



# UNDERSTANDING THE NEEDS OF VULNERABLE SENIORS IN YORK REGION

Summary Report of a Community-Based Participatory Research Project  
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## EXECUTIVE SUMMARY

As York Region's population ages, providing services to seniors with complex vulnerabilities will be a challenge for our community. In order to offer quality care, support, and relevant services for York Region's growing senior population, we must better understand the service context for seniors with complex vulnerabilities such as life limiting and chronic illnesses including HIV/AIDS; addictions and mental health; and homelessness. These vulnerabilities are all associated with social stigma and often result in poorer access to services or increased risk of income insecurity and poverty. The core collaborating agencies on this project all serve York Region's vulnerable senior populations who are faced with complex health and human service needs. We jointly undertook this community based research project to improve our own understanding of the health and human service experiences of elderly and aging people with complex, cross-sector vulnerabilities in the region. However, our goal was also to demonstrate the needs of these vulnerable populations to build better systems in York Region to connect people to their communities so that seniors are not marginalized precisely when they are most vulnerable. We hope that the findings of this research will foster the development of intersectional and collaborative service delivery strategies across York Region, strengthen the capacity of professionals, volunteers, and caregivers to support the complex needs of vulnerable seniors, and thus lead to the improved well-being of seniors in York Region.

The core research partners on this project included AIDS Committee of York Region, Addiction Services for York Region, Krasman Centre, CHATS - Community & Home Assistance to Seniors, and Dalla Lana School of Public Health (University of Toronto) with developmental evaluation support from Eko Nomos.

This project used community-based participatory research methods, qualitative interviews, and focus groups and engaged 43 participants, including service providers, caregivers, and older adults.

### SIX MAIN THEMES IDENTIFIED:

- Seniors and their family caregivers in York Region are resilient, and generally positive about their personal situation.
- There are significant training needs across the health and social services sector with respect to senior care. These needs may be most critical within the senior population itself, and amongst the population of family, volunteer or professional caregivers.
- The rationale behind service fees for different programs offered to seniors in York Region is unclear to service users; understandings of what 'affordability' means in programming are not consistent from service users to service providers.
- Experiences or ideas about stigma and marginalization are diverse and often conflicting, depending on individuals' experiences.
- It is difficult for seniors to satisfy their basic needs, including finding a sufficient income.
- Without being prompted, many respondents brought up the topic of suicide and assisted death.

## COMMUNITY SPECIFIC RECOMMENDATIONS:

Develop more opportunities to include seniors in the social life of York region, especially opportunities for older seniors to contribute to decision-making about issues affecting seniors

Develop more peer-lead educational opportunities for seniors and their caregivers including culturally appropriate resources and opportunities

Start educating older adults and seniors as early as possible about the potential of technology to assist in communicating, contributing or otherwise learning about resources in their community

Ensure that social, leisure and/or recreational services are provided free of charge for seniors who need them

Invest in senior-led public education and discussion regarding the nature, experience and dangers of stigma and social exclusion

Develop and invest in peer-driven stress-management counselling for seniors and caregivers

Develop and perform new research on seniors' perceptions of and attitudes toward suicide, assisted dying and palliative care

Develop and invest in more holistic service models that acknowledge the primacy of material conditions as a determinant of individual health

Develop a regional advocacy agenda that supports full access to incomes sufficient for all people to live in dignity



Overall, the research team found that there is a need in York Region to better educate the general public about HIV, mental health, and the current system of support for caregivers. Research participants often mentioned education as a way to fight against stigma. They also recounted stories that showed how education can change people's attitudes. York Region also needs to finance the systems of care more efficiently and provide due funding supports to service providers for the work they are already doing. For example, social service agencies often provided free food for their participants, even if they were not funded for this service.

## BACKGROUND: YORK REGION AND ITS SERVICES

### **York Region Seniors Strategy: Summary**

York Region recently developed a Seniors Strategy to address coming demographic changes in the next two decades (York Region, 2016). This strategy sees four roles as fundamental to the Region: a) balance the needs of seniors with the needs of the younger population; b) keep seniors healthier for longer; c) support the development of age-friendly communities that allow aging in place; d) connect seniors and caregivers with the existing services when needed. Underlying these four goals, are five main guiding principles: a) evidence-based decision-making; b) partnerships, alignment, and collaboration; c) prevention and promotion; d) education; e) fiscal sustainability and finance. This strategy itself was developed in line with York Region's Vision for 2051 and the World Health Organization's goals for healthy aging.

### **A Profile of York Region's Seniors and Existing Services**

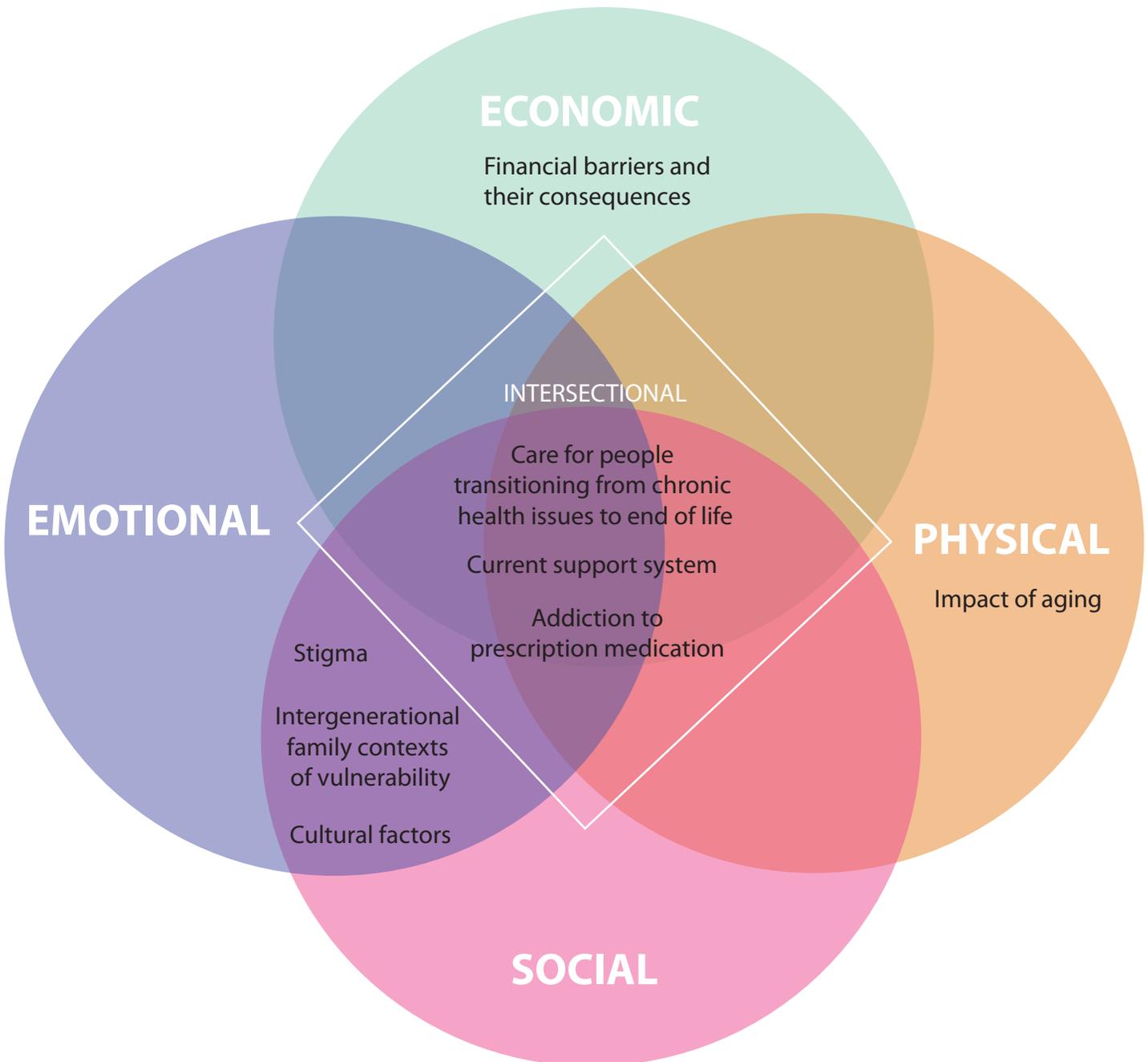
York region developed a profile of its seniors to prepare for the changing demographic (York Region Profile, 2014). In reviewing literature for this project, the lead researcher noted first a strong distinction between literature focusing on younger seniors (aged younger than 65) and older seniors (older than 65 years). In general, the latter have more complex health problems (Kinsella et al. 1995; York Region Profile, 2014), while the younger seniors more closely resemble working age adults (York Region Profile, 2014). Younger seniors are also more likely to be employed, educated, and technology-savvy (York Region Profile, 2014). They are more likely to want to age in place, to rely on multiple sources of income, and to seek out personal growth opportunities (York Region Profile, 2014). Though older adults make up a minority of those with low-income, older adults remain more likely than the rest of the population to incur health and other government costs (CIHI, 2011; Statistics Canada, 2008).

Existing services for seniors funded by the government are all 'part' of larger services. For example, income tax credits, government pension plans, tax-free savings plans, and priority access for veterans to long-term care are provided at the federal level. The province of Ontario also delivers income tax credits and senior homeowner property tax credits. The province operates the Ontario Drug Benefit Plan, provides priority access to primary care and family health teams, introduced the Ontario Pension Plan, Ontario Seniors Strategy, and a Seniors Secretariat. Meanwhile, at the regional level, seniors may access property tax deferrals, long-term care, paramedic services, public health programs and services, public transit and fare discounts, social housing, or programs that support aging in place. Finally, at the local municipal level we find snow clearing, local planning and community design, recreation and leisure are the focus. In sum, the service context for seniors is complex, and a significant portion of this complexity emerges from the interaction of the numerous levels of government and the proliferation of programs intended to help seniors in many different ways, but each ultimately accountable to different governing bodies. In addition, seniors in York Region have access to a range of programs and services that provide support with housing and shelter, food security, transportation, health and wellness, social engagement and recreation, long-term and palliative care.

# RATIONALE FOR THIS STUDY

This research provides the basis for further design and implementation of collaborative service delivery strategies across York Region, with the objective of improving the service context for vulnerable seniors. These strategies will ensure that as Ontario’s population ages, human service professionals and volunteers are equipped to deal with the complex needs of vulnerable seniors. York Region (2014, p.71) describes the “growing need to deliver Region programs and services [to seniors] in accessible, inclusive ways”, and how “programs that help seniors maintain overall good health and limit the development of chronic conditions will be important”. This project assists in creating better systems to connect people to their communities, so that seniors are not marginalized precisely when they are most vulnerable.

This study sought to address the current need in York Region for a service system that supports older individuals with complex vulnerabilities and their caregivers. Research questions were based on several vulnerability areas identified by the project partners. These were broadly classified into five categories of vulnerability: Economic, Physical, Social, Emotional, and Intersectional.



## METHODS

This study used community-based participatory methods to understand the needs of seniors and their caregivers. As such, peer researchers from the community were recruited and trained to interview the participants in this study with assistance from a Masters' of Public Health student from the University of Toronto. Our community researchers were involved at every stage of the project, from designing the questionnaire, to analyzing the research data, and giving their feedback on the final report. Eko Nomos, the evaluator for this study, helped with the development of community-based participatory methods, using previous work experience in the areas of harm reduction, women's economic development and transitions to sustainable livelihoods.

The five themes (resilience, significant training needs, affordability, stigma, finances) are briefly summarized in the table below, for each of the participant types (caregivers, older adults, service providers). Each of these themes will then be explained.

	Resilience	Significant training needs	Affordability	Stigma	Finances
Care-givers	Appreciated the positive attitude of older adults	Wanted personal support workers to be trained in providing social support	Thought services were affordable if they knew how to advocate for themselves	Noticed older adults being treated badly and were unhappy about this	Felt they had enough finances for the time being, but were concerned about the future
Older Adults	Able to make light of their situation	Oftentimes mentioned compassionate care as an important training	Thought services were not always affordable	They either normalized stigma or denied its existence	Felt their finances affected their quality of life, especially their participation in leisure activities
Service Providers	Sometimes felt that older adults were being taken advantage of	Thought that they can always be more educated, but were overall satisfied	Thought their services were affordable	Stood firmly against stigma and said they do not hold any such attitudes	Were not aware of seniors having particular difficulty with finances

## THEME 1 - RESILIENCE

Seniors and their family caregivers are resilient, and generally positive about their personal situation.

### SENIORS

*A senior who was in a difficult situation, mentioned: "But I'm pretty much withdrawn from everybody except for the few things where I volunteer. And to be honest, I work with some people where I volunteer who are seniors and they face the same challenges. So I know I'm not alone."*

*Others seniors also reported positive experiences when accessing peer-led counselling services: "And there was nothing competitive, no finger point for anybody; you could just sit and talk. The hardest part was going through the doors for the first time to see what it was like. And it was run by volunteers and everybody [had gone] through [something similar] at one point or another."*

### CAREGIVERS

*When talking about an older adult who often falls, a caregiver told us: "And I'll admit, she's good with it, she's fine with it, like she's got a sense of humor about it."*

## THEME 2 - SIGNIFICANT TRAINING NEEDS

There are significant training needs across the health and social services sector with respect to senior care. These needs may be most critical within the senior population itself, and amongst the population of family, volunteer or professional caregivers.

We also heard that service providers and personal support workers need to access more training. Culturally appropriate training (e.g., services provided in other languages) might help reduce social isolation among seniors from minority groups. We found evidence that there is an informal burden of counselling placed on service professionals or volunteers, who may voluntarily offer advice or try and make connections for clients to other services. This situation creates risks that some informal/unfunded counselling may be 'required to perform one's job adequately', and/or that care and counselling is provided outside of proper settings or the realm of a caregiver's qualification.

### SERVICE PROVIDERS

*"I mean, these things are documented so caregivers that will drop in and say like, "This is happening at home, is there any way that you could address this in the program?"; like, "This person is having some sort of [difficulty]"... I wouldn't even say informal counseling, but there are things that caregivers do talk to us about... it's not a support group; we're not sitting in a circle and talking about it. But in private they do approach... workers to express any concerns they have and they do have that support from us, on a program level."*

### CAREGIVERS

*"I'm not a hundred percent sure whether it was my mother's age or [the service provider] was just ...arrogant and impatient, but he sort of didn't give me the time of day and I was still trying to discuss with him when he started treating her. And that did not make me happy"*

*"Just...you know, talk to her. Have a tea and cookies with her and talk to her... be with her. But not sit on your phone looking at text messages while you're sitting with her."*

### SENIORS

*"Anything that I would probably need is going to be nine to five and that's it. If you get in to trouble after [hours], I would go to the hospital. I've never gone to the hospital for years; for anything outside of medical, I wouldn't go there."*

## THEME 3 - AFFORDABILITY

The rationale behind service fees for different programs offered to seniors in York Region is unclear; understandings of what 'affordability' means in programming are not consistent from clients to service providers.

Affordability was identified as an issue by the older adults interviewed. While they did recognize the presence of services in their community, they felt that there were often long wait times, even for urgent medical necessities. Seniors also reflected that with lower incomes come more barriers to accessing the things they need and want.

### SENIORS

*"Getting older, if you're on the lower end of the spectrum of money, there's definitely stairs that will come into your life... the less money you have the more amount of stairs it seems there will be."*

*"When you don't have the finances and so you have to take the lesser quality of life, that impacts you."*

*"When I went to the hospital recently and the doctor said, 'why did you wait so long,' I said because I couldn't get in to see my physician. He said, 'what do you mean?' I told him [I couldn't afford to go] and he said that's unacceptable too. That's the way it is. You can't get in. The rest of them - if there's an emergency you're just told to go to the hospital, so it's not the answer that you want to hear."*

### SERVICE PROVIDERS

*"It varies program to program, so there are smaller fees for certain programs; there's a one-time fee for certain programs and then there are programs that don't charge at all."*

## THEME 4 - STIGMA

Experiences or ideas about stigma and marginalization are diverse and often conflicting, depending on individuals' experiences.

When asked about their own attitudes, service providers said they do not hold such attitudes and that anyone who holds such an attitude should not work in this sector: "No, we don't [stigmatize people]. We are in the sector. That's why we are in the sector."

### SENIORS

*"Because of where I live, I won't tell people where I live so I won't socialize. I don't want people to know that I live in a basement. I tried when I first moved to the town I live in now - I thought, I'm going to step outside of this."*

*A participant living with HIV said that he lost his job after telling his employer that he had HIV. People did not want to work with him anymore. People did not understand how HIV is transmitted, and that "drinking from the same water bottle" does not result in HIV transmission.*

### CAREGIVERS

*"In terms of finance, [among caregivers] I have noticed that there is a notion, that... 'because we're taking care of you, it's okay to'- I won't even say financial abuse, but 'it's okay for us to take a portion of your money because you are under our roof and we are taking care of you' and sometimes their financial needs are neglected in terms of even just having a little bit of money... for leisure, like coffee and stuff like that. So I feel like sometimes [seniors are] left with no dollars because the caregivers have taken that from them as a means of... paying rent or whatever it may be, so there's that expectation that 'because we're taking care of you, your funds belong to us.'"*

*"Actually, the first time I encountered it, I have to say, it was her own physician in her home town. So I sort of got the impression that... [the doctor thought] 'she's old, she's not worth anything, just put her in a home and throw away the key'. And that was from her own physician."*

## THEME 5 - FINANCES

It is difficult for seniors to satisfy their basic needs, including finding a sufficient income.

### SENIORS

*"You're right, I am concerned because of the financial end of it. I don't know how you get help when you only have pension. I don't know."*

*In response to the question "so financial concerns and financial burden has affected your health in terms of being able to afford services?," a participant said: "In the past it has triggered my mental health. And it has led me to the addiction world. [...]working five hours a week helps a lot. But that five hours a week is all I can do."*

*Older adults also felt that it is not necessarily true that older individuals are wealthier:*

*"So I'm thinking, wow, and yet these two ladies came to me and said they've run out of their retirement money and they had to take back money from their house. You don't know how long you're going to live, you don't know how much money you need, plus, they worked for fifty years to buy a house. That... that bothers me. And I've heard the mayor say that, [name], I've heard him- I read an article where he said about older adults are the wealthiest that they've ever been."*

## RECOMMENDATIONS FOR YORK REGION

1. Develop more opportunities to include seniors in the social life of York region, especially opportunities for older seniors to contribute to decision-making about issues affecting seniors.
2. Develop more peer-led educational opportunities for seniors and their caregivers, including culturally appropriate resources and opportunities.
3. Ensure that social, leisure and/or recreational services are provided free of charge for seniors who need them.
4. Start educating older adults and seniors as early as possible about the potential of technology to assist in communicating, contributing or otherwise learning about resources in their community.
5. Invest in senior-led public education and discussion regarding the nature, experience and dangers of stigma and social exclusion.
6. Develop a regional advocacy agenda that supports full access to incomes sufficient for all people to live in dignity.
7. Develop and invest in more holistic service models that acknowledge the primacy of material conditions as a determinant of individual health.
8. Develop and invest in peer-driven stress-management counselling for seniors and caregivers.
9. Develop and perform new research on seniors' perceptions of and attitudes toward suicide, assisted dying and palliative care. Suicide often came up as a topic, unprompted. Caregivers themselves felt conflicted about this subject and sometimes held different attitudes towards their own death than towards the death of the person they were caring for. Service providers also heard such concerns and did not know how to broach this subject. Therefore, we recommend more research be conducted on this topic.

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