enough flexibility among case managers. CCACs are handcuffed.

Home making very important and should be included.

Participants like the idea that everyone should get enrolled and therefore unmet need be measured.

Most wanted more accountability to the public. Noted that there is no evaluation and the system is fragmented.

# Follow-Up Interviews with Round Table Participants

## January & February 2015

In January and February 2015, we conducted follow-up interviews with participants from our earlier round table consultations to update our report. We contacted all participants that we could find and asked them the following questions:

- Has public home care improved, worsened, or stayed the same?
- Has the organization of the home care system improved, worsened or stayed the same?
- What has changed in the last year, if anything?

Respondents include the full range of groups and individuals represented in the round tables in June 2013, among them: seniors, faith leaders, workers and unions, representatives from community agencies providing care, representatives from health care agencies that advocate for patients, primary care providers, academics, and home care patients'/ clients' families. We received responses from rural and urban areas across Ontario including: Hamilton, Sarnia, Thunder Bay, Toronto, Ajax, Kitchener-Waterloo, Peterborough, Sudbury and Niagara.

The following is a summary of their responses:

### Has public home care improved, worsened or stayed the same?

All but one responded that home care is the same or worse now, as follows:

- Worsened because of the loss of chronic long-term and short-term beds.
- Seniors are accused of blocking beds because they have nowhere else to go.
- Services remain very acute.
- Since there is an increase in the senior population there are insufficient home care workers to meet our needs.
- The hours allotted for home care services are insufficient to meet our needs.
- There is a lack of culturally competent care, new immigrants are marginalized, there are language barriers.
- It has stayed the same because there are no new funding policies.
- Public home care has worsened because of an increase in wait times.
- Public home care has worsened because services are not available.
- It has stayed the same with frequent complaints about missed visits.
- It has worsened. Wait times are worse because of a lack of funding.
- There is an increase in wait times.
- Low and medium acuity clients receive insufficient care and physiotherapy time.
- There is also a diminished quality of care being delivered.
- It has worsened; home care workers have an increase in client caseloads.
- It has worsened because there are not as many workers available to see clients. It is difficult for patients to access these services.
- Home care has worsened because of an increase in wait times.
- Home care has worsened because CCAC has no consistency in providing services to families in different regions. When the hospital discharges people to home care there are not enough services due to budget cuts and restrictions in home care. There is a decrease in the number of hours given to patients. Services are not being reinstated, and services like physiotherapy are just not being publicly covered.

- There is an increase in wait times.
- Home care has worsened because of a decrease in funding, however, this is not within their control.
- Home care has a difficulty in predicting the demand for care.
- It has stayed the same due to a decrease in funding.
- There is no compassion.
- Home care has worsened because of the long wait times. Clients receive different home care workers every time they receive care – there is no consistency in care. Home care workers are not properly trained. They are given low wages. Individuals with higher management positions earn high salaries. There is a decrease in funding and less time being provided in patient care.
- Access to home care has worsened with increased wait times.
- Access to public home care has worsened because there is a decrease in resources. Home care focuses more on patients with acute care needs. Home care is not a sustainable way to meet these clients' needs.
- Access to home care has worsened. There have been times when patients have been denied due to lack of staffing. It routinely takes about one week to contact any case manager within the CCAC system, for primary care providers.
- I do not think community care has improved.
- Families of people who need home care are reporting that access to public home care has worsened. Wait times for services are longer.
- Note: there are 2-tiers of home care. One that is 100% funded (CCAC) and the other

that must fundraise for the provision of services. It has worsened. There is a total disregard for the social determinants of health of our population and a disregard for our most vulnerable populations such as persons with cognitive impairment. The following concerns are being reported:

- Little training of front-line workers and professionals with a comprehension of the needs of those who have Alzheimer's or related dementia/cognitive impairment
- Poor inclusion of caregivers in service planning
- Poor access to respite and crisis support
- Problems with CCAC management of day program. It should be 100% funded and seen as a home care program.
- Increasingly we have to fundraise to support the needs for financial assistance and transportation costs
- Staffing is not comparable from the south to the north of this province.
- Transportation needs are not being met.
- Home care is in a state of disarray and getting worse.

One person responded that they think home care has improved as follows:

- There is an increased amount of funding to the LHINs and from there to the CCACs, at least for seniors. There is some indication that this is being extended to younger adults with neurological disabilities.

Has the organization of the home care system improved, worsened or stayed the same?

All but one responded that it has worsened or stayed the same as follows:

- Stayed the same because there are no new funding policies.
- Remains disorganized because patients do not receive holistic care. Improved planning and integration must take place.
- Home care workers are not paid enough and are not compensated for their travel time.
- Planning remains disorganized.
- There remains a lack of care being given to seniors.
- There needs to be better organization, co-ordination and communication.

- Organization of home care is not better. It has remained the same. Care remains insufficient.
- There is no consistency between various regions providing home care.
- The organization of the system has worsened. There have been two strikes since 2013.
- There is a complete lack of consistency between regions.
- The organization of the system of home care has stayed the same.
- Home care workers have increased caseloads.
- The government is providing less funding and less services.
- The organization of the system has stayed the same.
- There is reduced access to resources, insufficient funding.
- It has stayed the same but there are more patients in need of services.
- It is more disorganized. Information is not properly communicated.
- Home care workers do not provide proper information and resources to clients in order to make informed decisions.
- The information and instructions given to families are not consistent (eg. rural Ontario and Sudbury).
- If you are in Toronto and you get passed to the next CCAC, the client has a higher risk of being dropped and not getting the care they need.
- No change.
- Stayed the same.
- It is the same.
- It is the same.
- It is the same.
- There is terrible communication.
- Home care workers do not read client records before providing care.
- Disorganized because of the lack of communication in home care.
- Home care workers are not properly compensated.
- Disorganized. Inequitable across the province.
- I believe the organization of the system has worsened:
  - Eg. There were 18 beds funded to the local LTC facility for rehabilitative care for high risk seniors or those who have, say, a hip or knee replacement and require more support and physio for 90 days. The gatekeeper for those beds is the CCAC.
  - I have personally talked that program up to any of my high-risk patients prior to their procedure. I have contacted patients struggling at home with discharge [from hospital] after a fall which resulted in a fracture. In every single case the family has reported back to me that the CCAC never contacted them despite the faxed referrals and calls I made on their behalf.
  - In recent months I have had 2 different patients call and need IV restarts. They are on service with CCAC and there is either no one available to re-start their IV or no one with enough skill to accomplish the task. Patients were told to call us to get it done. But CCAC is funded to provide this service. The care provider from the community has never provided any communication about the problem in the home. It should not be the patient's responsibility to organize their own care for a skill they do not possess.
- CCAC is the gatekeeper for every aspect of the system and inefficiencies are created by them.
- CCACs refuse to share information with primary care providers.
- It appears there are more administrators and fewer front-line workers which is backwards to how the system should function.
- Home care is more disorganized.
- There is no accountability and too much administration in the organizations that are 100% funded [CCAC and providers]. Wages are not comparable putting community support sector organizations at risk. Recruitment and retention of staff is a cost that the community care sector must take into account and a strategy must be in place to educate organization that are funded at 100% and unions of this matter if we are to build a comprehensive system.

- Dementia care must be funded appropriately as we have wait lists in many programs and have to take staff away from front lines to fundraise to meet the needs of our population.

### What has changed in the last year, if anything?

Several respondents noted that the only positive change is an increase in awareness and advocacy around these issues and regarding health care cuts. All respondents but one either did not know of any changes in the last year, think there have been no changes, or reported that things are worse in their experience as follows:

- People are more aware of the issues.
- There has been an increase in advocacy concerning health care cuts.
- No change; however there is more awareness, engagement and advocacy in health care cuts.
- There is an increase in frustrated people looking for a solution.
- No changes because home care continues to be understaffed.
- Public home care has a lack of funding.
- Nothing has changed in the last year.
- PSW wages have been enhanced. \$1.50 in 2014 and \$1.50 in 2015. However there is still cutting of hours of low and medium acuity clients.
- There is a greater need for services because of hospital cuts.
- Government is providing less services and funding.
- Reduced funding and fewer hours of service delivery.
- Increase in wait times.
- Increase of infections.
- No changes.
- Not many changes.
- There is an increase in clients.

One person felt that the organization of the home care system has improved in the Central East LHIN area, stating:

- The CE LHIN has reorganized PSWs into a larger pool that are more flexible to manage.

- More pressure on home care workers.
- There has been a decrease in funding.
- No changes.
- Home care has not changed for the better. People are waiting longer for services if they qualify at all. People are being discharged from hospital beds when the services they need are not available in the community.
- Having home care doled out by the CCACs and funded through the LHINs is not working for the communities in Ontario.
- Too many well-paid positions in administration.
- Not changes that I'm aware of except that they are on strike.
- Community services that provide better quality (more continuity of care, appropriate dementia training) are inadequately funded.
- The CCAC is a barrier confusing care for clients.

The one respondent that felt that there were positive changes reported:

- The CCAC had told their group that everyone leaving hospital is assigned a case manager to ensure that they receive appropriate home care including OT and RT to improve their ability to live independently or with family. "No more dumping of stroke victims [sic] from hospital into a long-term care facility."