# Care Watch

## Speaking UP/Speaking O U T

Volume 12.1 Winter 2010

### Challenges & Choices In a Changing World

The first decade of the 21st Century has been characterized by change: global warming continues, financial insecurity is rampant from nations to neighbourhoods. As the populations of the world age, we are looking at what will certainly be an enormous shift in world wide demographics. This will likely mean that some of the structures of our society will also change. There will, undoubtedly, be new ways of looking at the world, new choices to make and challenges to meet. And, perhaps there will even be opportunities for life to be better for more people.

Our particular interest within this context is the population balance. The very large increase in the number of older people, combined with low fertility rates, means a much larger proportion of older people in society. Many in the developed world, certainly in Canada and the United States view this shift negatively, describing it with words like '"tsunami", "looming disaster" and "a major financial drain".

The good news, of course, is absolutely clear. Many people in developed regions, particularly, are living longer, healthier lives. This results from lifestyle changes, advancements in education, some improvements in the determinants of health and the near daily enhancement of medical technology and pharmacology – all most certainly a cause for celebration.

While these changes in population status may, in themselves, have no directional implications on society, a number of forward looking people see them as an opportunity and a challenge to engage older people more fully in dealing with situations and solutions which affect their health and wellbeing. There are, in fact, some current factors that may push this attitudinal change toward greater self determination, and empowerment for older people, not only as service recipients but as "change agents".

TSUNAMI?

This can occur, however, only through the continued and increasing engagement of older people in the development of policy and practice. In Ontario the Friendly City movement as it goes forward from its elementary focus on "street furniture" may begin to create attitudinal change and thus be a positive force in this direction.

Perhaps this could be an opportunity for older adults, including those who are frail or chronically ill, to become "partners" in their health care, rather than "patients", "consumers", "clients" or "customers". Perhaps services might no longer be "delivered" (imposed) but rather people who need

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help will be engaged (*as is possible cognitively and functionally*) to participate with health care professionals and others on mutually agreed upon goals.

How might all this affect Care Watch? For one, Care Watch may want to continue to press for the representation of older people at all levels of engagement, including the development of policies and practices. There must be older people “at the table”.

Advocacy in today’s political and economic climate must mean leveraging the change that is going on all around us to achieve the greatest health and wellbe-ing possible for each older adult. Advocacy towards this outcome doesn’t begin in hospitals but in homes. And its aims must include health promotion and prevention.

There are, for instance, examples of a better use of existing resources: the **Veterans’ Independence Program**, the **SMILE Program** (*Seniors Managing Independent Living Easily)* from the South East Local Health Integration Network, and an incipient move-ment: the **Community Independence Program** on the part of the Central Toronto CCAC as well as the **Individualized Support for Seniors Program** described on page 3. Each of these depends upon greater self-direction.

Change is always a challenge, as a society and as a community we must not sit back and let these changes roll over us. What can you do? What can we do? What can we do together? One thing is certain, as we move forward, we must not let opportunities slip away.

# AGE-FRIENDLY CITIES

## A Case in Point

Once upon a time, an older, seemingly frail woman was looking very tentative about crossing a busy street in Downtown Toronto. A kindly, well-meaning stranger saw her.

Realizing her dilemma, he grabbed her arm and propelled her across the street. She was quite astonished and a little frightened.

Sometime later, the same woman was again standing on the curb, preparing herself to cross the street. Another kind, insightful stranger saw her plight and ASKED IF HE COULD HELP.

Depending on their conversation:

- The woman would continue to cross the street on her own
- She would be shown a better crossing spot
- Traffic would stop briefly while she crossed
- The kindly stranger would walk with her at her pace across the street.

Age-Friendly isn’t only about changing stop lights and lowering curbs—its about keeping a look out for each other and ensuring we ASK people what they need & not just assume we know what is best for them.

# Individualized Senior Support Program

## Seniors Direct their Own Care

By
**Lisa Manual**
Director, Changing Lives &
Family Violence Programs
&
**Erica Leibovich**
Communicatins Intern

**FAMILY SERVICE TORONTO**

Chronic disease now accounts for a large majority of our healthcare spending, with four percent of patients who have chronic and/or complex diseases accounting for 90 per cent of the Local Health Integration Networks' health care expenses, according to Toronto Central LHIN.

The Individualized Senior Support Program (ISSP) is working towards the goal of allowing seniors with chronic disease to live at home by providing individualized supports at two program sites. This innovative program, funded through the Toronto Central LHIN's Aging at Home Strategy, is a partnership between lead agency Family Service Toronto, St. Clare's Multifaith Housing and programs of the City of Toronto, including Margret Frazer House, Birchmount Residence and Seaton House.

ISSP supports 20 participants who have experienced homelessness or were marginally housed. Some have mental health challenges and all have one or more physical health issues that affected their ability to live at home. Through this program participants control the process of defining their needs, directing their care and selecting who will provide them with supports. A **C**ommunity **R**esource **F**acilitator (CRF) assists participants in identifying the services and supports they need for day-to-day tasks such as personal care, nutrition support, medication monitoring, homemaking and other issues. Together they work out a detailed budget which is approved by a funding review committee. By allowing individuals to select the services they need and develop their own budgets, participants are able to maintain control over their lives, and self-manage the chronic diseases they are living with.

Once approved, the facilitator may guide the participant to resources or help them to locate an appropriate support provider. Counselling is an integral part of the CRF's role when participants face matters relating to psychological adjustment, to getting older or experiencing a decline in functioning. The strengthening of family and significant other relationships is promoted as a means of encouraging emotional and practical support for the participants.

"This program gives me new hope in life," wrote one client in a satisfaction survey. "I feel heard for the first time in a long time." Those sentiments were echoed by many other participants. Many commented on how much their lives have improved and how grateful they were for this program.

***Speaking* UP*/Speaking O U T*** is grateful to those who write about innovative ideas in home and community care. If you have a comment, a story or an article about older people, please send it to us by email at:

**info@carewatchtoronto.org**
or
by post to:

**140 Merton St. Toronto, M4S 1A1**

# HOME CARE

## From Adequate Funding to Integration of Services

*Thoughts on an Article written by* ***Réjean Hébert***,[1]

**By Ethel Meade**

A recent paper by Réjean Hébert[1] may mark a pivotal turn in the fight for adequate in-home care, the core issue for Care Watch and its partners. Readers of our Newsletter will remember that Hébert directed PRISMA (the **P**rogram of **R**esearch to **I**ntegrate **S**ervices for the **M**aintenance of **A**utonomy). This four year program for integrating services was developed in three areas of Quebec (one urban and two rural) and, as he reports, proved highly successful. The health outcomes of the 1500 participants being served demonstrated its improved effectiveness at no extra cost.

His paper opens with the assertion that "with the aging of the population, the healthcare system needs to shift from the hospital-centered system developed in the past century for dealing with acute diseases and a young population toward a home-centered system more appropriate for serving older people with chronic diseases."

Moreover he believes that "the aging of the population will not be the catastrophe predicted by some, who see it as the perfect excuse to privatize the healthcare system. The projections on which these dire predictions are based assume that neither people's health nor the service delivery method will change in the next 20 years."

Care Watch has, in fact, already understood these premises, though we have not fully succeeded in persuading Queen's Park to adopt them as the basis for all their health care planning. We must credit the Health Ministry with creating the Aging at Home Strategy, though the funding allotted for this purpose showed it to be a pilot project, with no attempt to meet population needs.

What Hébert proposes goes far beyond this first tentative step. He calls for an "Autonomy Support Benefit (ASB) to cover costs related to disabilities, irrespective of living environment." He defines the ASB as "a public universal autonomy insurance program." Quebec's health care has always used "autonomy" as a measure of need, with their home care program targeting persons whose autonomy was threatened by inadequate home support. It might create an improvement in perspective if Ontario adopted this term.

Hébert recognizes that in-home care is a "much more complicated service delivery environment than hospital care" and concludes that home and community service delivery needs to be "coordinated and integrated". This, of course, was what PRISMA aimed to accomplish.

For older persons with chronic diseases the hospital-centered model of health care delivery is not appropriate. And, he says, "we are seeing more and more evidence of this in overflowing emergency rooms and hospital beds being occupied by older persons waiting for placement" in a long-term care home. But he says "the hospital is not the source of the problem; but since it is the place of last resort, that is where we see the effects."

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*1) Longwoods Publishing, Health Care Papers, 10(1) 2009*

We know too well that "Home Care is the poor relation in our health care system…with only 4% (in 1999) of expenditures for health care" going to support home care. Hébert says that "for equal disabilities, it costs 10 times more to care for a person in an institution" than in his/her home. And, of course, it is well known that people prefer to be at home and we "cannont ignore the risks" in a hospital "of infection transmission".

The proposed Autonomy Support Benefit would be based on assessed disability and in Quebec management tools already exist that can be used to assess personal disability on the basis of 29 functions covering Activities of Daily Living (ADLs) and the Instrumental Activities of Daily Living (IADLS) and mobility, communication and mental functions.

All in all, Hébert's paper gives Care Watch and its members and friends a lot to think about.

## FUTURE SMART HOMES

### Helping Older Adults with Dementia & Their Caregivers

*Barry Trentham, a Care Watch Board member submitted the following report about work being done by Dr. Alex Mihailidis at the University of Toronto. . It is an example how care recipients and their caregivers can be involved in the development of technology that will eventually affect their lives.*

U of T is developing a "smart home" that can help people with dementia maintain independence and an improved quality of life, while reducing the stress and burden on caregivers. An example of a smart home system called the COACH has been developed. This system monitors older adults performing a common activity, such handwashing. It then provide reminders of the steps that they need to complete. The goal is to provide both assistance to a user during common everyday activities, as well as some relief to the person's caregivers.

To understand and enhance the role that this technology plays in the complex relationship between a caregiver and a person with dementia they promote the idea of participatory design. In participatory design end-users cooperate with researchers and developers during an innovation process. U of T is now in the initial stages of re-designing the COACH system so that it can be easily installed and used in a person's own home. As part of this process they hope to include the opinions and thoughts of caregivers in a new study based on a survey which caregivers complete online or by mail. The survey results will be used to guide subsequent focus groups and interviews with caregivers to explore the technology in more detail. Ultimately they would also like to recruit any caregivers interested in future participation in the project.

If you are interested in becoming involved in the project, contact U of T at **416-946-8573** or by email at **alex.mihailidis@utoronto.ca**. You may also complete the online survey at **www.iatslsurvey.org** or contact Dr. Mihailidis for a paper copy.

# LONG OVERDUE

## A National Strategy on Aging

The interest in a National Strategy on Aging is growing. It was called for loud and clear by the Special Senate Committee on Aging's report entitled ***Issues and Options for an Aging Population***. The Ontario Seniors Secretariat is recognising the importance of such a strategy and the The Registered Nurses Association of Ontario (RNAO) has been pursuing this for a number of years. The following Letter to the Editor was published by The Toronto Star:

*Your lead editorial Saturday May 2 amplified the call of the senate committee for a national strategy on aging. For the last twenty years there have been a number of well researched reports concluding that Canada's aging population calls for a national home and community care policy that echoes the strengths of the Canada Health Act. There is a flurry of comments shortly after each report is released and then – silence.*

*Across the country provinces and municipalities have put in place a variety of programs, some more successful than others, that try to shore up the local situation. In Ontario we have the Aging at Home Strategy, but it has a very limited mandate, time and resources.*

*One wonders what it will take to drive home the need for a national vision; one that will provide a framework that supports rather than dissipates local efforts? It took SARS to awaken us to the cost of neglecting the public health sector. It is taking an economic recession to jolt us into remembering that it is active public policy, not the market, that builds a country like Canada.*

*What catastrophe will have to occur before we act on repeated calls to put in place a national strategy for aging?*

***Sheila M. Neysmith**, Care Watch, Member of the*

The following unpublished letter to The Toronto Star reflects the long held Care Watch thesis. The sad part of the story is that the Province with its Aging at Home Strategy, seemed to be on the right road staying with the very clearly expressed local desire of people to age at home – with appropriate supports.

We seem, unfortunately to have lost both the local direction and the Aging at Home priority.

**Letter to the Editor, Toronto Star**

**Re: Daunting View on Aging, Editorial January 5, 2010.**

Hooray, it would appear that some person, somewhere is paying attention to the real needs of the Aging Population; early intervention and fall and illness prevention, home and community care, managing chronic disease and dealing with the "tasks of daily living". As Ted Ball, a health critic and prominent systems and strategy consultant says, "We suffer from a false assumption that acute disease is at the hub of the system."

The Provincial "Aging at Home Strategy" is essentially over; some money has been removed from the 3rd year and there are no comments on the continuation of existing projects. Thus the initiatives and priorities initially intended to be local, were, after the first year, usurped by the Ministry of Health and Long Term Care. At this point outcome standards became ridiculously short term and so finely focused as to be almost irrelevant. There are a number of studies that demonstrate empirically the cost effectiveness and positive health outcomes of supportive home care. The Ontario Government persistently seems to ignore or fails to make the connection between supportive home care, cost containment and happier, more independent older adults. We have to begin the serious realignment of funding now, the shift must be clearly intentional and transparent so that it is understood by both older patients, potential patients and health care professionals. We've said it before**… It can be done!**

*Signed*
**Charlotte Maher,** Vice-Chair, Care Watch

# Getting Old in the LGBT Community

By

**Dick Moore**

Getting old is always a challenge. Becoming invisible, hearing the jokes, being written off by younger people although not universal experiences does happen frequently enough to raise my hackles. However, for older LGBT people, like me, aging has some other consequences that straight folk may not know about.

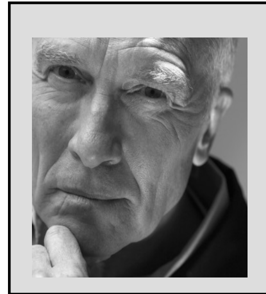
Most of us experience homophobia daily. At some age, early for some and later for others, we realize we're different and know that the difference is not one of which our parents, teachers or friends approve. We often rejected these feelings and joined the ranks of those who jeered and poked fun or even beat up the "sissies" and made fun of the "dykes".

We finally admitted to ourselves and then to others who we were and accepted the fact, but we still heard the jokes and read about the stereotypes. Our career choices were limited. Gay men and lesbians cannot be teachers or child care workers for fear they might be the stereotypical - "bad influence" on the kids. Job insecurity was common as we might be "outed" at any time. Medical and social services were not always accessible or respectful to us due to the ignorance/bigotry of doctors, nurses and other providers. We learned to avoid such services as a way of insulating ourselves from discrimination and hatred.

As we grow older and may need some help in managing we are reluctant to ask, and especially reluctant to turn to medical or social service providers lest we again face neglect, poor treatment and or outright hatred by staff or volunteers.

The thought of needing long term care is especially painful. Will we have to return to a closeted life in order to get the care we need? Will the other residents reject and isolate us if they know who we are. Will those responsible for looking after our needs "forget" to feed us, change our diapers or give us a bath?

Such were the fears and terrors I discovered when I first went to work at The 519 Church Street Community Centre. I met with small groups of older lesbian, gay bisexual and transgender/transsexual (LGBT) people. I vividly recall one "trans" man telling me to get out there and do training for service providers. "I don't want to be the first one they give the bath to." Since then I have presented at conferences, run training sessions, given workshops to groups and long term care homes. I have tried to open up a respectful, knowledgeable and caring environment for older LGBT people. There have been some breakthroughs, notably in the City of Toronto Homes and Services for the Aged Division. There is still a long way to go…….



"Nobody grows old by merely living a number of years. We grow old by deserting our ideas. Years may wrinkle the skin, but to give up enthusiasms wrinkles the soul…" Samuel Ullman

*Announcing the…*

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