

# Institute for Life Course and Aging UNIVERSITY OF TORONTO

## **Mapping Aging** in Place in a Changing Neighbourhood



## **Prepared by**

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May 2008

## Acknowledgements

We would like to thank all of the 140 community members who participated in our consultations and focus groups and shared their experiences of aging in place in West-central Toronto.

Many thanks to our community partners at St. Christopher House: Maureen Fair, Rick Eagan and Odete Nascimento for support during project development, for hosting one of our consultations and for providing us with a fantastic interpreter and community animator: Lúcia Ramos. Also, thanks to our academic partners at the Centre for Urban and Community Studies for data support. Thanks, also, to Masaryk-Cowan Recreational Centre and to Loyala Arrupe for hosting consultations.

Thank you to the staff of Loft, Queen West Community Health Centre, Parkdale Golden Age Foundation, Community Outreach Programs in Addictions, Careable Inc. Healthcare Consultants, Extendicare, Sistering, Older Persons Mental Health and Addictions Network, Parkdale Community Health Centre, Toronto Central Local Health Integration Network, Centre for Addictions and Mental Health, St. Joseph's Hospital: Elderly Community Health Services, Toronto Community Housing Corporation, Toronto Western Hospital: Geriatric Clinic and St. Christopher House who graciously attended our focus group or gave us feedback by email and phone communications. We would like to recognize the fine work of Creeshla Hewitt who designed our attractive and accessible three layered map.

Finally, to the members of our community working group: Albertina Alexandre, Maria Andrade, Idalina Azevedo, Ana Furtado, Jadviga Kwiatkowski, Nelly Mankarious, Patrick Mudry, Lúcia Ramo, Harvey Toews, Sharon Ullmer, and Cynthia Zaragoza thank you for sharing your time, knowledge, and experience while refining the key issues of aging in place and developing solutions and strategies to support older adults in your neighbourhoods. The map represents your vision of a future where older adults are valued, celebrated and supported.

And we wish to acknowledge our funder: the Community University Research Alliance (CURA)<sup>1</sup> program of the Social Sciences and Humanities Research Council of Canada (SSHRC). We also wish it to be known that the research and recommendations herein are those of the authors of this report and do not necessarily reflect the views of the CURA program of SSHRC.

<sup>&</sup>lt;sup>1</sup> This project is a component of **Neighbourhood Change and Building Inclusive Communities from Within: A Case Study of Toronto's West-Central Neighbourhoods** a five-year a participatory research and community development partnership between **St. Christopher House** and the **Centre for Urban and Community Studies.** 

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## **Executive Summary**

#### **Introduction and Rationale**

Urban neighbourhoods across Canada are undergoing immense change due to gentrification. For older adults, particularly those who are socially and/or economically marginalized, these changes can be potentially alienating and isolating. Older adults may be at greater risk of displacement to alien communities or institutional settings due to factors associated with aging and post-retirement socioeconomic status. For example, housing instability can occur due to episodic hospitalization or escalating care giving demands. Further, many older adults rely on fixed incomes that are less responsive to the inflationary effects of gentrification. This project<sup>2</sup> engaged a working group of older adults to "map" how well Toronto's West-central housing, neighbourhoods and health and social service agencies are equipped to support aging in place, and identified what barriers exist, as well as strategies to enhance the "livability" of these communities for older adults. The purpose of the "map" is to assist the community in recognizing, expanding and mobilizing individual and neighbourhood social capital to secure appropriate and accessible support to older adults and their caregivers.

#### Objectives

- To map facilitators and barriers to aging in place in the community, with particular attention to how gentrification shapes these factors.
- To use the data collected to build a schema ("map") of micro and macro factors impacting aging in place in the context of neighbourhood transition.
- To engage the community in the development of the "map" and to make visible the forces impacting their capacity to age in place.



• To make transparent to the community the "policy and program portals" for action to secure appropriate resources to support aging in place.

<sup>&</sup>lt;sup>2</sup> This project is a component of Neighbourhood Change and Building Inclusive Communities from Within: A Case Study of Toronto's West-Central Neighbourhoods a five-year research initiative funded by the Community University Research Alliance (CURA)<sup>2</sup> program of the Social Sciences and Humanities Research Council of Canada. The CURA is a participatory research and community development partnership between St. Christopher House and the Centre for Urban and Community Studies. The "Mapping Aging in Place" project was conducted by researchers at the Institute for Life Course and Aging, University of Toronto.

#### **Research Questions**

- 1. What formal and informal resources exist to support aging in place and how are these affected by gentrification?
- 2. What other resources and supports are needed but absent, inadequate or inaccessible?
- 3. How can the community then impact relevant policy making systems to enhance supports to aging in place and mediate the effects of gentrification?

#### Methodology

This project adopted a participatory action methodology which incorporates, values and makes actionable the knowledge and experiences of the older adults participating in the project. Inclusion of participants in the data collection, analysis and dissemination offers substantial benefits including: animating the findings, expanding consumption beyond academic circles to civil society and the state, and building participant and community capacity for sustained action. Data was collected during 3 community consultations (N=80) and 3 focus groups (N=40) attended by older adults, caregivers and service providers in the CURA neighbourhoods.<sup>3</sup> Participants in the community consultations and focus groups were invited to join a project working group. Ten participants were randomly selected to participate in 8 working group sessions. The ten participants analysed the data collected in the consultations and focus groups. Key issues were refined using adaptations of qualitative research techniques such as saturation, hierarchical clustering and matrix analysis to produce a tool for dissemination and mobilization. The tool created was a large format "map" representing what is currently available to support aging in place, what could be available to better support aging in place and finally, what actions could be taken to ensure better supports to aging in place in Toronto's West-central neighbourhoods.

#### **Key Findings**

Overall, the working group identified three thematic clusters where greater accessibility is critical: in their housing, neighbourhoods and local health and social service agencies, to sustaining aging in place. Despite the rapid gentrification occurring in the neighbourhoods, surprisingly, the impact

<sup>&</sup>lt;sup>3</sup> The seven West-Central Toronto neighbourhoods of the CURA project include Dufferin Grove, Little Portugal, Niagara, Palmerston, Roncesvalles, South Parkdale, and Trinity-Bellwoods.

remains largely invisible to older adults and their service providers. Several rationales are put forward to explain the absence of reported gentrification effects including:

- Social polarization which leads to a "tectonic" social structure that is characterized by minimal
  cross-group interaction where gentrifiers and longer standing residents occupy parallel social, if
  not physical, space;
- The forces of gentrification are subsumed into more generic phenomena such as escalating costs of living and crime; and
- Gentrification is following different trajectories in the seven CURA neighbourhoods and therefore the perception of change may be quite diverse and diffuse.

#### Findings associated with the three thematic clusters of accessibility:

- Accessible housing is reliant on the appropriate modifications to the built environment (e.g. first floor bathrooms with walk-in shower stalls or tubs), as well as generous subsidies for structural accommodations, city services (e.g. garbage fees), rent and property taxes. Human supports in the form of health and homemaking assistance are also crucial, as is relevant information broadcasted into the home through TV, radio and mail;
- Accessible neighbourhoods are fostered by more opportunities for community building (e.g. frequent neighbourhood social and cultural events, free or low cost space to congregate and significant seniors' discounts). Inclusive zoning is a necessary scaffold to the development of "livable" communities (e.g. adequate benches, washrooms, well lit sidewalks, ramps and broad aisles in retail spaces) with more affordable supportive/assisted housing options; and
- Accessible agencies require more flexible program eligibility, more translated materials (from multiple sources) and interpreters, and more outreach to isolated seniors and to ethnocultural and faith communities. Accessible, multi-lingual community information portals are vital to older adults (and their caregivers) locating the supports/services they need. Also, it is essential that agencies empower older adults to participate in decision-making, peer programming (e.g. "train the trainer" workshops on aging and ageism) and community led advocacy. Finally, the vital role of caregivers must be acknowledged and supported by agencies (e.g. respite care, training).

Findings associated with the community engagement process:

- Older adults have tremendous talent and a surfeit of time. Therefore, they are ideal candidates to determine the issues that are relevant to them and to direct how they are to be addressed;
- Community-based data analysis yields distinct yet complementary findings to those reported in the aging literature. For example, the focus on built environments evident in the project's findings, though acknowledged as significant to aging in place, is scarcely evident in the literature;
- Accessible tools and activities are crucial to tapping, documenting and disseminating local knowledge;
- Relationships must be reframed and power rebalanced within the project team so that community participation moves beyond rhetoric and tokenism to partnership; and
- Funding and project timelines must accommodate action and dissemination activities by
  attending to legislative calendars, other policy relevant events and to the relationship and
  community capacity building that is necessary to entrances to policy-making circles.

Findings associated with the community taking action:

- Actions **targeted to six sectors**: informal, program/agency, private and all 3 levels of government present a range of mobilization opportunities and multi-sectoral responses;
- Actions rely on a matrix of strategies including: advocacy, community capacity building and forging partnerships to enhance aging in place;
- Although some actions are time sensitive, **enduring options for neighbourhood action** are critical to extending the utility of the project findings and tools;
- Sustainable actions require the funding and support to formalize project working groups into neighbourhood councils or civic panels with institutionalized ties to local government; and
- Actions to support aging in place call for paradigm shifts in health and social care: from ageist to life course frameworks, from "human-centric" to environmental supports, from disease to wellness models and from person-based to place-based policies.

## **Section 1.0** Introduction

"Mapping Aging in Place" is a component of *Neighbourhood Change and Building Inclusive Communities from Within: A Case Study of Toronto's West-Central Neighbourhoods*<sup>4</sup>, a five-year research initiative funded by the Community University Research Alliance (CURA) program of the Social Sciences and Humanities Research Council of Canada. The CURA project is a partnership between St. Christopher House and the Centre for Urban and Community Studies (CUCS) at the University of Toronto. "Mapping Aging in Place" considers how neighbourhood change affects the ability of older adults to age in place, and how older adults in the community might act to shape those changes.

"Mapping Aging in Place" conducted by researchers at the Institute for Life Course and Aging at the University of Toronto, adopted a participatory action methodology which incorporates, values and makes actionable the knowledge and experiences of the older adults participating in the project. The participatory nature of this project assists the community in recognizing, expanding and mobilizing individual and neighbourhood social capital to impact neighbourhood change and to affect appropriate and accessible support to older adults and their caregivers.

In considering the challenge of aging well at home, placed-based questions of what local factors act as facilitators or barriers become crucial to developing effective programs and policies for age-friendly living. Although many environmental and human factors impact the health and well-being of older adults, neighbourhood—wide changes such as gentrification may have differential effects on older adults. Older adults may be at greater risk of displacement due to factors associated with aging and with post-retirement declines in socio-economic status. For example, risk of displacement to institutional settings or to alien communities may be exacerbated by housing instability brought on by episodic institutionalization or by escalating caregiving demands. Also, older adults are often reliant on fixed incomes that are less responsive to inflationary effects of gentrification. The dislocation and dissolution of longstanding businesses and supports that occur in neighbourhoods in transition often have greater impact on older residents who rely on familiar staff, owners and products. Consequently, aging in a gentrifying neighbourhood may increase the likelihood of social exclusion and of diminished social capital.

Further, individuals residing in lower income neighbourhoods may have fewer individual or household resources and therefore, may be more reliant on neighbourhood social capital (Bridge,

<sup>&</sup>lt;sup>4</sup> The seven neighbourhoods in West-central Toronto include: Dufferin Grove, Little Portugal, Niagara, Palmerston, Roncesvalles, South Parkdale, and Trinity-Bellwoods.

2002). The majority of the neighbourhoods relevant to this project (e.g. Dufferin Grove, Little Portugal, South Parkdale, Trinity Bellwoods and Palmerston/Little Italy) have high concentrations of residents with incomes below that of the average for the Toronto Census Metropolitan Area (Hulchanski, 2007). The majority of the CURA neighbourhoods also have an increasing proportion of "senior" residents; the number of residents 65 years or older has grown from 8 percent in 1971 to 11 percent in 2001 (R. Maaranen, personal communication, February 8, 2007), and this trend will continue with the aging of the baby boomers. Consequently, there is a significant need to build capacity and mobilize this growing demographic to expand neighbourhood social capital and diversity.

Although there is a wide body of research and reports on health indicators associated with aging in the community, information regarding the impact of socio-economic, neighbourhood and policy factors on residential outcomes is scant. Much of what is known of the determinants of healthy aging in the community is based on research using scale-based assessments of functional and cognitive status. Although this is useful in health care planning, it does not capture the diversity of factors that impact aging in place nor does it document the voices of older adults themselves and their "expertise" in aging. As Oldman and Quilgar (1999) and others (Carter & Beresford, 2000; Taylor, 2006; Tetley and Hanson, 2000) have noted, genuine involvement of older adults in research and decision-making is extremely limited.

However, there is an emergent dialogue that as the baby boomers age health and social care systems will give way to the demands of active, skilled and educated older adults who will not only be critical consumers but advocates participating in the research and development of programs and policies that support aging in place. Further, there is growing support from all three levels of government to realize more meaningful civic engagement in policy making. For example, the 1999 Social Union Framework Agreement (SUFA) explicitly mandates that citizens be engaged in the policy process at three levels: priority setting, decision making and evaluation (Devon Dodd & Hebert Boyd, 2000). Participatory projects offer a mechanism for the community to develop and deepen their knowledge of key issues, as well as how those issues interface with various policy systems. Also, such projects ensure that the issues and solutions are locally sensitive, actionable and "owned" by the community.

In particular, this project sought to address the research questions guiding the overall CURA project, as they relate to the experience of older adults and their capacity to age in the CURA neighbourhoods. The three project specific research questions were:

- 1. What formal and informal resources exist to support aging in place and how are these affected by gentrification?
- 2. What other resources and supports are needed but absent, inadequate or inaccessible?
- 3. How can the community then impact relevant policy making systems to enhance supports to aging in place and mediate the effects of gentrification?

The "Mapping Aging in Place" project addressed these questions by a) producing a scan of promising community practices, tools and examples of civic engagement that support aging in place and b) identifying current resources and services to support aging in place in West-central Toronto, as well as barriers and gaps, to create a visual "map" to promote community engagement. The project enlisted a working group of older adults to accomplish four primary objectives:

- a) To map facilitators and barriers to aging in place in the community, with particular attention to how gentrification shapes these factors;
- b) To use the data collected to build a schema ("map") of micro and macro factors impacting aging in place in the context of neighbourhood transition;
- c) To engage the community in the development of the "map" and to make visible the forces impacting their capacity to age in place; and
- d) To make transparent to the community the "policy and program portals" for action to secure appropriate resources to support aging in place.

The data collected on facilitators and barriers to aging in place provides a proximate picture of what currently exists and what is required to enhance older adults' quality of later life. This data was then analyzed by a community group and visually represented on a large format "map" which is a multi-layer distillation of current needs, solutions and strategies for community mobilization. The map includes "portals" for interacting with and impacting relevant programs and policies and is adaptable to multiple targets (e.g. homecare, alternative housing, transitional supports during institutional stays) and to multiple policy making systems (municipal, provincial and federal governments, as well as service agencies).

Although the participatory process of generating a map of aging in place and of identifying sites of action and strategies for civic engagement focused on local and instrumental knowledge, it was informed by the following scan of the relevant literature on aging in place and community engagement practices (particularly those involving older adults). Section two of this report presents relevant terminologies,

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evidence-based research and promising practices and tools used to realize age-friendly environments and supports. Section three describes the project methodology (including detailed descriptions of the <u>process</u> of community data analysis) and is followed by a fourth section which outlines the project findings. The fourth section is relatively brief due to the objective of documenting all of the findings on the "map" and avoiding text-rich reporting that may not appropriately convey the voice of the community. The fifth section describes various dissemination activities and the sixth section offers a discussion that reflects on the key outcomes and processes of the project.

## **Section 2.0 Environmental Scan**

This environmental scan is not intended as a comprehensive review of the literature<sup>5</sup> but rather as an introduction to the central concepts and research associated with aging in place and community engagement practices with older adults.

## 2.1 Definitions and Terminology

#### 2.1.1 Aging in Place

Aging in place is a widely held preference of older adults and of current health and social care policy-making systems (Division of Aging and Seniors, 2006; Gibson & Verma, 2006; Ministry of Health and Long-term Care [MOHLTC], 2007; Toronto Central Local Health Integration Network, 2007). In contrast, the majority of older adults view residing in an institutional long-term care setting as an option of last resort. Interestingly despite the rhetoric of realizing strategies to age in place, the reality is that this is exactly what the majority of older adults are experiencing; only 7 percent of Canadians 65 years of age and over reside in institutional settings (Statistics Canada, 2002). Therefore, the challenge is not so much to ensure that older adults age in place but to realize the supports that will maximize the quality of later life while aging at home.

The preference for aging in place has proven to be a powerful determinant of actually remaining in the community. Robinson and Moen (2000) analysed secondary data from two waves of the Cornell Retirement and Well-Being Study (N=702) and found that one of the two most powerful predictors (the other was home ownership) of aging in place over the two year interval was expressed expectations of remaining in one's current home. Further, aging in place appears to be associated with better clinical outcomes for older adults. Marek and colleagues (2005) compared community dwelling older adults participating in an Aging in Place (AIP) program with a nursing home control and found significantly better health and quality of life outcomes for the AIP intervention group. The terminology is also used to describe those features of the health and social care systems, as well as of the built environment, which support older adults in maintaining independent living. While aging in place is significant to the health, autonomy and dignity of individual older adults, it is also is advantageous to society as a whole because the support of older adults with home and community services is effective and cost-effective when compared to expensive institutional long-term care (Chappell, Havens, Hollander, Miller, & McWilliam, 2004; Lum, Ruff & Williams, 2005).

<sup>&</sup>lt;sup>5</sup> For a more information, a recent literature review of aging in place conducted by the Institute for Life Course and Aging is available on request.

#### 2.1.2 Civic Engagement

The term civic engagement is used to describe a range of activities including: volunteerism, voting and involvement in political campaigns, various forms of activism and paid and unpaid community work. Attempts to generate definitions inclusive of all of these forms of engagement have led Ramakrishnan and Baldassare (2004, p. v) to define civic engagement as "both political participation and civic volunteerism." Other definitions stress the latter component, such as that used by the Harvard School of Public Health which highlights the active participation of older adults in the life of their communities (2004, p.3).

Although definitions vary, mainstream understanding and representation of civic engagement tends to focus on volunteerism. Further, this form of engagement is often heralded as the antidote to the "apocalyptic demography" discourse often represented in the popular press where depictions of a "silver tsunami" of older people overwhelming health and social care systems (Goldenberg, 2007) are common. Rather than being a burden, the aging boomers, in the context of volunteerism are "untapped assests" and are described as a "treasure trove" of resources to enhance the life of their communities (Martinson & Minkler, 2006). Both the Gerontological Society of America and the American Society on Aging have launched multi-year projects aimed at institutionalizing civic engagement through research and policy recommendations that promote and increase civic participation by older adults.

#### 2.1.3 Social Capital

Social capital, although a contested term, is understood to encompass individual social networks, as well as institutional assets associated with the community whether they be tangible: such as residents associations and the density of geriatric health care providers or value-based: such as higher perceived levels of trust and goodwill among neighbours. Nahapiet and Ghoshal (1998) link the two levels together stressing that social capital is the sum of actual and potential resources associated with the particular network of an individual or social unit. A critical element of this broader understanding of social capital is that an older adult may experience isolation and an impoverished personal social network but still benefit from available neighbourhood level social capital.

## 2.1.4 Gentrification and Displacement

Gentrification is generally understood to be a process whereby demographic and social transformation redefines the status of a neighbourhood (Ley, 2003). Explanatory models tend to fall on the continuum of demand to supply centred discussions. Ley (2003) for example, focuses on the demand

side identifying the roots of gentrification in the changing industrial and economic landscape of major urban centres which give rise to a "new" middle class who follow on the cultural transformation led by artists and other members of the creative economy. On the supply side of the continuum, authors such as Smith (2002), see gentrification as driven by property developers and real estate agents who capitalize on under valued inner city neighbourhoods.

Other distinctions made in the literature are that of the 'emancipatory city' (a Canadian construct) and the 'revanchist city' (an American construct). Revanchism, largely associated with studies of American cities, is negative construct associated with the white middle-class reclaiming inner city space from the disadvantaged groups. In contrast, emancipatory gentrification, associated with investigations of Canadian cities, casts the process as a transformative reclamation of the inner city where enlightened citizens reject the bland conformity of the suburbs and embrace social diversity. Slater (2003) suggests that neither accurately capture the complexity and locality of gentrification and puts forward a more nuanced geography of gentrification that is sensitive to a range of contextual factors. Of particular relevance to this project, Slater's (2004) investigation of gentrification in South Parkdale, Toronto challenges assumptions of emancipatory processes by attending to the experiences of those most vulnerable to displacement and/or further marginalization. Older adults may constitute one such vulnerable group which experience greater exclusions and risk of displacement due to factors associated with aging and limited economic resources.

#### 2.1.5 Informal and Formal Supports

Formal supports are those services provided by paid professionals or paraprofessionals. Formal supports may include unpaid support from volunteer programs as these services are typically administered by professionalized sites such as nonprofits or community health centres. Informal supports are unpaid assistance provided by family, friends or neighbours. These latter supports may be intermittent or ongoing as in the case of dedicated caregiving. It is not only the absolute levels of formal and informal support provided to older adults that is of interest but the relationship between the two sources of support. Generally there are two models of interaction: complementary and substitution. Complementary interactions assume that the formal and informal support provide distinct forms of assistance while substitutions models contend that one form of support can act as a surrogate for another. The more contentious explanatory model is substitution as it may be associated with cost containment efforts by health planners who may rationalize reductions in formal support by appealing to the preferences older adults indicate for family and other informal caregiving. The substitution model is also associated with gendered disadvantage as caregiving is largely provided by women who bear considerable socio-

economic disadvantages by providing informal support (McDonald, 2006). Evidence suggests that the model of interaction is context, especially to health policy, sensitive. For example, Davey and colleagues (2005) found that while older community dwelling adults in Sweden relied primarily on formal supports with a complement of informal support, older adults profiled in the US sample engaged formal support only after informal support was exhausted. However, other authors (Cox, 2005) have suggested that patterns of utilization may vary according to the characteristics of the caregivers and whether they engage ongoing formal support for themselves and their care recipients or whether they wait till the caregiver burden reaches an untenable threshold and only then look for substitute formal care. This last distinction suggests that the caregivers must be central to any investigation of supports to aging in place.

## 2.2 Key Factors Influencing Aging in Place

There is a wide body of research investigating what predicts institutionalization and conversely what facilitates aging in place, most of which is focused on traditional health indicators such as cognitive and functional status rather than the social, neighbourhood, household and policy factors which influence community tenure. As a result these latter factors are promising but do not yet have the same weight of evidence as factors such as limitations to Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs) or various measures of cognitive functioning. The following section will offer a brief summary of the current literature as it relates to the research question of what formal and informal resources exist to support aging in place. Resources, for the purpose of this scan, are understood to be supports that are extrinsic to the individual (with the exception of the socio-demographics in Section 2.2.1) and as such the research investigating factors such as health and functional status are not included<sup>6</sup>.

## 2.2.1 <u>Demographic and Socio-economic Factors associated with Aging in Place</u>

As would be expected, as older adults age the likelihood of remaining in the community diminishes. For example, the percentage of older adults living in the community in Ontario drops from over 90 percent for all adults over the age of 65 to 66.8 percent of adults over the age of 85; notably, the vast majority of this age group continue to reside in the community (Statistics Canada, 2003). According to estimates from the 2001 Census, less than 10 percent of senior women and 5 percent of senior men resided in institutional settings in 2001 (Table 1: Statistics Canada, 2002). The 2001 Census also indicates

<sup>&</sup>lt;sup>6</sup> For a more information on health and policy factors, as well as limitations to the literature, a copy of a recent review of aging in place can be accessed on request from the Institute for Life Course and Aging.

that the proportion of older adults residing in institutions has been declining steadily over the last two decades for both men and women, and for all age groups.

 $Table\ 1$  Living arrangements of seniors aged 65 and over by sex and age group, 2001

			Living with	Living	Living in		
	Age	Living	spouse or partner	with	health care	Other living	
Sex	group	alone	(no children)	children	institution	arrangements <sup>1</sup>	Total
							(numbers)
Males	Total 65+	16.0	61.4	13.3	4.9	4.4	1,666,400
	65-74	14.0	64.4	15.4	2.1	4.0	1,008,735
	75-84	18.3	60.7	10.2	6.2	4.6	533,705
	85+	22.7	39.5	8.5	22.6	6.7	123,960
Females	Total 65+	34.8	35.4	12.1	9.2	8.4	2,224,395
	65-74	28.2	48.1	14.1	2.3	7.3	1,135,475
	75-84	42.8	27.7	10.8	9.6	9.2	798,300
	85+	38.5	7.2	8.4	35.4	10.6	290,620

<sup>&</sup>lt;sup>1</sup> Includes living with other relatives, e.g. a niece or nephew, or with non-relatives, e.g. a lodger. Source: Statistics Canada, Census, 2001

Source: Statistics Canada, General Social Survey, Cycle 16, 2002

A systematic review and a meta-analysis of the literature examining predictors of institutionalization among American seniors (Gaugler, Duval, Anderson & Kane, 2007; Miller & Weissert, 2000), conclude that advanced age is a powerful predictor of loss of community residence but that gender (female) was not a significant predictor of institutionalization. Inconsistent results for the effect of gender may be due to that fact that gender exerts an influence because women have a greater life expectancy than men. For example, in Canada women, on average, live longer than do men (82.5 years compared with 77.7 years, in 2004) and they represent two-thirds of those over age 80 (Statistics Canada, 2005). Consequently, in Canada, gender differences exist, with more females hospitalized and institutionalized than are males (National Advisory Council on Aging, 1999).

Another factor that appears to be associated with a reduced likelihood of remaining in the community is having a "Caucasian" identity. Although there is a limited body of research investigating differences across ethno cultural groups, there are a few studies that report that older adults identifying as "Black" or "Hispanic" are significantly more likely to reside in the community (Friedman, Steinwachs, & Rathouz, 2005; Miller & Weissert, 2000). However, whether this is a result of barriers to long-term care or an ethno-cultural preference (e.g. regarding filial responsibility or inter-generational living arrangements) is unclear.

Income, wealth, and education are variables used to capture the effect of socio-economic status (SES) on residential outcomes. Income is the most commonly measured variable but has proven to have inconsistent effects. Inconsistencies in the findings for income have been attributed to a number of factors including inadequate weighting for the number of persons within the household, sensitivity around disclosure leading to under reporting and the exclusion of other financial resources that contribute to overall wealth. Cox (2005) notes that it is not just disclosure and measurement issues that constrain the effect of income but that as a dollar measure, it varies across context, living arrangement and need for supports. In the same way that perceived quality of health is often a more powerful measure than an inventory of chronic conditions, Sachs-Ericsson and colleagues (2006) suggest an alternative measure that relies on a subjective assessment of adequacy of income rather than any single or bundled quantifiable measure. The authors found that perceived problems with meeting basic needs significantly influenced the rate of decline in physical functioning.

Other measures of SES evaluated for their impact on community versus institutional living are wealth and education. Wealth, a more difficult measure, is less frequently used and often is measured as non-housing assets; while education is a relatively commonly measured variable investigated in the literature. The Miller and Wiessert review (2000) found that, overall, the research findings did not support that either non-housing wealth or education had significant effects on residential outcomes. However, the review did find that home ownership had a significant impact on older adults' ability to remain in the community. The majority of studies (53 percent or 8 out of 15 studies) found that "not owning a home" was associated with greater risk of institutionalization. A similar positive association for "not owning a home" and institutionalization was also found in Gaugler and colleagues' (2007) meta-analysis of the literature. The researchers suggest that homeownership may affect length of community tenure in two ways: as a proxy for accumulated wealth and as an indication of social attachment to place.

## 2.2.2 Factors Associated with Individual and Neighbourhood Social Capital

In the context of aging in place and the isolation that accompanies some older adults' experience of aging, neighbourhood social capital may mediate the risk of displacement either to an institutional setting or to another distal neighbourhood. Health Canada has adopted a "social capital" framework to examine how networks of social relations support healthy aging, thereby recognizing the strong association between social supports (individual and institutional), health status and mortality rates (Health Canada, 2006). Also, relevant to the discussion is the influence of gentrification on social capital which inevitably is a dynamic process where some groups experience a loss at the same time as in-movers may begin to experience a gain as the socio-economic landscape of the neighbourhood changes. For example,

the literature suggests that upward pressure on the housing market associated with gentrification increases the risk of older adults moving to institutional long-term care facilities (Mutchler & Burr, 2003).

## Informal and Formal Support

Informal support, as it relates to social capital, is a crucial source of assistance and of well-being for many older adults. The 2002 General Social Survey Cycle 16 on Aging and Social Support found that of those seniors receiving care 45 percent reported relying exclusively on informal networks and that deficits in these networks precipitated needs for greater formal care. Further, 84 percent of all Canadians aged 65 and over report some kind of assistance with day to day activities (Health Canada & the Division of Aging and Seniors, 2002). Older adult are not only recipients but providers of informal support. They contribute widely to informal social support activities such as: visiting other seniors, helping with shopping, transportation, housework and household maintenance. A recent Health Canada report found that nearly 60 percent of senior women and men participated in these types of activities outside their homes in 1997 (Health Canada & the Division of Aging and Seniors, 2002).

Supportive informal networks are more common in communities with higher proportions of seniors and of individuals who have resided in the community for a relatively long time (Keating, Swindle & Foster, 2005). The steady increase in the percentage of seniors living in the CURA neighbourhoods suggests that these communities may have a mature stock of social networks. However, the displacement of seniors and long time low income residents associated with gentrification may adversely affect remaining older adults' store of social capital.

Informal support is often understood in terms of social networks. The literature investigating the role of social networks play in health and well-being includes comparisons of composition, descriptions of locality and various typologies but very little research addresses the instrumental features of the networks and how they might be supported by policy and programs. Several authors (Campbell and Lee, 1992; Logan and Spitze, 1994) have noted that proximal networks or place-based neighbourhood networks play an increasingly important role for those groups with limited mobility and resources such as older adults. One important trend emerging from the literature is that of the crucial role of "weak ties" in individual and neighbourhood social capital. Weak ties are those understood to be relationships that "bridge" diversity and in their breadth offer opportunities to access a greater range of resources (Cattell, 2001). This trend led the Economic and Social Research Council for Neighbourhood Research (Bridge, 2002) to recommend that policy interventions aimed at enhancing social capital should focus on fostering weak instrumental ties within and extending outside of neighbourhoods rather than supporting existing

strong ties characterized by socially homogenous groups. The significance of fostering weak ties may be particularly important in neighbourhoods undergoing the socio-demographic shifts associated with gentrification.

Overall, the literature indicates that the level of social support available to an older adult exerts a positive influence on aging in place. Particularly, adult children (Akamigbo & Wolinsky, 2006) and higher levels of community engagement (Hays, Pieper, & Purser, 2003; Kersting, 2001) were predictive of community dwelling whereas living alone significantly increased the risk of moves to institutional settings (Akamigbo & Wolinsky, 2006; Gaugler, Duval, Anderson & Kane, 2007; Kersting, 2001; Mutchler & Burr, 2003). This is a significant finding given that, according to 2007 Toronto census data, there were 89,790 seniors living alone in Toronto in 2006, an increase of 5.4% since 2001 (Toronto, 2007a). Programs and policies targeted to strengthening ties to neighbourhood and community, as well as outreach to socially isolated older adults, are critical to offsetting the deficits in social capital associated with aging and ageism. Interestingly, the literature reveals an often paradoxical relationship between the presence of a dedicated caregiver and the risk of moves to institutional settings. For example, Gaugler et al., (2007) meta-analysis found that, overall; the presence of a caregiver was a strong predictor of nursing home admission. Miller and Weissert, in contrast, found that in 67 percent of the studies they reviewed, there was reduced risk for those with greater levels of caregiver support (Miller & Weissart, 2000). This latter measure of the relative degree of available caregiving support may be a more effective way of assessing the impact of caregiving than the blunter measure of whether or not caregiving is available. Future research should attempt to isolate the dimensions of informal support and evaluate their effect on different groups and in different contexts.

The literature reveals a modest association between the presence of formal (paid) help and greater risk of institutionalization. Many of the factors which drive the paradoxical relationship between caregiving and residential outcomes may be associated with this finding. For example, that the existence of support creates opportunities for monitoring and detection of deterioration. Another reason that may underlie the conflicting findings is that the diversity of forms of help (from Personal Support Workers to doctors and a family member paying bills to bathing) leads to a diluted effects and difficulties in interpretation.

Neighbourhood Socio-economic Infrastructure

Neighbourhood socio-economic infrastructure exerts an influence on aging in place through a number of mechanisms including SES, place attachment, service characterictics, residential options and

"livability" (the degree to which neighbourhood structures, including housing stock, and services accommodate older adults). For example, an Ontario study investigated the association between place of death and neighbourhood characteristics and found that seniors living in areas with higher social deprivation were more likely to die in long-term care facilities than either in the hospital or at home (Motiwala, Croxford, Guerriere, & Coyte, 2007). Likewise, Hou and Myles (2004) using National Population Health Survey 1996/97 data, found that individuals, regardless of their income status, who reside in neighbourhoods with higher SES status report significantly better self-perceived health. Deeg and Thomése (2005) provided an alternate view of neighbourhood influences by investigating the gap between neighbourhood SES and income as a predictor of declines in health. This study found that older adults with low incomes in neighbourhoods with high SES had significantly poorer health. Consequently, the authors suggested that it was not so much the neighbourhood characteristics that affected health and well-being but the gap between individual levels of income and the overall SES of the neighbourhood.

This gap is often referred to as "income polarization" a phenomenon that is frequently evident in urban environments subject to gentrification. For example, Hulchanski's (2007) analyses of changes in individual incomes across Toronto census tracts between 1970 and 2000 found alarming trends indicating a growing polarization of high and lower income groups. Hulchanski's (2007) report revealed that much of the seven CURA neighbourhoods had incomes that were at least 20 percent lower than the average for Metropolitan Toronto. For those residents with lower incomes, the rising property values accompanying gentrification create conditions of risk of displacement. Older adults who frequently have modest resources and rely on relatively fixed incomes are highly disadvantaged in their capacity to be responsive to these market pressures and are more likely to bear the adverse effects associated with neighbourhood transitions. For example, El Kalache, Fang, Moriah, Rodríguez, and Tapper (2005) found that the residents of South Parkdale, Little Portugal, and Niagara neighbourhoods with incomes of less than \$35,000 were far more likely to notice the negative impacts of gentrification on housing affordability.

A related phenomenon to income polarization is the social polarization that Slater (2004) identified in South Parkdale where different groups live in parallel social space with limited bridging that creates silos of disadvantage and dislocation. For retired adults who may have fewer opportunities for social interaction, neighbourhood polarization can lead to increasing risk of displacement. Displacement to other neighbourhoods with less costly housing presents a number of age exacerbated challenges: ageism and nonparticipation in the labour market make it more difficult to establish new links in the alien community; the outlying lower income communities are largely under serviced and therefore, lack the

supports critical to aging in place; and these communities tend to have highly concentrated retail infrastructure under serviced by public transit and often at a great distance from many residential clusters.

Although multiple of outcomes may occur in a particular neighbourhood context and to a particular population group, perhaps the most useful way of framing the matrix is to consider the balance (or "tipping point") between adverse effects of gentrification (e.g. displacement and exclusion) and healthy neighbourhood change. Lowe (2005) argues that if the original residents of the community are not among the primary beneficiaries of community change than gentrification in that context should not be considered a force driving healthy neighbourhood growth.

Another dimension of the influence of neighbourhood on long-term residential outcomes is residential stability, which is a proxy for place attachment to either housing and/ or neighbourhood. Using the longitudinal AHEAD data, Aykan (2002) found that greater residential stability (residing in the same housing for 10 or more years) significantly predicted lower risk of institutionalization for men but not women. The researcher suggests that residential stability may be a proxy for non-kin informal support but does not comment on the gendered effect of the findings for this variable. Future research might examine the determinants of place attachment and its role in residential outcomes, as well as it meaning across gender and ethno cultural identity.

#### Neighbourhood Residential Support Options

Characteristics and density of neighbourhood residential support options have been shown to influence the capacity of older adults to remain in the community. For example, several studies have found that living in an area with a greater supply of nursing home beds increased the likelihood of institutional living (Burr et al., 2005; Hoerger et al., 1996; Miller and Weissert, 2000). Conversely, the supply of community-based supports appears to exert a protective effect on aging in place. A longitudinal study, using data from the National Survey of Families and Households, found that older adults living in counties with a greater density of community-based geriatric services were significantly more likely to live independently than in a nursing home (Burr & Mutchler, 2007). Another study found that older adult's perception of their ability to age in place was significantly affected by their proximity to health and social services (Sherman & Combs, 1997).

Indications of the systemic failure to realize appropriate residential and support options is evidenced in the extent of over or under care reported in the literature. For example, Berthelot and colleagues (2000) found that approximately 10 percent of Canadians residing in institutional settings are

assessed to have "no disability." Although this proportion is modest, it still warrants questioning whether these individuals could be better accommodated in community settings. A landmark American study, that used data from a sample of 3,170 older adults residing in long-term care facilities, estimated that between 15 to 70 percent could be appropriately cared for in less restrictive settings (Spector, Reschovsky & Cohen, 1996). Even at the most conservative criterion level, the proportion of older adults receiving too much care in this American sample is alarming. Under care is an equally disturbing phenomenon. A recent study by the American Association for Retired Persons found that almost one-third of the 865 older adults surveyed reported having unmet needs for personal assistance (Gibson & Verma, 2006). Davey and colleagues (2005) found that of those Americans in the highest risk group for nursing home placement, a high proportion (one in ten) was without any support whatsoever. Canadian data from the National Population Health Survey and Canadian Community Health Survey have shown that community-dwelling seniors reporting unmet health care needs rose significantly from 5.1 percent in 1998/1999 to 8.1 percent 2000/2001 (Sanmartin, Houle, Tremblay, & Berthelot, 2002).

## Housing Conditions

Another dimension of neighbourhood infrastructure influencing aging in place is that of housing conditions including characteristics of the housing itself, as well as the housing market. Supportive housing (otherwise referred to as assisted living and supported housing) is often promoted as an effective alternative situated between independent and institutionalized living. The demand for affordable supported living accommodations far outstrips the supply even though health economists have noted that it is both an effective and cost-effective means of supporting older adults. For example, Coyte and colleagues in their revision of the forecast produced for the Health Services Restructuring Commission in Ontario noted that "many people who currently are being admitted to Long-Term Care facilities would be able to receive care in their own homes or in a supportive housing setting" (Coyte et al., 2002, p.9).

However, despite the rising demand for supportive housing and championing by various service providers, community groups and academics, there are very few studies that use longitudinal, random control trials or even quasi-experimental methodologies to examine the effects of supportive/assistive housing on extending community tenure for older adults. In the grey literature, a recent large-scale American demonstration project: HOPE for Elderly Independence Demonstration Program (HOPE IV) was evaluated (Ficke, & Berkowitz, 1999). The intervention combined government rental assistance with provision of case managed supportive services to low-income persons aged 62 and older who had three or more limitations to personal care and home management activities such as bathing, dressing, and

housekeeping. The intervention was intended to help low-income, "frail," elderly persons maintain the highest possible quality of life in the least restrictive environment. The quasi-experimental longitudinal evaluation found that the care management and rent subsidy intervention had several positive outcomes across multiple domains of health and functioning (e.g. mental health, social functioning, and vitality). However, there was no significant impact on the interventions group's length of community tenure. The authors explained that this is common to a number of evaluations, which have shown significant improvements in social functioning and overall health and well-being but not in longer-term outcomes such as time till institutionalization.

A recent Canadian study (Lum, Ruff & Williams, 2005) investigated health and housing outcomes for older adults living in supportive and social housing. The findings from the report challenged conventional assumptions about thresholds for institutional care and the peripheral status assigned to community supports outside of the traditional health sector. Almost all the older adults in the study met the criteria for placement in a long-term care facility yet with minimal supports like housekeeping, grocery shopping and for some, supports for personal care, they were able to continue to live in the community. Further, for those living in housing with onsite support, the use of costly emergency services was reduced, leading the authors to conclude that community supports for aging in place are not an "add on" to an already overburdened healthcare system but rather a cost effective alternative to acute and institutional care. The cost effectiveness of supportive housing was highlighted in the authors' comparison of average annual costs to the Ministry of Health and Long-term Care for supportive housing services in Toronto of \$6,984 (Lum et al., 2005) as contrasted with estimated annual costs to the government for long-term care services in the range of \$26,000 per year (Ontario Association for Nonprofit Homes and Services for Seniors, 2005). A follow-up study in Waterloo, Ontario estimated that a full three quarters of those on the long-term care wait list for nursing home admission could be accommodated if more options such as affordable supportive housing were available (Williams, Paul, Devitt-Wilson & Kuluski, 2007).

Other available research demonstrates that service-enriched housing promotes resident satisfaction, successfully provides service to "frail" populations, and supports aging in place (Pynoos, Liebig, Alley & Nishita, 2004). Pynoos and colleagues found that low-intensity programs involving only service coordination can support aging in place, while higher intensity programs for the more severely impaired may extend the option of community living for older adults with higher needs. However, the authors found that in their comparison of community-dwelling and institutionalized older adults, high-needs older adults in the community were slightly less physically and cognitively impaired than those

residing in nursing home facilities indicating that home and community-based services (HCBS) may not provide appropriate levels of support for some older adults.

Emergent, though under represented, housing factors associated with sustaining community tenure include access to assistive technologies and home modifications. For example, Tomita (2007) conducted a two-year random control trial where the intervention group received an enhanced package of smart home technologies including a computer, Activehome software, lighting system and remote chime for security/medication, as well as ongoing support from a geriatric nurse specialist trained in information technologies. The findings from this study indicated that a significantly greater proportion of the intervention group was living independently at year two.

Housing market characteristics such as vacancy rates and the availability of affordable small unit rentals have been found to influence residential outcomes for older adults. Mutchler and Burr (2003) found that lower vacancy rates and higher median rents were significantly associated with higher rates of institutionalization for both unmarried women and men. These findings suggest that a scarcity of affordable housing may force many older adults into lower cost institutional living arrangements. The authors also found that a lower percentage of small residential units (e.g. bachelor apartments, second suites or garden flats) was significantly associated with institutionalization for unmarried women.

Bartlett and Peele (in Andrews and Phillips, 2005) conclude that while there are indications that housing and neighbourhood factors exert an effect on older adults ability to age in place, there is limited research in this area. Studies are required to investigate issues such as availability and access to supports; as well as to identify those features of liveable housing and communities that foster healthy aging and independent living. Particularly, evidenced-based evaluation of the many promising community care and supportive housing programs is sorely needed to support the business case for increased funding for home and community-based supports to aging in place. Future research should foster long-term partnerships with the community to create consistent indicators (Jones, 2007) and modeling of supportive/ed housing and to utilize wait list controls to effectively evaluate programs.

#### 2.2.3 Promising Practices that Support Aging in Place

The following are a selection of projects relevant to aging in place, as well as useful tools developed to forward the development of age-friendly communities. A common feature of all the programs outlined below, is a focus on individualized home and community-based care management. The merit of developing specific and evidence-based care packages is highlighted by Greene and

colleagues (1993) who linked the type of support provided with different profiles to identify the most effective combinations of HCBS. For example, they found statistically significant reductions in nursing home admissions for the following combinations: nursing services provided to those using a wheelchair, home-health assistance provided to those who have cognitive impairment and personal care and housekeeping supports provided to those who experience functional impairment. The implications of these findings are that HCBS must be targeted and that more research to determine the relationship between client characteristics, HCBS, and loss of community tenure is critical to achieving the best possible fit and risk reduction. Regrettably, few of these programs addressed features of the built environment.

Program of All-Inclusive Care for the Elderly (PACE) and Comprehensive Home Option of Integrated Care for the Elderly (CHOICE)

Models of integrated care targeted to enabling older adults with complex needs to remain in the community as long as possible include the Program of All-Inclusive Care for the Elderly (PACE) and in Canada, the Comprehensive Home Option of Integrated Care for the Elderly (CHOICE). These programs provide care through a single portal (one organization which may contract out certain services) typically a Day Centre with a multidisciplinary team who assess and support clients. A recent analysis of the records for 4,646 participants aged 55 years or older who were enrolled in PACE programs during the period from June 1, 1990, to June 30, 1998 found that the cumulative risk of nursing home admission for PACE respondents was less than 15 percent (Friedman et al., 2005). This level of risk was evaluated as low considering that a hundred percent of the enrollees met the threshold for nursing home care.

Program of Research to Integrate the Services for the Maintenance of Autonomy (PRISMA)

Other models of community care emphasize coordination across organizations such as the Program of Research to Integrate the Services for the Maintenance of Autonomy (PRISMA) which offers a single entry point case management model with individualized care plans and coordination between decision-makers and case managers. Preliminary results from a pilot of PRISMA (Hébert, Durand, Dubuc, Tournigy & PRISMA Group, 2003) show a promising decline in the number of older adults who indicate a need to leave the community and move to institutionalized settings, as well as declines in limitations to functional ability and caregiver burden.

System of Integrated Community-based Care (SIPA)

Research suggests that the consistently high risk of institutionalization associated with living alone may make targeting HCBS to this group worthwhile. For example, Beland and colleagues (2006)

found that a Quebec model, the System of Integrated Community-based Care (SIPA), significantly delayed time to nursing home admission, but only for those older adults who were living alone or those who had few chronic conditions. SIPA relies on community-based multidisciplinary teams who deliver integrated care through the provision of community health and social services and the coordination of hospital and nursing home care. The authors' champion the capacity of the case managers to problem solve and set up systems of support that convince hospital staff of the appropriateness of community discharge. They also found that the intervention resulted in greater caregiver satisfaction, as well as no increase in caregiver burden. This study demonstrates that caregiver satisfaction is critical to sustaining older adults in their homes, and that longer community tenure is not necessarily achieved at the cost of increasing caregiver burden.

## The ENABLE-AGE Project

ENABLE-AGE is a five country European initiative that used random sampling of older adults living alone in the community (N=1,918) to examine both the objective and perceived qualities of their housing with the goal of developing evidence-based home assessment tools and guidelines for structural modifications (Iwarsson et al., 2007; Oswald et al., 2007). Age sampling was adjusted to reflect the different mortality rates of the five countries: Sweden, Latvia, the United Kingdom, Germany, Hungary and Sweden. The findings from the surveys of older adults from 75 to 89 years of age indicated a significant link between living in an accessible home (which was valued as useful and meaningful) that is not subject of external controls and reporting fewer limitations to ADLs and higher scores on various measures of well-being. The findings from this study, though emerging from a more vulnerable population (i.e. advanced age and living alone), will be used to further investigate the predictive value of housing-related health outcomes and to initiate European policy and programming to support client-determined housing modifications.

Grassroots Initiatives: "Villages" and Naturally Occurring Retirement Communities

Grassroots support to aging in place has always existed whether from informal church support networks to more organized "friendly visitor" programs supported by local agencies. A recent New York Times article (Gross, 2007) profiled a new model of community organizing where groups of seniors create a neighbourhood-based association with yearly membership dues. The association acts as a conduit to access supports (many of which are provided by other members) and extra "a la carte" services. These so-called "villages" are located in about a dozen American localities and still others are being initiated in less advantaged neighbourhoods by social service organizations.

A variant on this type of community-based organizing is the Naturally Occurring Retirement Communities (NORCs) which are

areas where shifting socio-demographics have resulted in higher concentrations of older adults. These communities are receiving recognition and government funding to support aging in place. For example, the New York State government recognized the efficiencies in providing resources to these senior saturated localities and has funding social services in many NORC neighbourhoods since 1995 (Gross, 2007).

## 2.2.4 Tools that Support Aging in Place

Various guides and evaluation tools have been developed for use by communities to assess their assets and priorities, as well as systematically measure the "livability" of their neighbourhoods. The following is a short selection of promising tools developed to support aging in place.

The "Global Age Friendly Cities Initiative"

The World Health Organization (WHO) spearheaded the "Global Age Friendly Cities Initiative" with 33 international pilot cities (including 3 in Canada) identifying key components and indicators that maximize the social capital and inclusion of citizens of different ages and abilities. The information was collated and then disseminated as a multi-use guide for groups, organizations and governments working toward developing age sensitive environments (World Health Organization, 2007). The guide recognizes that material conditions, as well as social factors, affect the quality and quantity of years spent in the

community. Figure 1 illustrates the interplay of these factors which were used to identify goals and chart progress over time.

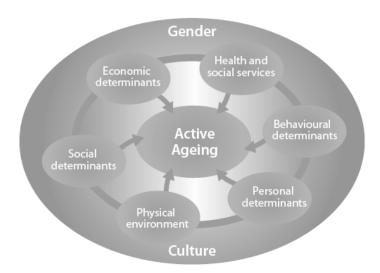


Figure 1: Determinants of Active Aging

The Aging in Place Initiative

The Aging in Place Initiative (AIP) is a partnership between Partners for Livable Communities (Partners) and the National Association of Area Agencies on Aging (n4a). In 2006, Partners and n4a

collaborated with the International City and County Management Association (ICMA), the National League of Cities (NLC) and the National Association of Counties (NACo), with support from the MetLife Foundation, to conduct a survey of 10,000 US cities and counties to determine how they were addressing the needs of their aging population. The findings from this survey were used to produce a comprehensive toolkit: *A Blueprint for Action: Developing Livable Communities for All Ages* (AIP, 2006). The toolkit will be used by communities to facilitate discussion, assessment and action toward becoming more livable for all ages.

The American Association of Retired Persons' (AARP) Livable Communities: An Evaluation Guide

In 2005, AARP updated its 2000 *Livable Communities* evaluation guide and included a community survey to be used by groups to assess the current status of their neighbourhoods and develop strategies for action (AARP Public Policy Institute, 2005). The revised 2005 guide includes new material emerging from efforts to confirm and expand the contents to reflect more input from older adults and their caregivers. The survey produces findings that can then be presented to policy-makers as evidence of the need for enhanced supports to aging in place.

## The AdvantAge Initiative

The AdvantAge Initiative, a project of the Centre for Home Care Policy and Research in New York, has developed a set of indicators to evaluate community capacity to support the health and well-being of its older citizens. The model proved remarkably consistent across the multiple sites of inquiry and, as the authors contend, was relevant to both older populations and participating adults in the younger age range of 30 to 59 years of age (Hollander-Feldman & Oberlink, 2003). This last point of extending the dialogue outside of the traditional age frame to a life course, diversity and community building dialogue which emphasizes that livable communities benefit all citizens, not just particular groups, is gaining endorsement as a means of ramping up support and activity.

#### 2.4 Community-based Research and Engagement

Community engagement whether in the context of research, projects or community councils is particularly relevant to older adults who have may have fewer options for participation (i.e. activities linked to employment may be no longer viable etc.) but more time to engage with issues affecting their lives and their communities. Projects that meaningfully engage citizens foster community capacity to effectively prioritize, problem-solve and advocate for programs and policies that support healthy age-

friendly communities. Another key feature of community-engaged projects is that they produce findings that are relevant to policy and program development. As Bryant, Raphael and Travers (2006) point out, community participation in the research process produces issue and action based findings that directly address policy analysis and reform.

However, project or research based community engagement is often short-lived and for the express purpose of collecting data. A crucial distinction that determines the scope of community-based research is defining community. For many research projects, community partners are individual service providers or nonprofit organizations. Although these projects may include some of the "service users" or other citizens in the community, it is still rare that nonprofessional individuals or groups are the primary partners (Taylor, 2006).

While methodologies such as the variously named "community-based," "participatory" or "social action" research or "campus-community partnerships" have extended the processes, outcomes and objectives of engaging community members, engagement tends to be occur in a context where power and decision-making is weighted toward academic partners. Also, there remains a tendency to value the expertise of the academy and construct the flow of knowledge as moving from the campus to the community. Seifer and Greene-Moton (2007) acknowledge that Community-based Participatory Research (CBPR) does not "go far enough" in supporting the research capacity of community organizations nor does it challenge university control of the research enterprise. A working group convened by Community-campus Partnerships for Health (Seifer & Greene-Moton, 2007) concluded that for most part CBPR does not meet the threshold for an "authentic partnership" and that community capacity building and social justice are often not overt goals of the projects. Further, campus-community partnerships are situated within two very different cultures. In their analysis of the collaborative process, Buckeridge and colleagues (2002) found that the culture of academic and community partners brought distinct and sometimes conflicting expectations, objectives and outcomes. The authors contend that funders must accommodate the time and resources necessary to build relationships and negotiate differences between partners.

As a counter to the limitations of the CBPR model, an alternate is proposed by Heaney, Wilson and Wilson (2007): Community-Owned and – Managed Research Model (COMR). COMR is distinct in that it empowers community organizations to seek funding directly as principal investigators who then engage experts from academic institutions or from the nonprofits as appropriate and determined by the community. COMR also allows the community to have full ownership of the data to drive actionable

outcomes. Although this requires a great deal of organizational capacity, a model such as this places the community at the centre of the process and project. COMR may permit the project activities and actions to be sustainable - something that Taylor (2006) acknowledges is a major pitfall of campus-community partnership.

Shifting power is identified by several authors (Carter & Beresford, 2000; Taylor, 2006; Tetley and Hanson, 2000) as essential to meaningful and inclusive participation by older adults. If research is to prove to be truly inclusive of older adults and power is central to the meaning of that participation than the role of professional researcher needs to be reconfigured to that of an enabler or facilitator. However, as Adams (2003) notes the shift from coordinator to facilitator introduces the tension between empowerment and responsibility to minimize risk (psychological and otherwise) and between process and capacity building and products and outcomes. Although these tensions will never be entirely ameliorated, vigilant reflection (both on the part of the professional and community members of the research team) on the balance between these often competing objectives is a critical.

Many policy frameworks mandate the involvement of those individuals most affected by the issue being (Bryant, Raphael & Travers, 2007; Devon Dodd & Hebert Boyd, 2000). Consequently, research and project advisory committees composed of older adults are becoming quite a common practice and extensive consultation forums are preliminary to many investigations and initiatives. However, engagement and participation that extend beyond steering, preliminary or confirmatory exercises are rare. A recent review of the literature to evaluate the extent of involvement of older people in health research found that the majority of participation took the form of advisory groups or preliminary consultation (Fudge, Wolfe & McKevitt, 2007). Only three of the 30 articles reviewed involved the participants in data collection and analysis. Although only four of the studies formally evaluated the impact of involving older people, the majority of studies did reflect on the experience of engaging older adults. The majority of evaluation and reflections reported in the studies focused on the impact to individual participants highlighting capacity building such as increased confidence and understanding of the issue(s) and ability to interact with policy-makers. The reviewers note the scarcity of formal evaluations of the affect of engagement of older adults on research/policy processes and outcomes. However, anecdotal evidence from two other studies (Roe, Minkler & Saunders, 1995; Ross et al., 2004) describe how involvement by older adults extends awareness of the findings and encourages action by the participating older adults and other community members to shape public policy. Despite these few formal evaluations and some promising anecdotal reporting, there is very little evidence of the outcomes associated with participation or of the processes that best support participation (Dewar, 2005).

Some authors caution that a critical analysis of the structural and economic rationales for such a push on civic engagement of older adults is crucial (Biggs, 2001; Martinson & Minkler, 2006). Like the productive aging paradigm, civic engagement as a marker of successful aging excludes many older adults who can not or will not participate in their communities in this manner. For example, civic engagement frequently marginalizes those with lower levels of socio-economic resources and as such is often associated with individuals and neighbourhoods with higher levels of social capital. Martinson and Minkler (2006) found that a structural analysis of volunteerism reveals the clear links between the devolution and retrenchment of the welfare states and the emergence of the voluntary sector and kin/nonkin support as alternative sites of care for older adults. Further, as Biggs (2001) proposes, all the focus on productivity and the value of contributions draws this segment of the life course back into the norms associated with youth and mid-life, therefore, erasing other notions of late life meaning and activity.

Overall the literature suggests that while there is some momentum in increasing engagement of older adults in research and project activities, it remains largely tokenistic. Alternative models that offer sustained participation and are linked to policy-making systems (e.g. local government), such as neighbourhood councils and civic panels, should be explored in future research and development. Finally future research should, as Fudge and colleagues (2007) note, document evidence-based engagement practices and evaluate both the process and outcomes of community participation so that replication is possible in different contexts.

#### 2.4.1 Promising Practices and Tools for Community Engagement

Elder Friendly Communities Project

The Calgary "Elder Friendly Communities Project" is a three year pilot aimed at creating senior-led community development initiatives that challenge dominant paradigms of service delivery (and transformed clients into citizens) and that are sustainable and culturally appropriate (Austin, Des Camp, Flux, McCelland & Seippert, 2005). An extensive Phase II evaluation revealed that the community groups convened for the project had effectively prioritized actions critical to developing elder friendly communities. Further, enhanced individual and group capacity was evident in the increased knowledge and problem solving skills demonstrated by the project's workgroups. Major challenges reported by the older adults and community development workers were: finding a balance between facilitation and community autonomy, garnering the support of direct service workers, and acknowledging and

accommodating the time intensive work of relationship building that was key to effectively organized the workgroups. Longer-term outcomes such as impact on the quality of life of older adults and the social capital available in their neighbourhoods have not been assessed but the authors are confident that the initiatives underway will have lasting and positive effects on individuals and communities.

## Participatory Planning and Neighbourhood Councils

Participatory planning and decision-making models such as those pioneered in Porto Alegre, Brazil and replicated to some degree in the Canadian cities of Toronto and Guelph are promising models of empowering civic engagement (Maxwell, 2007) that may be particularly timely and appropriate to the CURA neighbourhoods. As Siemiatycki (2007) suggests, the new City of Toronto Act affords opportunities to pilot more inclusive and participatory modes of governance. A variant that offers sustained opportunities for older adults to engage and impact policy and program development is that of neighbourhood councils. Maxwell (2007) describes neighbourhood councils as a formal mechanism to inclusively engage people in the decisions that affect them, as well as enhance social cohesion and citizenship. A key dimension of this form of engagement is that it has twin objectives of achieving breadth (in that it includes more and more people) and depth (in that the community of people has increasing knowledge and resources to act in decision-making processes). The structure of these councils lie on a continuum from very loose associations to more formalized groups with direct links to municipal government; some are even mandated and institutionalized through municipal charters. Maxwell (2007) contends that the support of local government is crucial and that the benefits are mutual: neighbourhood councils gain access and municipalities gain credibility.

#### Inclusive Cities Canada

Inclusive Cities Canada (ICC), a cross country project, utilized civic panels and neighbourhood councils linked to municipal governments to explore dimensions of social inclusion. Participants in the ICC project voiced concerns over what was characterized as a "democratic deficit" experienced by many Canadians who feel disconnected and excluded from local decision-making (Clutterbuck, Freiler and Novick, 2005). A critical distinction made by ICC participants is that engagement must move beyond consultation to more substantive and sustained forms of participation that expand community capacity to act on issues while building skills, understanding and a greater sense of agency. Maxwell (2007) has documented the merits and the processes of neighbourhood councils as a sustainable and empowering mechanism of civic participation.

## INVOLVE Project

Institutionalized and government funded mechanisms such as the U.K. INVOLVE project are a good example of how ongoing funding and effective resources can promote and support active public involvement in public health and social care research. For example, INVOLVE has funded several participatory projects engaging older adults in identifying issues and strategies relevant to enhanced health and social care. INVOLVE has also funded the development of various tools for engaging older people in research, development and project evaluation including: *Good Practice in Active Public Involvement in Research* (INVOLVE, 2007a) and *Strengthening the Involvement of People with Dementia Toolkit: A Resource for Implementation* (INVOLVE, 2007b).

## Section 3.0 Methodology

#### 3.1 Data Collection

Data was collected through a series of community consultations (N=80) and focus groups (N=40) that "mapped" aging in place using Kretzmann and McKnight's (1993) methodology of Asset-Based Community Development (ABCD), which assumes that communities have assets, and that change comes from the inside-out as communities mobilize their capacities. To begin the project, a focus group was held with service providers with expertise in programs and services for older adults. Community consultations were then held in three locations across the seven CURA neighbourhoods. From these consultations, participants were invited to attend one of two focus groups. In the consultations and the focus groups, participants were recruited to participate in a working group. This group met for eight working sessions from August to December, 2007. In the working group sessions, the data collected in the consultations and focus groups was analysed to identify key themes and priority issues which would then be represented in the visual form of a multi-layered map (Appendix 3). Not only did the working group collectively analyze the data but the group also crafted reccomendations in the form of solutions and strategies to enhance aging in place (Appendix 3: layer 2 and 3 of the map).

## Focus Group with Service Providers

The project began with recruiting service providers for a focus group with the assistance of the project's community partner: St. Christopher House and by the project team's network of agencies (for a list of participating agencies see Appendix 1). Participants were selected who had expertise and experience in providing supports and services to older adults aging in place. The focus group with service providers was 2 hours in length and the data gathered there provided a preliminary framework that established key issues and concerns relevant to the project.

## Community Consultations

Following a grounded theory methodology, each stage of data collection informed the revision and refinement of subsequent data collection protocols. The protocol used in the community consultation was informed by the main themes and issues identified in the first focus group. A selection of protocols are included in Appendix 2. St. Christopher House was the site of the project's first community forum held to collect data and to recruit for further participation in the project. Interpretation was provided so that members of both the Portuguese and Vietnamese communities were able to participate. A second consultation was held at Masayrk-Cowan (a local community recreation centre) with support from Sistering, an agency serving low-income women. A third and final community forum was held at Loyola Arrupe, a supportive housing site that also has congregate dining for seniors in the wider community.

Posters were widely distributed to agencies, libraries, community health and recreational centres to encourage broad community awareness of the consultations. The consultations were one to two hours in length. The project coordinators solicited feedback from community members on the services and supports that were needed, used and absent in the present and in thinking about their futures. The project coordinators took detailed notes at the consultations. Note-taking as well as the artefacts used in the focus and working group sessions were used to document the project processes and findings. Although audio recording is more commonly used for interviews and focus groups, community participation in all aspects of the project demanded briefer mediums to convey the data than that produced by lengthy transcripts.

#### Focus Groups with Older Adults

A lottery was conducted to select participants for the two focus groups with older adults from lists compiled during the consultations. Two bilingual focus groups were held, one with the assistance of a Vietnamese interpeter, and the second with a Portuguese interpreter. The project coordinators facilitated discussion and conducted consensus excercises to explore emergent themes and to seek more detailed and deeper understandings of key areas identified during the consultations and the preliminary focus group.

#### Working Group Sessions

The working group participants were randomly selected from the focus group participants who indicated interest in continued participation in the project. Due to practical constraints, only one non-English speaking group could be accommodated. A tiered lottery was conducted which led first to the selection of Portuguese-speaking participants. A subsequent lottery was conducted to select from English speaking participants to determine a final working group comprised of ten members. An interpreter was recruited who was currently working for St. Christopher House with the Portuguese community. A meal was provided at each session, and the participants also received an honorarium at each meeting. In line with the principle of valuing all participants in the work of the project, the interpreter was an active participant in the working groups in addition to providing assistance with interpretation and translation. Text-based activities were limited to accommodate differences in language and literacy. However, at times internet translations, vetted for global accuracy by the interpreter, were used to inform the working group's activities. This constraint may have limited the depth of text provided but it also ensured that jargon and complexity did not exclude community participation. Methodologies that are adaptive to the group's needs and capacities are crucial. Though challenges may initially pose difficulties, the adaptations often offer distinct advantages that enhance processes and outcomes. For example, activities that rely on brief bulleted materials produce plain language results that are readily understood by the community.

#### 3.2 Collective Data Analysis

Analyses of data collected during the community consultations and focus groups was exploratory with the objective of preliminary clustering of emergent themes to inform the working group's further analyses resulting in the creation of the map. Different strategies were employed at each working session to achieve three primary mapping objectives 1) to map existing neighbourhood assets/resources that support aging in place (Appendix 3: layer 1 of the map), 2) to identify issues, barriers and solutions that expand current supports, as well as brainstorm innovative new supports to aging in place (Appendix 3: layer 2 of the map), and 3) to document strategies to take action on these innovations at six different levels: informal networks, non-profit programming, private sector and all three levels of government (Appendix 3: layer 3 of the map).

**Session 1** focused on building group cohesion, mapping personal geographies by linking individual life history with place using a global map, inventorying working group assets using the Asset-based Community Development Institute's Capacity Inventory and then polling for skills to be shared and learnt.

Session 2 was the first distillation of key issues identified during the focus groups and consultations. The working group prioritized issues using a "dotmocracy" exercise where participants "vote" using colour-coded dots. Issues were examined for links and overlaps until saturation was achieved and five thematic categories emerged in an exercise of hierarchical clustering (as listed in Section 4.2.1). Also, this session included a visioning exercise which identified individual, group, community and structural outcomes desired by the working group including: working together in a frank inclusive space, provoking innovative thinking and identifying gaps associated with aging in place and effectively representing the community and taking action on health promotion to "change the community."

In Session 3 the group created a timeline for the project, outlined our objectives and brainstormed about how we would achieve them using a back-casting exercise structured as a variant on logic modeling where outputs, inputs and activities are linked to outcomes. The group used the outcomes identified during the visioning in Session 2 and then worked backwards to identify the constituent parts. Next the working group, individually and in small groups, used a map of the CURA neighbourhoods to indicate with a schema of symbols what health, social, and educational/recreational/cultural supports they used on a regular basis. Supports that come into the home were also identified according to five categories: personal care, homemaking, paying bills and other day to day concerns, meal support and health care. The

results of these maps were collated and augmented with other known senior-specific sites. The final collation is represented on layer 1 of the map.

During **Session 4** the collated results of the mapping of existing supports were shared back with the group and revisions/additions invited and included. Next the group used the issues identified in Session 2 to build a matrix to analyze the barriers embedded in those issues and solutions to address those barriers. The matrix analyses yielded an 11 point table to be used in Session 5 to construct content for layer 2 of the map.

Session 5 used the 11 point matrix to cluster the solutions and strategies into 3 categories under the thematic rubric of accessibility. Each point was then situated within the context of housing, neighbourhood or agency. Three transparencies were created with a visual representation of each context and "ideal supports" to aging in place located on the appropriate visual. These ideal supports formed the content of layer 2 of the map.

Session 6 used a version of deliberative dialogue to strategize and document how the group and later the community could take action to realize the ideals identified in Session 5. Deliberative dialogue is well suited to exploring the most promising strategies for action, as it moves the focus from the questions of "What are the issues?" to "What should we do?" The question was applied to a matrix of six sectors: informal, program/agency, municipal, provincial and federal levels of government for each of the three content themes: accessible housing, accessible neighbourhoods and accessible agencies. Participants worked in two small moderated groups to first identify, then modify or recast strategies for each sector until the group was able to endorse a menu of actions for the three content clusters.

**Session 7** focused on planning of dissemination activities. One half of the participants who were presenting the project map and findings at the community forum engaged in scripting and then rehearsal of a collective narrative of aging in place in the CURA neighbourhoods. The script was crafted to link individual stories with the aggregate findings in an accessible and animated manner. Individuals were given a brief table of participant speaking cues and bulleted content to review prior to the community forum. The other half of the participants spent the session planning and prioritizing for future actions.

**Session 8** was an action session where the first small group and the coordinators shared the project findings with the community at a forum at St. Christopher House. Service providers, policy makers, politicians and individuals and groups from the neighbourhoods were invited to participate in a

dialogue about aging in place with a focus on those issues and strategies identified by the project working group.

**Session 9** was a termination session where the group convened to reflect on the project's rewards, contributions and limitations. A discussion of the how the map might be used in the future identified a number of targets for extended community action including: further dissemination to the Toronto Central and other LHINs, at various conferences and events, and via the sharing of resources with key Ministries and seniors groups.

In keeping with the project's objective of community capacity building, as emergent needs were identified during the working sessions resources were produced for use by participants and later the community at large. Two resources were produced: a fact sheet outlining information and resources to improve housing and supports to independence and another sheet outlining housing option for older adults (Appendix 4).

#### 3.3 Limitations of the Methodology

A number of factors limited the findings from this study including convenience sampling that leads to participants who do not have serious cognitive or functional limitations, who are the "young" old and who are well connected to service systems and other informal support networks. Although the impact of gentrification and the challenges to aging in place are shaped by inequalities of class, ethno-cultural group membership, gender, different abilities and sexual orientation, the limited scale and open-ended recruitment of this project allowed for only cursory inclusion of these intersecting identities. No formal inclusion or exclusion criteria was used, although every attempt was made to engage older adults and their caregivers who were currently residing within the seven CURA neighbourhoods. Initial attempts to engage caregivers in the project were unsuccessful. When agencies were contacted, several noted that their support groups for caregivers had been discontinued and therefore caregivers were difficult to locate. However, many of the older adults participating in the project (and about one-third of the working group) had formerly or currently provided care to parents, spouses and other family members.

Also limiting the findings of this project, like much of the literature documenting community engagement, is the absence of a formal assessment of the data analysis, though dissemination at a community forum did provide an opportunity to verify the relevance of the findings. In keeping with

<sup>&</sup>lt;sup>7</sup> For the purpose of this project, "older" adults included all those individuals who self identified as an older adult.

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place-based research, localized knowledge informed the findings and as such the issues, solutions and recommendations emerging from this project may not be generalizable to other localities. As to process outcomes, this project also did not formally evaluate the experience of participants or document capacity-building. However, anecdotally, participants expressed various benefits accrued during the project including: greater knowledge of aging in place resources, of systems that impact these resources, and of strategies for community mobilization and self-advocacy. Future, participatory research with older adults should incorporate evaluation of the findings and processes, as well as of individual and community-level impacts.

#### **Section 4.0** Key Findings and Recommendations for Action

Data was collected and progressively distilled through three mechanisms: three community consultations, three focus groups and eight working group sessions. The findings from each stage of data collection will be presented as they relate to the three research questions adressing existing formal and informal supports, barriers and enablers, and taking action to support aging in place.

#### 4.1 Existing Formal and Informal Supports to Aging in Place

Supports were understood to include formal (paid) and informal (unpaid) human supports and those features of the built environment (both within household and outside of household) that promote mobility, participation and inclusion. Existing supports were only indirectly addressed during the focus groups with older adults where the emphasis moved to issues and barriers. For this reason only the findings from the 3 consultations, the focus group with service providers and the 8 working group sessions are presented in this section.

# 4.1.1 <u>Community Consultations, Focus Group with Service Providers and Working</u> <u>Group</u> Community Consultations

Many of the participants attending the community consultations reported high levels of affiliation and participation with local nonprofits and community centres. As would be expected individuals attending the consultations tended to be actively engaged in the community and spoke of health, social, recreational and faith-based sites as meaningful "third places." Third places, a term used by geographers and planners, is used to denote public spaces such as streets and sidewalks, parks and cafes, theatres and sports facilities (Frumkin, 2003). As older adults leave the work force (second place) and experience the first place (home) as a potential source of isolation, third places take on more significance especially as sites of social connection and capital. Further, as individual's age third places extend to health and social services which play an increasingly greater role in older adult's lives. As has been found in a number of studies (McDonald, Dergal & Cleghorn, 2004; McDonald, Donahue, Janes & Cleghorn, 2006; Russell & Schofield, 1999) service providers are often identified by older adults as a major source of companionship and social connection.

Although third places were identified as significant sites of community involvement, there was little interest in providing an inventory of formal health and social supports that were currently available. However, many participants did report a deep affiliation with a single site, typically in the context of social support rather than traditional health services. For example, participants attending the consultation at St. Christopher House, a multi-service community organization, spoke of many layers of care and an

overall sense of a community of support. At the supportive housing site: Loyola Arrupe, participants spoke of not needing to venture elsewhere because most of there social and recreational needs were met onsite in the communal areas within the buildings. However, participants at the recreational community centre spoke of multiple sites of connection and meaning including faith-base groups, agencies and libraries.

In terms of informal supports, most participants reported receiving assistance from family and friends. The nature of the support was often targeted and instrumental. For example, weekly delivery of groceries, assistance in an emergency and transportation to appointments. Although this support was most often provided by adult children, some participants reported assistance from extended family members, as well as friends and neighbours. Despite widespread reporting of informal supports, participants stressed that they were careful to avoid "burdening" their family and friends and would seek formal alternatives if more were available. This finding is aligned with Davey and colleagues (2005) suggestion that in North America informal care is often a substitute rather than a complement to formal care. Many of the participants had current or historical experience of caregiving and consequently appreciated the demands, including lack of formal support, associated with providing ongoing care.

The impact of gentrification, on aging in place generally and on aging supports and services specifically, was presented at the onset of each consultation. Each participant was asked to introduce themselves by name and comment on any changes they had noticed in the neighbourhood. This query was intended to obtain information about visible and tangible indicators of change. Gentrification was revisited later in the discussion of neighbourhood livability and the emotional dimension of change and place attachment was sought through discussion of how participants "felt about their neighbourhoods" and "what communities they felt a part of" (complete protocols are included in Appendix 2). Stories of violence and victimization were reported. However, these issues were not linked to gentrification but to a clustering of disadvantage that exists in some of the CURA neighbourhoods. Although this "clustering" is exacerbated by the rising housing costs associated with gentrification which may be driving lower income (and otherwise marginalized) households to concentrate in the remaining affordable housing options, it was only indirectly acknowledged through a generic concern with rising costs of living. Other issues embedded in the theme of "high costs of living" included: concern over fees for services (e.g. garbage collection), increasing costs of utilities, low levels of income benefits, the high cost of desired medication, dental care and other health supports.

In contrast to those who felt victimized, a significant proportion of participants reported that there were "no changes" and maintained that their neighbourhoods were "good," "clean," and "safe." Gentrification is following different trajectories in the seven CURA neighbourhoods and therefore the perception of change may be quite diverse among participants living in the different neighbourhoods. Another rationale for limited awareness of gentrification is offerred by Slater (2004) who describes the process of gentrification as creating a "tectonic" social structure that is characterized by minimal across group interaction where gentrifiers and longer standing residents occupy parallel social, if not physical, space. Nevertheless, gentrification as a distinct phenomena appears to be largely invisible to the project participants and its impacts collaspsed into the more generic trends of rising costs and crime.

#### Focus group with Service Providers

The distinction between formal and informal supports was highly contested. Service providers felt that the distinction between the two was "artificial" and "blurred" with a fine line between informal and formal. It was suggested that the distinction is really between paid and unpaid and even this is not always clear.

In terms of formal supports, the majority of service providers championed existing case management programs as effective and cost effective models of individualized care for older adults. Although many service providers spoke of the need for age-targeted formal supports, several suggested that discussion of informal networks should not be restricted to networks between older adults but to all members of the community. Service providers expressed a range of observations on the extent of informal support mechanisms in their service communities from those who felt that there were a considerable number of existing peer supports and networks, some "official and some unofficial," to those who observed that informal networks were on the decline and that generally older adults were less inclined to derive social and instrumental support from informal networks.

Regardless of the quantity of informal support available, such networks were seen as evidence of valuing the "voices of experience" which are institutionalized through such mechanisms as board participation. Further, service providers suggested that there were many other opportunities for advocacy by older adults but that not everyone chooses to advocate and that there is no money to support advocacy work. The "New Horizons for Seniors" grant was cited as an example of monies to support advocacy.

Several innovative programs were described including: an initiative utilizing city recreational centres for a fall prevention (taking care to where the older adults are at); a discharge program that links

hospital and community-based providers and provides a coordinated transitioning package (e.g. "Home at Last"); various examples of value-based supportive housing providing coordinated, flexible care 24/7; and the Local Health Integration Network's (LHINs) "Family Health Teams."

On the issue of service provision and gentrification, most service providers felt that the forces of gentrification were "difficult to see." Others conjectured that the influx of more affluent and more highly educated residents would exert an upward pressure to improve neighbourhood social capital. Some suggested that the upward pressure would result in higher property values for older adult homeowners which would enhance their assets. However, it was also raised that this would increase property taxes and add to the paradox experienced by many home-owning older adults of being "asset rich but cash poor." One service provider suggested that this stress could be mediated by options to defer tax increases until the house was sold or estate settled (the barriers to deferral programs that levy against the estate were voiced later in the context of advance planning). Some service providers suggested that informal care may be enhanced with further gentrification through the mechanism of increased volunteerism by the younger upwardly mobile new residents.

Negative impacts identified as emerging from gentrification included increases in rents and in conversion of rental properties (particularly concerning given the high number of rooming houses in the CURA neighbourhoods) which would result in fewer affordable rental housing options. This outcome was considered even more distressing given the huge wait list for subsidized housing. Another concern raised was that if gentrification increases the displacement of older adults to other neighbourhoods and institutional settings, services and supports would be diminished for remaining older adults. A twin concern was the limited supports that would be available to older adults displaced to service poor suburbs. This potential reduction in services, driven by gentrification, displacement and changing sociodemographics, was flagged as a critical issue for older adults.

Inclusion and engagement of diversity was seen by some as being weakened by gentrification but by others it was seen as a source of increased "tolerance" for difference. Several service providers put forward that the influx of people into the neighbourhoods would result in greater diversity and enhanced ethno culturally sensitive services. A few service providers thought that diverse groups of in-movers might lessen the stigma attached to "different behaviours" (e.g. acceptance of ethno culturally specific practices might be generalized to behaviours arising from poor mental health). However, others felt that new residents could be less tolerant of others and embrace NIMBYism and rate payers' demands to preserve the market value of housing by blocking the development of congregate living arrangements,

such as assisted/supportive housing and rooming houses. To mediate the potential conflict between current residents, new residents and new alternative housing initiatives the group strongly endorsed the need for outreach, education and building rapport between neighbourhood residents. Several service providers emphasized that if rapport, awareness and relationships are consolidated neighbours will accept integrated, diverse communities.

#### Working Group

Through a series of individual and group facilitated activities, the working group members mapped formal supports they personally use that were within or proximal to the CURA neighbourhoods. Supports were clustered into four categories: health, social, recreational/educational and faith-based services with many services providing support in multiple categories. Informal supports, were not included on these maps for a number of reasons including: that most informal supports did not occupy a location(s) but were diffuse and occurred in multiple settings and that those more institutionalized informal supports such as associations (e.g. Portuguese Women's 55+ Support Group and the Vietnamese Women's Association) were staffed by paid employees and therefore outside of the definition of informal supports as understood in this project. Paid formal supports that occur within the home such as home health aide or meal delivery were located at the source agency. The working group's utilization of services was collated and then supplemented with sites that specifically supported older adults<sup>8</sup> (Appendix 3 layer 1 of the map). Overall use of health and socio-recreational services was moderate and usage was scattered throughout the seven neighbourhoods. However, notable clustering emerged in the Parkdale and Dufferin Grove neighbourhoods suggesting that these areas may be particularly service rich.

As for informal supports, the majority of working group participants received assistance from members of the family in three key areas: help with health care issues (e.g. medication and health aid management), help with paying bills and help with homemaking.

#### 4.2 Barriers and Enablers to Aging in Place

Although preliminary issue identification emerged during the 3 consultations and 3 focus groups with older adults and service providers, it was during the subsequent 8 working sessions that priority issues were defined and refined, as well as solutions put forward to enhance supports to aging in place.

<sup>&</sup>lt;sup>8</sup> Those agencies identified by working group members as a useful support were not subject to any specific criteria whereas those added by the project coordinators must have an overall mandate (not just a program) of servicing older adults and be located in the CURA neighbourhoods.

#### 4.2.1 Barriers: Priority Issues and Associated Challenges to Aging in Place

Community Consultations and Focus Groups with Older Adults

Initially, the issues were clustered into five provisional thematic categories: safety and comfort in the home, safety and comfort in the neighbourhood, barriers to accessing existing formal supports, limitations in scope and quality of formal supports, and challenges to informal and/or social supports.

Participants stressed several factors that were instrumental in feeling **unsafe in their homes**. Although some participants reported structural and technological supports in their housing, most had experienced or anticipated challenges brought on by **inadequate accessibility accommodations** (especially access to and within bathrooms). Few participants were aware of the various government resources to finance structural modifications (e.g. Federal Disability Tax Credit, Home Adaptations for Seniors Independence, Residential Rehabilitation Assistance Program and Emergency Repair Program) and even fewer were aware of emergent assistive technologies (e.g. medication alerts, "smart home" software, and "smart appliances") <sup>9</sup>.

Participants were concerned with the "high costs of living" which were creating conditions of risk of displacement to less autonomous settings such as residing in the homes of adult children and long-term care facilities, as well as to less costly alien communities. As Sachs-Ericsson and colleagues (2006) found, there is a powerful relationship between perceived problems with meeting basic needs and declines in physical functioning. Rising property taxes, as well as utility costs and property maintenance were challenging participants' capacity to maintain their homes and generating considerable stress associated with poor health outcomes. Lack of affordable rental options coupled with long wait lists for subsidized seniors housing were cited as limiting moves to more affordable and/or age-appropriate housing. Concerns about current housing were exacerbated by a lack of resources for future planning <sup>10</sup> for housing and estate (e.g. POAs), legacy and funeral planning and by a lack of information on options <sup>11</sup> between independent living and nursing home and support for transitions.

<sup>&</sup>lt;sup>9</sup> As noted in the methodology section, an fact sheet was produced that outlined resources for structural modifications, assistive technologies and rights and responsibilities of landlords and tenants to accommodate disability.

<sup>&</sup>lt;sup>10</sup> Lack of resources for future planning was also mentioned in regard to living wills, Substitute Decision Making, as well as POAs for treatment and care.

<sup>&</sup>lt;sup>11</sup> As noted in the methodology section, a resource was produced to address this gap in knowledge regarding the continuum of housing and support options available.

Many participants expressed concerns about feeling unsafe in their neighbourhoods. A lack of safety was attributed to both acts of violence and to poor infrastructure that limited mobility or created conditions of physical risk (e.g. lack of curb cuts, ramps and appropriate lighting). A significant proportion of participants shared stories of violence where they or someone they knew were victimized. Many participants felt that age-segregated housing created clusters of vulnerability where older adults were targeted and exploited for their perceived "weakness." Several participants spoke of stores in the neighbourhood that were inaccessible to individuals using walkers or wheelchairs. However, participants also spoke of neighbours addressing this challenge by buying groceries for other older adults left outside due to the lack of ramps and wide doorways and aisles. Although a few participants noted changes in the neighbourhood such as increased crime and lack of affordable housing options, these effects were not linked to in-movers. Rationales for these trends focused on the general scarcity of appropriate supports to substance users and to people with poor mental health, as well as escalating housing costs.

Access to formal supports was a key area of concern for many participants. Barriers identified included: lack of interpretation, translation and ethno culturally appropriate services; and exclusions and differential access (e.g. confusing and inconsistent eligibility demands and means testing). Other participants focused on constraints to service delivery such as long waiting times, evening and weekend gaps, lack of affordable home care, unresponsive programs that can not accommodate emergencies or episodic needs, and limited transportation/parking/public transit.

Difficulties negotiating the system were experienced by the majority of participants who noted that even professionals found it difficult to navigate available information and referral resources. Finally, many of the participants felt that service delivery was frequently ageist and paternalistic citing examples of doctors who did not take their concerns seriously and services that failed to accommodate the slower mobility associated with aging.

Beyond the barriers to accessing existing formal supports, participants expressed concern over the **limited quality of support** available. **Inferior care** due to under care, but also due to professional environments that devalue the work and worker (e.g. personal care workers), was mentioned by many participants, as was the lack of **holistic models of care** that incorporated alternative or complementary therapies and paid attention to quality of life not just medical markers. Another area identified as requiring improvement was elder abuse programming. Programs were characterized as ineffective in engaging and supporting older adults experiencing abuse and in raising awareness of elder abuse in the community.

A primary focus of the discussion of barriers to **informal/social support** was that there were **few options for community and relationship building**. Participants felt that there sense of belonging to a community was restricted by the lack of events, few meetings and limited information available. Increasingly participants had replaced wider geographic or neighbourhood-based community with that associated with a particular service site. Participants' feelings of estrangement extended to concerns for the increasing number of older adults who were **socially isolated** with few or no points of contact with informal or formal supports. At the other end of the spectrum, those participants who were actively engaged in the community via **volunteering** and through other less formalized roles expressed **dissatisfaction** with the opportunities available and the recognition or support provided. Many participants noted that even public transit fare, previously provided to volunteers, was frequently no longer available. Also, many participants expressed a desire to have more input into the evolution and ongoing management of volunteer programs.

#### Focus Group with Service Providers

Service providers felt that a number of factors limited formal supports: **poor coordination and** limited availability of cross-sector care packages, nine to five service provision that is unresponsive to the crisis care required evenings and weekends, and the **overall lack of funding for community-based supports**. Several service providers identified a systemic **bias toward funding institutional or hospital settings** and that overcoming this bias (characterized by a kind of "institutional inertia" sustained by physicians and government health agents -political and bureaucratic) was critical to improved community-based support to aging in place. However, it was acknowledged that the LHINs were genuinely moving in the direction of valuing and supporting community-based supports to health and well-being and that some momentum may be achieved in the coming year. A caveat was raised that although the LHINs have developed a number of creative community care initiatives, they may ultimately lack the funding to fully implement the innovations. Another caution voiced was that institutional settings may "exploit" community-based service providers to transition older adults more quickly into the community, therefore freeing up beds and enhancing wait list numbers, without tying any increased funding to the provision of the community-based care.

Although some participants emphasized the importance of attending to older adults with fewer resources (economic and social) and more challenges (e.g. poor mental health or problematic substance use), others stressed that issues associated with aging in place are similar across groups. However, it was acknowledged that lower SES, along with other risk factors such as gender, different ability or ethno

**cultural membership may increase the probability of displacement** due to gentrification or institutionalization.

Most service providers were concerned that unpaid informal care was often provided by **family** that neither wished to caregive nor had the skill, resources or knowledge to appropriately support the older adult. The emphasis on how difficult it was for caregivers to access information was highlighted by several service providers who spoke of their own challenges in seeking resources for their aging parents, even with the considerable "insider" knowledge they possessed. Also, the lack of centralized and accessible information portals was not only an issue for caregivers/families and older adults but for service providers who may be unaware of other services to support their clients.

Further, the discussion of informal supports was characterized as provided "on the backs" of female family members, assisted by the largely female immigrant women workforce of Personal Support Workers (PSW). Two issues emerged regarding this **gendered and racialized support**: 1) that more female family members are working outside of the home and therefore fewer may be available to provide this form of care and 2) that advocacy and action were required to raise the "value" of PSWs through training, wage equity with peers employed in institutional settings and through efforts to stream funding and acknowledge the critical role of community-based health care. Another issue identified as impacting informal supports was that of **increasing litigiousness** acting as a disincentive to providing nonprofessional (and noninsured) care. Informal care was also characterized as uncoordinated and only sustainable if there was funding for at least one paid employee. Alternatively, there was broad endorsement of the vital role of bingo groups, and other informal groups for older adults, in providing social and instrumental support.

#### Working Group Sessions

Through a series of prioritizing exercises the working group participants reduced the scope of the barriers to three areas: accessible homes, neighbourhoods, and local health and social service agencies. Accessibility was understood to encompass both issues of obtaining supports/supportive environments and of the quality or appropriateness of the support/supportive environment. The barriers associated with these three areas were multi-faceted and included challenging features of the built environment, as well as exclusionary programs and policies. Overarching concerns relevant to all three areas were the dominance of disease models rather than upstream health promotion and prevention, the prohibitive costs associated with supports to health and inclusion, the differences across jurisdictions (provinces and municipalities but also from one health or social service site to another) and

the **lack of accountability to older adults** in terms of meeting expressed needs but also in determining who is the most appropriate conduit of support (e.g. family, friends, nonprofits, the voluntary sector, private or public sectors?). Once the key barriers associated with each of the three priority areas were identified, the working groups' focus moved to strategies and solutions or "enablers" to overcome these challenges and enhance support to aging in place.

#### 4.2.2. Enablers: Strategies to Expand Supports to Aging in Place

Although preliminary issue identification was a necessary scaffold, this project focused on documenting and disseminating community driven solutions to support aging in place (Appendix 3 layer 2 of the map) and associated strategies for community action (Appendix 3 layer 3 of the map).

#### Focus Group with Service Providers

The group highlighted that aging in place meant literally maintaining current housing in the community but they also stressed the importance of belonging and being a valued member of the community. In order to achieve "optimal functioning" and age with dignity, a number of key supports and considerations were put forward. Attention to and funding for the broader determinants of health such as adequate income and appropriate affordable housing were viewed as crucial to aging in place. Comprehensive networks of care were suggested as ideal mechanisms for supporting older adults in the community. These networks were characterized as inclusive of the multiple needs of the individual, their family and caregivers yet wherever possible directed by the older adult and individualized to avoid universal "one size doesn't fit all" packages. Service provision required careful negotiation with and between older adults and their family and caregivers. Mediation and conflict resolution training was put forward as a critical skill set for staff development. Lastly, service providers put forward that networks of care rely on timely and accessible information and that this information must be outreached to the community. Web-based information portals and agency specific referral services, which must be located by the individual or family members, were seen as ineffective, especially for ethno culturally and/or socially marginalized groups.

At the health policy level, service providers were cautiously optimistic that there was some willingness at all levels of government to shift the structure of healthcare and move resources to communities from institutions. However, this shift was seen to be constrained by the lack of incentives and the considerable stakeholder investment in the status quo. Service providers suggested that advocates must strategically present the efficiencies associated with community-based care rather that simply demanding more money from governments.

In conclusion, service providers identified a number of promising strategies for enhancing support to older adults. A single **comprehensive multi-lingual portal of information** with individualized localized problem solving was championed as crucial to older adults accessing supports to aging in place. This ideal telephone information service was described as having to be equivalent to a "social worker's really good little black book." Service delivery utilizing **individualized case management** and other models of taking care to older adults available **in real time and flexible to changing health status** were identified as key to effective programming. A variant on the case management model used widely in service delivery to those with different abilities was suggested: that of pairing older adults, who wish to have one, with an **individual/case advocate** (paid) to assist and accompany them in negotiating an often complicated and fragmented care system.

Further, service providers stressed that **linkages between service delivery and policy systems must be institutionalized** so that "circles of care" can be established which coordinate services across
community and institutional settings, as well as "break silos" within and between jurisdictions (e.g. three
levels of government and aging, housing, health and social service sectors). Finally, service providers felt
that **community-based health care must receive enhanced funding**, even if that means a shift of
monies from hospital-based care; and receive recognition for the vital role they play in preventative care
and in cost offsets to the health care system.

#### Working Group Sessions

Overall, the working group identified three clusters of **accessibility strategies and solutions** to enhance supports to aging in place: in their **housing, neighbourhoods** and **local health and social service agencies** (Appendix 3 Layer 2 of the map).

The group recommended that appropriate and affordable modifications to the built environment (e.g. first floor bathrooms with walk-in shower stalls or tubs), as well as more generous subsidies (available programs exclude many older adults with moderate incomes) and fraud prevention in the form of pre-vetted contractors be available to support older adults aging at home. Although the group championed expanded home modification programs, dissemination of information on existing programs was recommended, as was information on the rights and responsibilities of landlords to accommodate tenants' needs for supportive environments. The group also identified technological supports as an emergent resource to assist older adults in safely navigating their home environments and

recommended that **governments support the development and distribution** of "smart appliances" such as stove modules that automatically shut-off when the occupant leaves the room.

Affordability of housing was of general concern for the majority of participants whether they were renters or homeowners. Strategies endorsed by the group included: **expanding the rent supplement programs, utility subsidies**, **property tax** (not just deferrals but <u>significant</u> discounts) **and user fee concessions for older adults**, **as well as building more subsidized supportive seniors housing.** 

Assistance in the form of affordable high quality home support services (e.g. homemaking, more doctor house calls) was valued by many participants who were well aware of how many older adults are excluded by pay-per-use home care services. Beyond expanded health care funding of home care, the working group, like the service providers, advocated that quality care was dependent on valuing (through higher wages, benefits and training opportunities) the personal support workers providing the care. Home care could take the form of supports to older adults in independent housing or be offered in the context of on-site staff of supportive housing. However, the group was concerned with the challenges inherent in congregate living such as maintaining trust, privacy and autonomy. Although the group recognized the essential support provided by professionals, they also commended the effectiveness of informal "buddy systems" (e.g. telephone trees, mailbox monitoring and daily door-to-door checks) in detecting needs and ameliorating isolation.

A key recommendation that crossed all three clusters was that of the need for **innovative information outreach**. For example, the group cited **public service announcements** of the past as a model for the future where multilingual information would be **broadcasted on local TV and radio** stations, as well as mailed out in some form of **community newsletter**. Information available on the internet (a limitation raised by the service providers as well) or at local agencies was felt to be inadequate, especially in reaching socially isolated older adults.

Recommendations for creating accessible neighbourhoods focused on community building. The group stressed that there must be more opportunities to connect through neighbourhood social and cultural events, free or low cost space to congregate and significant seniors' discounts both for transportation and for the event itself. "Buddy walkers" were suggested as a model of safe street practices. Other informal supports suggested by the group included a "neighbourhood barter exchange" where older adults would "trade" supports, services and resources.

Another crucial aspect of community building identified was **inclusive zoning** that allowed for further development of various kinds of affordable, supported, congregate living. A feature of "livable" communities championed by the group was **municipal support and incentives to ensure an adequate number of benches and public washrooms; well-lit sidewalks, as well as ramps, broad aisles and doorways in retail spaces.** 

In terms of access to neighbourhood information, two recommendations were made: 1) that older adults have greater **direct access to policy and political representatives** (NOT just through professional representatives) and 2) that the **use of libraries and Community Information Centres as information and health promotion hubs be expanded and enhanced**.

The group felt that accessible agencies require more flexible and transparent program eligibility as to costs and "rostering", more translated materials (from multiple sources) and "on call" interpreters, and more outreach to isolated seniors and to ethno-cultural and faith communities. Although most of the group highly valued their volunteer experiences, they expressed a desire for more "enriched volunteering" with more choices, recognition and power. Also, the group felt that it is essential that agencies empower older adults to participate in decision-making, peer programming (e.g. "train the trainer" workshops on aging and ageism) and community led advocacy. Finally, the vital role of caregivers must be acknowledged and supported by agencies (e.g. respite care, training).

As for the focus of agency programming, the group endorsed more "healthy aging" programs and services (e.g. "student clinics" in alternative therapies or "well seniors" programs) and special time allotted to "seniors clinics" with reduced waiting times and age-friendly staff and supports. In terms of recreational programming, the group recommended a more diverse range of activities, not just gambling (e.g. senior's "summer camp" and intergenerational events). Finally, the group again stressed that agencies must move multilingual multi-access point information on these programs and other resources for older adults into the community and into people's homes.

#### 4.2.3 Taking Action to Enhance Supports to Aging in Place

Although some strategies for action were suggested by service providers during the focus group, notably formulating cost-effective business cases for expanded home and community-based support/services, the primary actions were put forward by the working group (Appendix 3: layer 3 of the map contains a selection of actions). In recognition of the multiple portals where the community might advocate for enhancements to support aging in place, six sectors were identified as sites of action: the

#### **Mapping Aging in Place**

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informal, program/agency, private, municipal, provincial and federal governments. Appendix 5 contains the full matrix of the six sectors and potential actions associated with the three clusters of accessibility: housing, neighbourhood and agency. Actions developed by the working group ranged from advocacy directed at local agencies, municipal committees and provincial ministries to community action to enhance neighbourhood resources to forging links between different health and social care providers and between seniors' groups. Although some of the actions identified are time sensitive, the majority are enduring options for community action which extend the utility of the project map.

#### **Section 5.0 Dissemination**

The findings and resources produced during the project: "Mapping Aging in Place in a Changing Neighbourhood," were disseminated in a number of ways to date. The map itself and two fact sheets: one on supports and subsidies to sustain independent living and the other on housing options between independent and institutional living, were first introduced in the context of a community forum. Participants and coordinators presented key findings and recommendations to a group of approximately fifty service providers, politicians, policy-makers and community members convened at St. Christopher House. Responses to the project and presentations highlighted how accessible a medium the map was for conveying multiple layers of information in a simple but provocative visual. The multi-lingual presentation combined aggregate information with lively personal narratives that animated the experience of aging in the CURA neighbourhoods.

Highlights from the project were shared with the Toronto Central LHIN's Senior Council during a presentation of a literature review created by the Institute for Life Course and Aging for Bridgepoint and the Toronto Central LHIN. Two central messages were conveyed about the project: 1) that unique issues and solutions emerge through participatory projects; issues which are often peripheral to findings from conventional methodologies and 2) that the community is able to prioritize key issues and craft actionable recommendations which lead to relevant community-owned solutions and strategies. The project resources were further shared with all 14 Ontario LHINs during the "Aging at Home Innovations Showcase." A member of the community working group and the coordinator presented the findings, map and shared other project resources at the 2008 Portuguese-Canadian National Congress' "National Action Meeting on the Health Status of Portuguese-Canadians. Other mechanisms for broader distribution include uptake of the project resources by the Ontario Seniors Secretariat and the many agencies that participated in the initial focus group or key informant interviews (Appendix 2 contains a list of participating agencies).

#### **Section 6.0 Discussion and Implications**

Aging in place is context rich, complex and contested. Projects such as "Mapping Aging in Place in a Changing Neighbourhood" capture a comprehensive picture of local challenges and solutions to aging in place developed by and for the community. Community capacity building was an explicit objective of the project, as was reflecting on and documenting the process of engaging older adults in the data analysis and development of recommendations. Community-based research/projects frequently provide opportunities for community members to participate in the collection of data, typically through surveys, interviews or "community sweeps." This project sought to extend the participation of community members through facilitated collective data analysis and recommendations for action built by consensus.

The process of community data analysis and crafting actionable recommendations by consensus yield distinct and complementary evidence to that reported in aging research. For example, as Huemann (2004) notes, factors associated with built environments are a neglected feature of modeling of risk and geriatric assessments, yet the impact on well-being and independence is widely acknowledged (Rodriguez, 2008; Zamperilli, 2008). Community-based analysis, such as that undertaken in this project, shifts the focus of a number of health and social science paradigms: from human to structural support, from disease and palliative care to health promotion and from person-based to place-based policies. Notably, the role of the accessible appropriate built environments (housing and neighbourhood contexts), of wellness programming and of localized community building were central to this project's findings.

Research on aging has tended to situate adverse forces such as disempowerment, ageism and dependency in nursing home or residential care settings without attending to the dynamics of care that occur in home and community health services (Oldman Quilgars, 1999). Likewise, the rhetoric of aging at home often ignores the transformations that occur when home becomes a site of health and social care consumption. As Lewin (2001) suggests, exploration of aging at home requires a nuanced investigation of the meanings of home at multiple levels: at a socio-cultural level of health policy and political rhetoric; at an intermediary level where home is a commodity that is a repository of debt and of assets, as well as consumption and maintenance; and finally at a personal level as a site of identity and life history. All three levels surfaced in this project's findings where "home" was constructed as a service delivery site, as an economic unit and as an embodiment of meaning and life course. Further, the participants were well aware that while aging in place is a laudable and desired outcome, it could also be a source of exclusion without appropriate responsive support systems. Consequently, participants avoided what they expressed as a false dichotomy (and false efficiency) of aging at home as "good" and aging in an institutional setting

as "bad." Participants were aware of the economies available in maintaining older adults in the community at the expense of overburdened informal support/caregiving agents, and underpayed, undervalued personal support workers.

A key issue relevant to the uptake of alternative housing and support options is that of socio-culturally constructed barriers to congregate living. As individuals age and leave the labour force, identity and meaning come to rest largely in the home environment and "third places": informal or public spaces distinct from work and home. North American notions of healthy aging such as autonomy are embedded in the valuing of independent and individual housing. Consequently, living arrangements which have elements of communal space and activities are perceived as diminishing personal control and quality of life. These negative associations may undermine the uptake of alternative housing options that involve congregate living even if they, indeed, offer self-determined and enabling supports. The extent of this aversion to congregate living was reported in the findings from a recent survey (N=702) of housing expectations of older adults between the age of 50 and 72. Robinson and Moen (2000) reported that the highest level of rejection of the eight housing options presented was that associated with "sharing household with unrelated people." This project's findings suggest that development and service delivery in the context of congregate living must strive to strike a balance between independence and support by ensuring client-determined care and built environments.

As for the role of place and neighbourhood, the significance of accessible and inclusive built and social infrastructure was clearly articulated. Issues such as safety and inclusion were linked to community development initiatives that reached across generations, faith and ethno cultural groups. Another key area of "neighbourhood building" identified was expanded affordable and supportive housing options through multi-government subsidies, incentives and inclusive zoning. Although the effects of gentrification were not explicitly identified by the community participants, references to escalating costs and conflict may be indirect impacts associated with neighbourhood change. Also, as previously mentioned, the different growth trajectories in the seven CURA neighbourhoods, as well as growing income and social polarization, may lead to quite diverse experiences and observations of change.

The final cluster: that of accessible health and social service agencies was identified as critically limited by shortfalls of funding, by a lack of ethno culturally appropriate service delivery, by the dominance of acute and palliative care and by the scarcity of holistic health care. Key strategies to address

these limitations included shifting the focus to health promotion and quality of life; and creating mechanisms for sustained participation of older adults in program and policy development.

The actionable recommendations put forward stressed that multi-sector, multi-jurisdictional horizontal initiatives are required to realize the matrix of human and structural supports necessary to enhance the quality and quantity of years an older adult may age in place. Without a paradigm shift toward age-friendly environments that sustain communities through the life course and accommodate different abilities, older adults (and other individuals whose environments are disabling) may experience aging at home as isolating and diminishing. The other shift necessary is to correct the imbalance of care that continues to stream funding to institutional rather than home and community-based care. Finally, perhaps the most fundamental shift is to challenge the ageist assumptions that underlie the inadequate supports to aging and the social exclusion of older adults. One of the most powerful strategies to address ageism is to include and empower older adults to have a real voice in the design of programs and policies targeted to aging. For example, the activities of this project provided a forum for a group of older adults to analyze, document and mobilize "lived" and local knowledge of aging in place. Opportunities such as this are critical to the valuing of older adults and of the supports necessary to age in place. Although the affluent baby boomers may purchase appropriate services, the market will not accommodate the needs of those who are economically or otherwise marginalized. The most vulnerable of adults will continue to rely on adequately funded, appropriate public programs.

Equally significant to the findings contained in this report are the lessons learnt in community engagement practice. Foremost is that older adults have tremendous talent and a surfeit of time and therefore are ideal candidates to determine the issues that are relevant to them and direct how these issues are addressed. Outreach to this group is best facilitated by local agencies with dedicated seniors programming and by community animators and leaders involved in informal activities. Using accessible tools is vital to enabling community participation both during project activities and dissemination.

Avoiding text rich materials or specialized technologies is crucial to tapping the knowledge of community participants and to conveying that knowledge to the broader community. It is most effective to take an iterative approach by leaving both methodology and research questions sufficiently flexible as to be responsive to new directions initiated by the community working group. As Ross (2005) and others (Buckeridge et al., 2002) suggest, assuming a flexible and responsive approach is vital to reframing relationships and rebalancing power to move beyond rhetoric and tokenism to genuine partnerships with the community.

Community-based projects are inevitably multi-lingual and therefore good translation and interpretation is crucial. Project budgets must provide adequate funding for these services throughout the life of the project. Another component of enabling participation is budgeting for training and development activities (Ross, 2005). Although not realizable within the budget of this project, other initiatives by the research team (McDonald et al., 2006) have drawn effectively on peer groups and professional consultants to ensure that community participants have the skills and strategies for various dissemination activities.

In terms of the balance between group autonomy and facilitated direction, the project coordinators must provide enough structure to support the development of project products but be sensitive to emergent needs within the group. It is also critical that the project coordinators do not assume that full participation is necessarily desirable or effective. Dewar (2005) questions whether community participants will assume a role resembling that of research assistants or a role characterized by "equal" but different contributions. It is the latter description that bests captures the contributions of this project's working group. Community participants had different interests and capacities and offer input when it is relevant and engaging. However, these "different" contributions from the community are no less valuable or "true" then those generated by professionalized methodologies. For example, this project's collective data analysis activities, though conducted without the use of current software programs, adapted techniques such as saturation, hierarchical clustering and matrix analysis to identify key issues and themes. Future research should develop and incorporate mechanisms to assess the rigor of these adaptations used in community-based analyses.

Finally, the challenge of sustainability and scope remains a central weakness of community-based research and of this project. An ad hoc working group convened for project activities lacks structural ties outside the project cycle. Actions and strategies for mobilization are likewise limited by the project time lines and budgets which do not accommodate the relationship building necessary to entrances to policy-making circles. As Roe and colleagues (1995) have suggested advocacy objectives should be explicitly included from the onset of the project so that legislative calendars and other key policy-making opportunities can be accommodated. El Kalache, Moriah and Tapper (2005) inventoried community responses to gentrification and found that a common thread linking successful initiatives was the presence of a strong organizational base supported by local agencies or municipalities. Future projects require greater funding and support to formalize working groups into sustainable bodies such as neighbourhood councils or civic panels with institutionalized ties to local government.

# **Appendix 1** Participating Agencies

Careable Inc, Healthcare Consultants

Centre for Addictions and Mental Health

Community Outreach Programs in Addictions

Extendicare

Loft

Loyola Arrupe

Masaryk-Cowan Community Recreational Centre

Older Persons Mental Health and Addictions Network

Parkdale Community Health Centre

Parkdale Golden Age Foundation

Queen West Community Health Centre

Sistering

St. Christopher House

St. Joseph's Hospital, Elderly Community Health Services

Toronto Central Local Health Integration Network (LHIN)

**Toronto Community Housing Corporation** 

Toronto Western Hospital, Geriatric Clinic

West Toronto Support Services for Seniors and the Disabled

### **Appendix 2 Protocols for Consultations and Focus Groups**

#### Community Consultations

- 1:30 Introductions & Project Overview-us, notetakers and translators + housekeeping and project: Community Led Mapping Of Aging In Place-identifying what helps people stay where they wish to live and what more is needed; how the changes in this neighbourhood effect older adults and how older adults might act on this information. We are here today to listen to what issues are important to you AND to ask those of you who are interested if they would like to continue with the other project activities, which we have funding to provide honorariums, meals and transit fare. We will talk more about the details later in the forum. First, we would like to begin by asking you to introduce yourself and comment on any changes you have noticed in your neighbourhood?
- 1:45-2:30 Supports/services available and those limited or absent but needed-across housing, health, aging, social sectors

What supports and services (e.g. day programs, recreational/social/cultural programs or groups, homemaking, personal care, health care, housing subsidies, housing repair funds and help to make your housing more accessible as you age e.g ramps & grab bars) do you use? What is most helpful to you? What isn't and why?

Who helps you: service providers (social workers, doctors/nurses, personal support worker etc.), family, friends, neighbours?

How did you find out about the supports you currently use? Where/who do you go to for new information and referrals?

What would help you continue living in this neighbourhood but isn't available (either difficult to get or too costly or not available at all)?

- 2:30 quick **break**
- 2:40 3:10 Neighbourhood Livability and Transportation

How do you feel about your neighbourhood? Do you feel safe in your neighbourhood? Are the public spaces clean and well lit? Are there areas where you feel comfortable sitting or meeting with friends (e.g sidewalk benches, parks or local coffee shops/cafes)? Are there shops you like close by?

Are the sidewalks and entrances to stores and agencies easy to move through? Are there enough street crossing options and enough time to cross? How do you get around (e.g. wheel trans, TTC, car driven by you or someone else, walking)? Does anyone help you get to appointments or pick-up groceries?

• 3:10 – 3:30 Social inclusion: volunteerism, informal groups and associations, activism, political participation (feeling heard), sense of belonging and being part of your community

Could you describe the community you feel most a part of? How is that community affected by changes in the neighbourhood?

Do you volunteer? Where and what do you do? Do you help friends, family or neighbours (e.g. help with housecleaning, buy groceries for them, give them money, and accompany them to appointments)?

Do you get involved in groups that are trying to make changes in the neighbourhood (e.g. more community health care or more educational programs)? Do you support any local politicians? Do you feel that the local politicians are aware and act on issues important to you?

#### If there is time left, but usually we leave it out:

 Planning for the future-financial, community-based care (professional and unpaid/informal), long term care, estate planning

What plans have you and your family made so that you can continue living in the neighbourhood?

How long do you think you will live at your current residence? Have you considered other options to living the way you are now (e.g. living with family, in a congregate setting-supportive or assisted housing, or a nursing home)?

If you are renting, have you explored asking your landlord to install accessibility supports such as grab bars or are you planning to transfer/move to more appropriate housing?

If you own a home have you considered reverse mortgages, tax deferral or accessing government assistance to help make your home easier for you to live in?

• 3:30 Sign up for Focus Group and Future Activities

#### Focus Groups with Older Adults

#### Introductions and setting the stage

#### Staying in the neighbourhood – 12:15 – 12:45

- Is your house outfitted for aging in place? What needs to be done? Who will do it? How will you pay for it? Or do you plan to move?
- Housing transitions: Has anyone recently moved (within the neighbourhood)? Where from/to? What was that like? Did anyone help you with moving, getting settled??
- How long do you think you will live in this neighbourhood? Have you considered other options to living the way you are now (e.g. living with family, in a congregate setting-supportive or assisted housing, or a nursing home)?
- What would help you continue living in this neighbourhood but isn't available (either difficult to get or too costly or not available at all)?
- Language barriers?

#### Having fun ... Social Networks/Support – 12:45 – 1:15

- Who do you rely on for support, friendship, company (social workers, social workers, doctors/nurses, personal support worker family, friends, neighbours)? What kinds of things do you do with these people?
- Tell us about the Portuguese Women 55+ group, First Portuguese? TPC-who is in it, what do they do, how often to they meet, **what about the men?** Are there any other groups that you belong to?

#### Planning for today and the future -1:15-1:45

- How do you feel about the future and your financial stability/security? If you imagine yourself 5 to 10 years in the future what has changed, what do you need, where and how do you live etc.? Have you made plans to designate someone power of attorney, if needed? Who will look after you if you need care?
- If you own a home have you considered reverse mortgages, tax deferral or accessing programs like RRAP, accessibility grants?

#### **Actions 1:45 – 2:00**

- What do you think is the most important issue for you today or for older adults living in West Toronto? (put some of the issues we heard on card stock and we can stick them up and move them up and down the list according to group direction, as well as invite new issues that we haven't caught or haven't been raised)
- What kinds of actions have you been involved in and what do you think works best? E.g HATS, protest/parade against privatization, talking to service providers, talking to MPP/MPs, other

#### Focus Group with Service Providers

**Introduction & Study overview** – 10 min.

#### Clarification of terms & agenda – 10 min

- What does "aging in place" mean to you?
- How is gentrification visible to you as it impacts service delivery to older adults?
- Focus for today's focus group: both formal and informal supports but we anticipate more on formal supports given the knowledge in the room; community assets rather than just needs; and aging in place across 3 levels: individual, neighbourhood and structural

#### **Topics for discussion:**

- Health and well-being? (e.g. in home and in the community; where and who; how are they institutionalized?; overcare and undercare; caregiving) 30 min.
- Housing supports (e.g. rent supplements, tax concessions) 20 min.
- Transportation 20 min.
- Social Inclusion (e.g. recreation, social networks, volunteering, community participation, civic engagement) 20 min.
- Have we missed anything? 20 min.

#### **Prompts for discussion:**

- Coordination/integration across sectors (health, social, housing, aging; information portals where, who?)
- Formal/informal (caregiving)
- Service delivery (fee-for-service/universal coverage)
- Gentrification impacting these areas (negative= displacement; positive= social capital; changing demographics, sense of belonging, social capital; accessibility in homes and neighbourhoods)
- Structural: Income support; housing availability; tax load; LHINs; civic engagement opportunities; energy/utility supplements LEAP; zoning/planning 2<sup>nd</sup> suites)

# Appendix 3 Map of Aging in Place in a Changing Neighbourhood (Please see following pages)

# Appendix 4 Fact sheets

(Please see following pages)



Fact Sheet # 1
Resources for Older Adults:
Information and Resources to Improve
Your Housing and Support Your
Independence

- A. Homeowner/Landlord <u>Subsidies</u> For Modifications to Your Housing:
  - You may claim product and renovation costs as a Medical Expense: e.g. the Disability Tax Credit Certificate
     T2201(Canada) available online at <a href="http://www.cra-arc.gc.ca/E/pbg/tf/t2201/">http://www.cra-arc.gc.ca/E/pbg/tf/t2201/</a> OR call 1-800-959-8281
  - Canadian Mortgage and Housing Corporation's (CMHC)
    "Home Adaptations for Seniors Independence" (HASI)
    and "Residential Rehabilitation Assistance Program"
    (RRAP) programs offer forgivable loans and other
    forms of financial assistance to eligible
    homeowners and landlords for renovations and
    repairs. For more information on eligibility and
    levels of financing available see the CMHC website:
    <a href="http://www.cmhcschl.gc.ca/en/inpr/prfias/index.cfmo">http://www.cmhcschl.gc.ca/en/inpr/prfias/index.cfmo</a>
    r or in Ontario call 1-800-704-6488
  - Department of Veterans Affairs-Veterans
    Independence Program offers financial assistance to veterans and their caregivers for housing modifications and maintenance. For more information access their website @ <a href="http://www.vac-acc.gc.ca/providers/sub.cfm?source=services/vip#whatorcall1-866-522-2122">http://www.vac-acc.gc.ca/providers/sub.cfm?source=services/vip#whatorcall1-866-522-2122</a>
  - Some individual companies provide financing e.g Seabridge Bathing (1-800-330-3307) or visit the website @ http://www.seabridgebathing.com/funding-walk-inbath.html#cdn

- B. Renters Rights & Landlord Responsibility to "Accommodate"your Needs
- The Ontario Human Rights Code (the "Code") maintains that housing providers have a "duty to accommodate" (short of "undue hardship") the needs of those who are experiencing disablement (physical or otherwise) according to the principles of respect for dignity, individual accommodation and integration and full participation. For example, a landlord cannot refuse to build a ramp for a tenant who requires a walker on the basis that only one person requires it. The Code also protects older adults from age discrimination by landlords. For more information call the Centre for Equality Rights in Accommodation 416-944-0087 or call the Ontario Human Rights Commission at 1-800-387-9080
- C. Homeowners and Renters <u>Information</u> and Guides to Improve Your Housing and Support Your Independence
- Ontario's Seniors' Secretariat has an online guide to programs and services (in seven languages) available @ <a href="http://www.citizenship.gov.on.ca/seniors/english/programs/seniorsguide/">http://www.citizenship.gov.on.ca/seniors/english/programs/seniorsguide/</a> as well as a multi-lingual telephone information line 1-888-910-1999
- Human Resources and Social Development Canada has a
  comprehensive guide on simple modifications and "tips"
  for older adults living at home, called: Aids to
  Independent Living: Breaking Through the Barriers
  available at
  <a href="http://www.hrsdc.gc.ca/en/hip/odi/documents/independentLiving/00\_toc.shtml">http://www.hrsdc.gc.ca/en/hip/odi/documents/independentLiving/00\_toc.shtml</a>
- In Canada, Aroga Assistive Technology offers various supports to independence available online @ http://www.aroga.com/default\_en.asp or call 1-877-551-6222
- In the US, Dynamic Living (ships to Canada)offers kitchen(including a "stove guard" that turns off your electric stove when you leave the room)& bathroom products that promote a convenient, comfortable and safe home environment for people of all ages @ http://www.dynamic-living.com or call 1-888-940-0605

This resource is available @ <a href="http://www.aging.utoronto.ca">http://www.aging.utoronto.ca</a>



# Fact Sheet # 2 Resources for Older Adults: Housing Options<sup>12</sup>

Social Housing for Seniors<sup>2</sup> is affordable housing available for seniors, with low to

moderate income. The owner of this type of housing may include private landlords with rent supplement units, municipalities who own public housing or non-profit/co-operative corporations who own housing projects. Contact a Toronto Housing Connections representative at 416-981-6111 to find out how to apply for social housing.

Co-operative Housing is a legal association formed for the purpose of providing homes to its members on a continuing basis. A co-op is different from other housing associations in its ownership structure and its commitment to co-operative principles. For further information, contact the

your local CCAC or the Regional Office of the Co-operative Housing Federation of Canada at 1-800-268-2537

Retirement Homes<sup>3</sup> are private businesses that sell combinations of accommodation, support services and personal care (prices vary widely in accordance with the type of accommodation and range of services selected). Retirement homes are nearly all for-profit facilities, and care and support services in these settings are neither directly funded nor regulated by the provincial government. However, some tenants may qualify for services funded by the Ministry of Health and Long-Term Care through Community Care Access Centres (e.g.visiting nurses or therapists). For more information contact Ontario Community Support Association (OCSA) at 1-800-267-6272

<sup>&</sup>lt;sup>12</sup> Much of the content of this fact sheet is excerpted from the Ontario Seniors Secretariat's Information Guide. The entire guide can be found at <a href="http://www.citizenship.gov.on.ca/seniors/english/programs/seniorsguide/">http://www.citizenship.gov.on.ca/seniors/english/programs/seniorsguide/</a>

<sup>&</sup>lt;sup>2</sup> This type of tenancy is regulated by the Social Housing Reform Act (SHRA)

<sup>&</sup>lt;sup>3</sup> This type of tenancy is regulated by the Residential Tenancies Act (RTA)

www.ocsa.on.ca or Ontario Association of Non-Profit Homes and Services for Seniors at 905-851-8821 www.oanhss.org

Supportive Housing<sup>4</sup> programs (mostly run by nonprofits with the provision of support services funded through the Ministry of Health and Long-term Care) provide on-site personal support services for seniors living as tenants in designated residential buildings such as a seniors' building. Services include personal support/attendant services, essential homemaking services, and staff available 24-hours a day. For more information call your local Community Care Access Centre (CCAC) or contact the Ontario Association of Non-Profit Homes and Services for Seniors (OANHSS) at 905-851-8821

Adult Lifestyle/Retirement Communities provide independent residences that combine home ownership with social and recreational activities. Local real estate agents are your point of contact.

Life Lease Housing is a form of housing tenure similar in appearance to a condominium. Typically, life lease housing is operated by non-profit or charitable institutions. A tenant is granted the right to occupy a dwelling unit in return for an up-front payment and monthly maintenance fee payment. If you are considering this option contact the Ministry of Municipal Affairs and Housing, Market Housing Branch, at 416-585-6541.

## Complaints Response and Information Service

Seniors and their families can call the Retirement Home Complaints Response and Information Service to get help with understanding the differences between various housing options, the services and level of care provided in different settings, local regulations governing retirement homes and help resolving problems experienced with any retirement homes. Contact 1-800-361-7254

This resource is available at <a href="http://www.aging.utoronto.ca">http://www.aging.utoronto.ca</a>

<sup>&</sup>lt;sup>4</sup> This type of residency can be regulated under either SHRA and RTA

# Appendix 5 Matrix of Community Actions: Sector by Accessibility Cluster

Sector	Housing	Neighbourhood	Agency
Informal	Establish a building or	Advocate to local	Explore the potential of
Imormai	neighbourhood "buddy	businesses or Business	how local informal
	system" to reach out to,	Improvement Associations	groups or associations
	support and share resources	to provide incentives for	can act as information
	with other older adults	retail accessibility	hubs for agency
		improvements	programs
Program or Agency	Request that agencies provide comprehensive information and resources on home modifications, assistive technologies, housing subsidies (RRAP, HAS, ERP), and tenant rights and landlord responsibilities regarding necessary structural supports	Request that the agency facilitate peer programs (e.g. "friendly visitors," "train the trainer" workshops on aging and ageism and peer translation) including in kind or financial recognition of volunteers, and attempt to secure outside funding for these programs (e.g. New Horizons Grant for Seniors)	Request that more agencies provide improved transportation options for their volunteers and service users (e.g. the St Christopher House model)
Private	Attend a business forum such as those held by the "City Summit Alliance" to highlight the importance of employee "caregiving" benefits (e.g. employer pays for home care)	Meet with various alternative health colleges regarding running special free/low cost seniors clinics at local health and social service agencies	Work with Roger's Cable TV or other local station to create a seniors program or "spot" that conveys up- to-date information on local services for older adults

Sector	Housing	Neighbourhood	Agency
Municipal	Advocate to the City Community Development and Recreation Committee on a range of topics related to aging in place (e.g. tax and user fee concessions, City management of home modification contractors to prevent fraud, incentives for the development of accessible, affordable housing)	Recommend that the City Social Services Division revisit eligibility requirements to ensure that agencies can decide on an individual basis who can participate in a program; Communicate to Police Services the need for expedited police checks for volunteers; and promote the idea of greater discounts for seniors to social and cultural events as a part of "Toronto Culture"	Make a deputation at the Advisory Committee on Accessible Transportation regarding greater senior TTC discounts, more liberal transfer use and the immediate need for escalators and elevators at every subway station; Advocate for a more "liveable" Toronto at City Council (e.g. more benches, free use of space at City recreation centres, expanded use of Library/Community Information Centres as information and health promotion hubs for older adults)
Provincial	Present at the Local Health Integration Network board meeting regarding priorities for the "Aging at Home" provincial funding	Meet with key actors at the Ministry of Health and Long- Term Care to emphasize the need for expanded home and dental care, as well as higher levels of subsidy for vision and hearing aids, and fair wages for personal support workers	Meet with the Seniors Secretariat to discuss improvements to online and telephone-based seniors' information portals
Federal	Participate in National Housing Day to raise awareness of the unique housing needs of older adults	Build strategic alliances with groups such as the Ontario Community Support Association, Ontario Coalition of Senior Citizens Organizations, Council of Seniors and Toronto Seniors Forum (currently dormant) to jointly advocate for expanded home care and the inclusion of these and community-based health services under the Canada Health Act to ensure accountability and quality of care	Write local MPs to highlight the need for expanded funding to ensure that the nonprofit and voluntary sector remain a vital resource for the community

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