

Forty is too young to die

**A call for action
from Toronto's
Early-Onset Illness
and Mortality
Working Group**



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Introduction

“What use is funding for seniors when our tenants die before their 65th birthday?”
– Housing Support Worker

For Mainstay Housing, the “ah-ha” moment came when it received an RFP for The Toronto Central Local Health Integration Network's (LHIN) 2008-2009 Aging at Home Strategy. Tenants in seven properties fit all the criteria: they all had chronic illnesses, suffered the same symptoms as the program's target clients, and lived in priority neighbourhoods. But they did not qualify for services. They had not reached their 65th birthday.

For Houselink Community Homes, the “ah-ha” moment came when 12 people died in 2010 from natural causes. None of them was a senior.

These “ah-ha” moments led Mainstay Housing to invite leaders from a cross-section of organizations – supportive and transitional housing; providers of seniors', addictions and community services; a community health centre; and two university professors – to join a working group. We realized we needed to collaborate with others who had their own “ah-ha” moments to understand and find solutions to the issues we all saw. In the process we found many others who, though not part of the working group, will share in the results.

The Early Onset Illness and Mortality Working Group met monthly from October 2010 till September 2011. During that time we:

- solicited the experiences of 60 direct-service staff, tenants and clients through three focus groups, 13 face-to-face or phone interviews, and a survey.
- gathered expert opinion through interviews;
- enlisted the help of Ryerson Sociology students to analyze the statistical relationships between personal habits, socio-economic status, aging, chronic health and mental health;
- conducted, with the help of a York University Social Work student, a brief review of the considerable literature that confirms our experience is not an isolated one.

This report reflects our findings.

The Early Onset Illness and Mortality Working Group

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Houselink Community Homes
WoodGreen Community Services
Community Outreach Programs in Addictions
Margaret Frazer House
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1. The perfect storm

“We talk about people with mental illness, and people with diabetes, and smokers and the obese, and so on and so on. We’re talking about the same people – just with different labels.”

– Working group member

Poverty. Mental illness. Addictions. A history of homelessness or housing instability. These are the experiences that our members, tenants and clients share in common.

There is a proven link between each of these experiences and chronic illness and early death. Here’s what the research says.

People with mental illness die young

In the US, people with serious mental illness die, on average, 25 years earlier than the general population.¹

The chief cause of death? Not suicide. Not overdoses. It’s “natural causes:” cardiovascular disease, diabetes, respiratory disease and infectious diseases such as HIV/AIDS.²

Among people 25 – 44, cardiovascular mortality in US Department of Mental Health clients was 6.6 times higher than in the general population.³

In every disease category, the rate of disease among people with mental illness was higher than those without a mental illness. People with a serious mental illness or concurrent disorder also had more multiple medical conditions than those without a mental illness.⁴

In Australia, the mortality rate for people with mental illness is 2.5 times higher than the general population.⁵

The greatest number of excess deaths were due to ischemic heart disease – double the number of excess deaths due to suicides.⁶

1 National Association of State Mental Health Program Directors (NASMHPD). *Morbidity and Mortality in People with Serious Mental Illness* (Alexandria VA: Medical Directors Council, 2006), 32

2 NASMHPD, *Morbidity and Mortality in People with Serious Mental Illness*, 5

3 NASMHPD, *Morbidity and Mortality in People with Serious Mental Illness*, 15

4 NASMHPD, *Morbidity and Mortality in People with Serious Mental Illness*, 14

5 D Lawrence et al., *Duty to Care: Preventable Physical Illness in People with Mental Illness*. (Perth: The University of Western Australia, 2001), xi

6 Ibid.

A major population-based study also showed a 30% higher fatality rate from cancer among users of mental health services – even though their incidence of cancer was similar to the general population.⁷

The study concluded that, notwithstanding high rates of illnesses related to smoking, alcohol and drug abuse, obesity, poor diet and other lifestyle factors, *people with mental illness had consistently higher mortality rates than incidence or hospital rates within the general population for all major diseases.*⁸

Among Nova Scotians with cancer, there was a 72% higher rate of mortality in men using mental health services, and a 59% higher rate in women.

Once adjusted for other factors, such as low income and urban/rural differences, there was still an overall 29% excess mortality rate in people with mental health issues.⁹

People who are poor die young

*“What good does it do to treat people’s illnesses, to then send them back to the conditions that made them sick?”*¹⁰

– The Hon. Monique Begin, Member of WHO Commission on the Social Determinants of Health

Poverty is now thought to be among the greatest determinants of (ill) health.

According to the summary report, *Social Determinants of Health: The Canadian Facts*:

- Residents in Canada’s most deprived neighbourhoods have death rates 28% higher than the least deprived neighbourhoods.¹¹
- Adult-onset diabetes and heart attacks are far more common among low-income than among other Canadians.¹²
- Stressful living conditions lead to unhealthy coping behaviours, such as the excessive use of alcohol, smoking, overeating carbohydrates, and the use of drugs, legal and illegal.¹³

People who are homeless die young

Homeless men in Toronto aged 45 – 64 years are 40% to 50% more likely to die of heart disease than men in the general population.¹⁴

The Toronto Street Health Report 2007 reports that among homeless people surveyed, three quarters have at least one chronic or ongoing physical health condition and one in seven are usually in severe pain. In comparison to the general population, they are 28 times as likely to have hepatitis C; 20 times as likely to have epilepsy; 5 times as likely to have heart disease; 4 times as likely to have cancer; 3.5 times as likely to have asthma; 3 times as likely to have arthritis or rheumatism; and twice as likely to have diabetes.¹⁵

These illnesses do not disappear when a person is housed. Although a permanent home can make it easier for a person to recover from some illnesses and manage others, years of homelessness inevitably take a toll.

7 Ibid.

8 Lawrence, *Duty to Care*, 3.

9 Stephen Kisely et al, “Excess Cancer Mortality in Psychiatric Patients,” *Canadian Journal of Psychiatry* 53, no. 11 (Nov. 2008), 758

10 Juhan Mikkonen and Dennis Raphael, *Social Determinants of Health: The Canadian Facts*. (Toronto: York University School of Health Policy and Management, 2010), 5. <http://www.thecanadianfacts.org/>

11 Mikkonen and Raphael, *Canadian Facts*, 12.

12 Ibid.

13 Mikkonen and Raphael, *Canadian Facts*, 10.

14 Tony C. Lee et al, “Risk Factors for Cardiovascular Disease in Homeless Adults,” *Circulation: Journal of the American Heart Association* 111, iss. 20 (2005), 2631

15 Erika Khandor and Kate Mason, *The Street Health Report*, (Toronto: Street Health, 2007), 4

There are added complexities

- **Problematic substance use:** More than 50% of Canadians seeking help for an addiction also have a mental illness; conversely, 15 – 20% seeking help from a mental health service also live with an addiction.¹⁶
- **Obesity:** Clinical studies have reported rates of obesity in patients with schizophrenia or bipolar disorder of up to 60%.¹⁷ There is also a substantial literature linking obesity with anti-psychotic, mood-stabilizing and anti-depressant medications¹⁸. Some studies show the connection between obesity and mental illness continues even *after* adjusting for medication use, diet, education, and smoking.¹⁹
- **Smoking:** According to US evidence, 75% of people with an addiction or mental illness smoke cigarettes, as compared to 23% of the general population.²⁰ The Toronto 2007 Street Health Survey found 87% of homeless people surveyed smoke, compared to 18% of the general Toronto population.²¹
Smoking is also associated with low incomes. When Ryerson students analyzed Statistics Canada's 2007 Survey of Canadian Health, they found people who smoke daily made an average of \$2,962 per year less than non-smokers, and were 92% more likely to rent their home.²²
- **Discrimination and stigma:** We have not seen studies of the direct affect of discrimination and stigma on health. However, their impact can be felt in every quote, and on every page of this report.

The combination effect

Members of the Working Group observe first-hand the cumulative effect of these factors in the lives of the people we serve. In *Section 2* we describe some of these effects as seen by our tenants, clients and direct service staff.

Ontario does not have a mechanism for tracking the physical health of supportive housing tenants or the clients of community agencies. (The introduction of OCAN may facilitate the collection of such information.)

However, we are aware of one internal study by The Western Ontario Therapeutic Community Hostel (referred to generally as WOTCH Community Mental Health Services), a mental health housing provider, that compares the health of their clients at intake with the population of the South-West Ontario LHIN. They found that, among their clients, the incidence of diabetes was 3.5 times higher, hypertension 3.8 times higher, obesity 3.4 times higher, and chronic obstructive pulmonary disease 6.4 times higher than among the general population.²³

The cost of doing nothing

The Toronto Central LHIN has already recognized the costs of caring for people with complex needs. According to the Toronto Central LHIN's own estimates, 1% of the population can account for as much as 30% of total costs.

We want to keep the people we serve out of the “costly 1%” – both for their own sake, and the sake of the entire health system.

We see, for example, that among Toronto homeless people surveyed for The Street Health Report 2007, 24% had been hospitalized in the past year, compared to 5% of the general population.²⁴ Hospital emergency departments were the most frequently used source of health care, used by 54% of all respondents in the past year.²⁵ In this same report, more than half of those interviewed reported they do not have a family doctor and one in five had negative experiences with hospital security.

We also note that many of the hurdles to good health listed in Section 2 can be overcome with low-cost interventions. As one of our Working Group members has said, “We know what works. We just need to do it.”

16 Canadian Centre on Substance Abuse. *Substance Use in Canada: Concurrent Disorders* (Ottawa: Canadian Centre on Substance Abuse, December 2009), <http://www.ccsa.ca/2010%20CCSA%20Documents/ccsa-011811-2010.pdf>

17 Susan L. McElroy, “Obesity in Patients with Severe Mental Illness: Overview and Management,” *Journal of Clinical Psychiatry* 70, suppl. 3, (2009), 13.

18 McElroy, “Obesity in Patients with SMI”, 14.

19 Nancy M. Petry et al., “Overweight and Obesity are associated with Psychiatric Disorders: Results from the national epidemiologic Survey on Alcohol and Related Conditions,” *Psychosomatic Medicine*, 70, (2008): 291-292.

20 NASMHPD, *Morbidity and Mortality*, 17.

21 Khandor and Mason, *The Street Health Report*, 26.

22 Lesley Mushet et al.; Fantaskie, Mary; Mundi, Jassi; Zamurjeva, Anna; Ghorbankhani, Azin. *An Analysis of Personal Habits on Overall Health and Social-Economic Status*. Sociology 483: Advanced Research & Statistics: Ryerson University, 2011.

23 Christine Sansom et al., “Introducing Primary Health Care Services into Community Mental Health Settings” (presentation, WOTCH Community Mental Health Services, London, ON, November 2009).

24 Khandor and Mason, *Street Health Report*, 33.

25 Khandor and Mason, *Street Health Report*, 32.

2. The hurdles to a long and healthy life

In the spring of 2011 we asked over 50 of the people we serve about their experiences with the health care system, what they found helped them live healthy lives – and what prevented them. We also interviewed Direct Service staff about their observations. As we expected, we heard a litany of hurdles that must be surmounted, one after the other, to reach the goal of a long and healthy life.

Given the complexity of the issues, we had expected to hear about intractable problems, about hurdles that could not be overcome without significant investment. We did hear about some.

But we also received some surprises. We heard about simple, inexpensive, measures that had already made a difference in removing hurdles – measures that could be adopted more widely. These ideas are discussed more fully in *Section 3*.

6 hurdles to overcome



Hurdle 1:

No money, bad food, no exercise, no information . . .

There is accumulating evidence that individuals who experience difficult living circumstances associated with poor-quality social determinants of health come to have maladaptive biological responses to stress, weakened immunity to infections and disease, and greater likelihood of metabolic disorders ... these models appear to be especially relevant to cardiovascular disease and type II or insulin-resistant diabetes.”²⁶

The research shows that an unhealthy lifestyle alone is not responsible for poor health or an early death. But when we talked to the people we serve, the day-to-day challenges of staying healthy were raised repeatedly.

The chief challenge, not surprisingly, was **poverty**. A lack of money made it difficult to afford good food, transportation for grocery shopping or medical appointments, or take advantage of recreational opportunities.

Here’s what we heard:

“Poverty squashes the spirit”

“Poverty – just the lack of money, of resources, has a debilitating effect. It squashes the spirit, and desire to move forward. Things that others would take on automatically seem impossible. If you’re poor, you spend very little energy on making a better future. The spirit has been somehow damaged. It spills over into the health care piece.” – Direct Service staff

“People are too ready to think they’re not worthy of good health. Society says you’re hopeless, so you feel hopeless.” – Working group member

No access to quality food

“If you’re in a shelter, you just eat what they give you. I went to a food bank once. They gave me grape-flavoured chips. Four-year expired goldfish. Expired tuna. They give you stuff you’ve never heard of – stuff from Third World countries. Toothpaste with names like Colgate but without the “L”. – Tenant

“I’m 53 years old, and I’ve had the one [heart] blockage. I guess it’s all the Doritos I’ve eaten. I had a lot of part-time jobs where you had to eat on the run, and could only get fast food. There aren’t a lot of good meals in that type of work.” – Tenant

Lack of transportation

“I used to have a family doctor, but he was so far away, and I wouldn’t have bus fare, so I stopped going. At first I stopped taking my medication because I couldn’t pay bus fare to go to the doctor.” – Focus group participant

Not enough health information

“In 2009 I had a stroke – out of the blue. I knew what it was – I’ve worked in health care all my life. . . . If I hadn’t had the knowledge about the symptoms, I might have ignored it. Knowledge – that’s the key. These are the things we need to impart to [other] members: when it’s time to go to the doctor, or to emergency. I went at the right time, but some of our members wouldn’t do that without prompting.” – Tenant

“There has to be a lot more awareness around health care, and how to care for yourself – the basics. . . . Any of the health services could stand to be improved. However, from what I’ve seen, it’s an awareness problem within the person, not the system.” – Direct Service staff

Inaccessible units

“The ideal is to house someone for life. I’ll be in a wheelchair in 5 years and my bathroom situation is not going to work.”

“I’m almost falling every time I use my bathtub facilities, and so I’m taking fewer baths.”

– Focus group participants

²⁶ Dennis Raphael, “Restructuring Society in the Service of Mental Health Promotion: Are we Willing to Address the Social Determinants of Mental Health?” *International Journal of Mental Health Promotion* 11, iss. 3 (2009), 22.

Hurdle 2:

"Our meds make us sick"

"Choosing between physical and mental health: that's a horrible dilemma."

– Direct Service staff

A growing body of research shows that newer psychotropic medications increase the risk of obesity, insulin resistance, diabetes/hyperglycemia and dyslipidemia.²⁷ There are studies that show some anti-psychotic mood-stabilizing and anti-depressant agents cause weight gain,²⁸ that schizophrenic patients taking drugs have higher obesity rates than those that don't,²⁹ and reduced pain sensitivity is associated with some anti-psychotic drugs.³⁰

We welcome news that CAMH and others are continuing to research the effects of medications on people with mental illness, and strategies for reducing these risks. In the meantime, we wish to raise some of the other medication-related issues raised by the people we serve.

Here's what we heard:

The nature of psychotropic drugs

"Medication takes a toll on physical health, but also on mental health, ironically. I remember one woman in particular. She had been involved in the community kitchens, and was interested in doing computer courses or English courses. She couldn't manage a lot, but she was feeling well enough.

A few years ago, after 5 – 7 years, she started to spend the entire day, day after day, in her apartment – only coming out for little snippets, avoiding people. She had gained a huge amount of weight, even though she's not eating well. I've seen a number of women gain this ballooning weight. She looked in the mirror and said, 'I don't even recognize myself anymore. This is not me. I wish I could find me again. This is the medication that has done this to me.'" – Direct Service staff

Inadequate case histories or diagnoses

"She medicated me before she knew me! She hadn't researched the case or anything!" – Focus group participant

Medication used as a substitute for therapy

"There's no such thing as therapy anymore. It's just take your meds and goodbye. I used to get therapy and I miss it." – Tenant

Medication used as a treatment for poverty

"Some doctors start with the prescription pad instead of finding out the basics, like does a person have food? A person could make a lot of progress with their mental health just by getting proper nutrition." – Working group member

Doctors not familiar with the impact of prescribed medications

"A member asked me to go with him to his doctor's appointment. His appointment was with a very young doctor – really on the ball – who reviewed all the medications, and said, 'You're taking medication to stop you drooling. But I've never seen you drool. How long have you been taking it?'

It turns out he'd been on it for years. The doctor said, 'I think I should take you off it. Hasn't anyone told you that a side effect of this medication is heart problems?' The man wanted to think about it, and made an appointment for the following Tuesday. But that weekend he died from a massive heart attack. He was 55, not obese. He'd just been on all this heavy medication.

I find young doctors really know about drugs. Older ones seem to know too. It's the gang in the middle."
– Direct Service staff

27 NASMHPD, *Morbidity and Mortality in People with Serious Mental Illness*, 22.

28 McElroy, "Obesity in Patients with SMI", 14.

29 Ibid., 14.

30 NASMHPD, *Morbidity and Mortality in People with Serious Mental Illness*, 17.

Hurdle 3: Seeking help

“Not one of our members has ever been successfully treated for cancer.”

– Working group member

“A lot of our members in their 40s or 50s have been through so much. They are so worn out. They just hope it [the illness] goes away.”

– Direct Service staff

For many of the people we serve, just getting out the door can be a major hurdle. The barrier may be the effects of the mental illness itself, such as depression or anxiety. It may be difficulty organizing oneself to seek out care; a traumatic history with the health care system; a failure to recognize symptoms, or conversely, a fear of seeing one’s worst suspicions confirmed.

Whatever the reasons, failing to seek help means illnesses are not diagnosed at all, or are diagnosed too late to benefit from treatment.

Here’s what we heard:

Denial that something is wrong

“I’m thinking of one woman – a bigger woman, perhaps because of medication, perhaps because of unhealthy habits. She was always dressed in large clothing. I’m not sure if she was intentionally or unintentionally hiding a growing bulge in her stomach.

She never changed her mannerisms or attitude. She never reported feeling unwell. The staff didn’t realize until spring that there was anything wrong, and even then they weren’t sure.

They learned it was ovarian cancer by chance. She was at the psychiatrist and doubled over in pain, and was sent for tests. It’s terminal now.

The doctors treated her well – it’s not a problem there. But why did it get to this state?” – Direct Service staff

Inability to recognize symptoms

“Some people don’t see pain as a sign that something is wrong. Pain is just part of their normal experience. They say, ‘I’m fine, I’m fine,’ but they actually have a bowel obstruction.” – Working group member

Discrimination

“We often see health care workers write off our clients. They see ‘The Alcoholic.’ ‘The Addict.’ They don’t see a childhood of abuse. Of watching your father kill himself. Of being handed off, unloved, through a series of foster homes. How do we get health care professionals to see people as they really are – as people with traumatic histories?” – Working group member

Shame

“Being stigmatized, overweight, poor, with an addiction – all these can make you feel ashamed and afraid to ask for help.” – Direct Service staff

“I know of one woman in her late 50s. She has a hoarding issue and significant anxiety – going outside pushes her over the edge. She is too afraid to go grocery shopping or go to the doctor. She has an embarrassing and dangerous home.

It all works together to stop her from getting adequate health care. She misses appointments and the doctor is irritated with her. She’s not eating. She can’t move around. She turns down homecare because of the shame, saying, ‘I can’t see you today,’ so they cancel the service.

She looks able-bodied, but she is rapidly becoming not able-bodied.” – Direct Service staff

Bad health care experiences

“My connection with the health system has been shaped by some interventions. I had some ‘formings’ that may have spared me from some immediate damage, but the shock and trauma of them have had a lasting effect.”

– Tenant

“We have bad doctor experiences all the time, but we never tell. You never know whether it will get round and you’ll be blacklisted. But I’ve cried out in pain in the hospital when a tube was inserted improperly and the nurse said, ‘What’s the matter? Do you miss your boyfriend.’ I’ve been standing naked in a doctor’s office and the doctor says, ‘You’ve got a nice body.’ How unprofessional is that?” – Tenant

Mental illness

“Sometimes depression gets in the way. I have to work my way through the maze of it. If I’m not feeling okay emotionally, it’s hard to care about the physical. It’s helpful if someone else is there, like a roommate.”

– Tenant

Fear of consequences

“When I used dope I had something go wrong with my heart. But I didn’t want to call 911 and put the heat on myself. A lot of people OD but won’t call 911. It’s easier just to die.” – Tenant

“A lot of people won’t seek help. They’re afraid of losing their independence and getting put in a nursing home. Or not being able to keep smoking – that’s a big one.”

– Working group member

Difficulty making and keeping appointments

“I’m the only one in my 19-unit building with a land phone. People bang on my door in emergencies. Even workers were knocking on my door before they had cell phones. So you can’t communicate with people, and can’t make appointments.” – Tenant

“Lots of us have trouble keeping appointments. You have to get 50 cents and find a phone. But you feel sick. So you get back into bed. . . . I have a mental illness. I accept that. But you still need money, you need to find a phone, you need money to get to the appointment.” – Tenant

Hurdle 4:

The doctor’s visit

While people with SMI are more likely than the general population to attend primary care, they are less likely to have key aspects of their physical health (weight, blood pressure, cholesterol) monitored.”³¹

“The VA (Veterans Health Authority) system offers better health care access and more support for recommended monitoring and disease management than is available to many people with SMI. Yet, in the VA system, the odds were greater that a diabetic with a psychosis or substance use disorder would not receive standard-of-care diabetic monitoring.”³²

The good news is that, despite a nation-wide shortage of family doctors, over half the people we spoke to had found a family doctor. Some see doctors through Community Health Centres, family practice teams or specialty

clinics. Others found their doctor through a friend or worker, online, or simply by walking into an office.

Many cited their doctor as the key to diagnosis and treatment, the gateway to screening and referrals, and the co-ordinator of their care – a role that walk-in clinics, emergency rooms, hospitals, street services and visiting caregivers could not fill.

The bad news is that many felt their doctors did not understand mental illness, or were too busy to listen and reach accurate diagnoses. In particular, some felt their doctors were too quick to attribute symptoms to a mental health issue. Others were frustrated by “one issue per visit” rules that prevented them from getting the help they needed. In contrast, reviews of community health or specialty clinics were almost always positive.

31 J. White et al., “The development of the serious mental illness physical Health Improvement Profile,” *Journal of Psychiatric and Mental Health Nursing* 16 (2009), 494.

32 NASMHPD, *Morbidity and Mortality*, 24

Here's what we heard:

Finding a doctor who will take you

"It's people who are on assistance and have complicating issues who get turned down by GPs when they look for a regular doctor. These people are the ones who have the most need for a regular practitioner."
– Direct Service staff

"When you're making a referral to other services, you need to emphasize the other issues and minimize the substance abuse. If we disclose an addiction our client simply won't get served." – Working group member

The doctor's lack of understanding about mental health issues

"How do you open up to a doctor who is always in a hurry, who wants to shut you down before you start? My doctor has no time for me but there is such a shortage of doctors that I have to stick with this one or risk being without one." – Tenant

"Professionals set up unrealistic expectations/demands on patients, such as losing weight. I've been avoiding appointments because I'm afraid of disappointing the doctor. I haven't done what I should have." – Tenant

"People are drinking, so they can't go to appointments or will feel very judged. There's a lot of judgment around substance abuse." – Direct Service staff

"One issue" visits

"You look at the sign in the doctor's office: 'One Issue Per Visit, Please.' You've got schizophrenia, diabetes and hypertension, and your back is killing you. Which one would you pick?" – Working Group participant

Communication during the visit; being taken seriously

"Doctors don't take you seriously when you have 'mental health' issues. I went to the doctor to get antibiotics for an infection and was told 'if you came here for pills, you've got another thing coming.' It turns out I had pneumonia." – Tenant

"I'm watching these people not really get what they need because the system is not designed for them. It's not because there aren't doctors, or they can't find doctors. Even when we go to doctors sometimes, it's like talking to the wall. We need a different type of doctor. You go to Regent Park, or you go to Queen Street in the basement – it's just so much better." – Direct Service staff

Lack of routine screening - focus is on mental health issues

"It took me six years to get a pap test because my GP didn't want to do it. He didn't want to touch me".
– Tenant

"When you look at the DSM, what are the symptoms of mental health issues? There's often a physical component. For example, for anxiety, it's irritable bowel, a heart racing, a pain in the chest. These get pushed aside as symptoms of mental health issues. Headaches, backaches, joint problems – all of them could be attributed to mental illness."

It's human nature to take the path of least resistance. It's hard to take the time to listen and find out what is really going on." – Direct Service staff

No follow-up

"By the time I get referred it is not consistent. It is always to a different person." – Focus group participant

"I've seen several examples, where we finally get a member to a doctor, they get a prescription, they won't take it, they miss the next appointment, and then forget it. We need someone who can liaise with the doctor, and could follow up with a phone call. This is a gap we're frustrated with." – Direct Service staff

Hurdle 5:

The emergency room experience

The Ontario Government and the Toronto Central LHIN have already made emergency room performance a priority. For the people we serve, the emergency room experience is especially important – and problematic.

We heard stories of being ignored or misunderstood. People found that if they revealed their medications or a history of mental illness, their physical symptoms were written off; if they kept their mental illness secret, they risked mis-diagnosis or an adverse drug interaction. Some people were told to go home, despite being visibly ill, with no-one to accompany them.

We also heard that long wait times – distressing for anyone – were intolerable. Some left the emergency rooms without seeing anyone.

This year, a study of 81 Ontario emergency rooms³³ found that people with a charted history of depression had “low-priority ER triage scores” and delays in testing and care. The study hypothesized that staff assume the symptoms are “somatization of the depression instead of ischemic in origin. Alternatively, their symptoms may be assumed to be anxiety-related. . . . It seems the label of depression influences many health care providers along the care pathway of patients with acute myocardial infarction.”³⁴

Here’s what we heard:

Intolerable waits

“If you have a mental health issue, it’s not so easy to sit for hours in a waiting room. You don’t have control over yourself. The legs start to shake. You feel hot on the shoulders. You have the headaches. It’s not so easy.”
– Tenant

“For people with mental illness, waiting 8 hours in emergency is just not feasible. There’s too much stimulus. Too much despair. Too many people in the middle of a crisis. If you don’t have a broken arm, or you don’t have blood [i.e. you’re not bleeding], it’s hard to explain in a few minutes why you need help.” – Tenant

Being ignored or misunderstood

“I accompanied a client to the emergency for a physical health problem. . . . I was sitting in the room with the client when we both overheard the doctor to state to the nurses, ‘I’m so sick of dealing with crazy people in this job.’ . . . He never provided an apology to the client.”
– Direct Service staff

“My daughter’s a surgeon. When she was in training in the Emerg, she saw a middle-aged woman sitting all day in the waiting room and never being called. She asked the other staff, ‘What about that person?’ They said, ‘She’s loopy. She just comes and sits here.’ So my daughter sat beside the woman and asked her, ‘What brought you here today?’ She said, ‘My legs are numb, but no-one believes me.’ While they were talking, the woman peed on the floor. She didn’t know she was doing it. She just couldn’t feel anything. It turns out she had a tumour the size of a grapefruit. Here was a woman who sought help, but no-one was helping her.”
– Direct Service staff

Mental illness masks physical illness, and vice versa

“All pain is seen as psychological. Or if somebody has a significant mental health issue, the doctor just wants to deal with the mental health problem and let the rest slide.” – Direct Service staff

“We had a person with a wobbly gait. Doctors put it down to alcohol. It turned out to be brain stem deterioration.” – Working group member

Bad treatment

“[When my leg was particularly painful] I called the ambulance to take me to hospital. I spent 7 – 8 hours on a stretcher in emergency with my partner sitting next to me. The doctor said, ‘We need to do these blood tests and x-rays.’ I said, ‘I’ve already done those tests.’ He said, ‘No, I need to do these tests.’ So for the 3rd time in a row I did the tests, and once again they couldn’t see anything.”

33 Clare L. Atema et al., “The effect of a charted history of depression on emergency department triage and outcomes in patients with acute myocardial infarction”, *Canadian Medical Association Journal*, 2011, 4.

34 Ibid., 5

I was getting a little upset. He said, 'I can see you are getting upset. I would like you to spend the night in emergency, and then go the next morning to the psychogeriatric ward.' He also said of my leg that the pain is all in my mind. I became very upset. I had to leave immediately, I had to get a wheelchair because I couldn't walk, and get a taxi home.

It's because I have had a psychiatric history, and they saw I'm still taking psychiatric medication, that they quickly came to the conclusion that 'it's not physical. It's psychological.' They assume it's all in your head.

I've had problems like this in the past. I usually don't tell them about my past, or that I'm taking medication. But this time, I wanted to be honest and help them reach a diagnosis by giving them all the information. They just jumped on the bandwagon. I tell others that it's better not to tell about your psychiatric history – they put you in a different compartment immediately.” – Tenant

Hurdle 6:

The hospital and discharge experience

Hospitalization can be distressing for many people. For the people we serve, this distress is compounded by errors in diagnoses, confusions about medications, and insensitive or dismissing treatment.

According to a US study on survival after a heart attack, rates of mortality increase by 19% if there was any mental illness; and 34% if the patient had schizophrenia. The study showed the main cause for the disparity was the quality of care.³⁵

Here's what we heard:

Symptoms of mental and physical illness mask each other

“A long-term member – a very active, employed, man – fell in his home and was rushed to emergency. That was when he learned he had a brain tumour. Should it have been discovered earlier? He was acting strangely – he often talks in riddles – but that could have been because he had schizophrenia.

A few weeks later he was in hospital in restraints and a diaper. The doctors assumed he was behaving strangely because of the brain tumour. They didn't realize he had schizophrenia, and so he wasn't receiving his medication.” – Direct Service staff

Bad treatment

“The last night [in hospital], I had some sort of episode. I was feeling a little anxious, and wanted to get out of the hospital because I had been there all this time and nothing had been done. That day I was walking in the hallway looking for a washroom because there wasn't one in the room. A nurse came up behind me and said, 'Where are you going?' I told her I was looking for the washroom. She started to push me from behind – she didn't know how to guide a blind person. I told her I could take her arm, but she kept pushing me. I got very upset with her. All of a sudden, she had called four big guys – I couldn't see them but I could feel them – who handled me very roughly. They pushed me around, took my cane away, grabbed me and strapped me to the bed, restraining my head, my arms and legs. I could hear the nurses talking and laughing at me, saying, 'He won't get away now.' That was the worst night of my life.”

– Tenant

35 NASMHPD, *Morbidity and Mortality*, 24.

Lack of a realistic discharge plan

“The day after I got out of ICU, they tried to give me the bum’s rush. It was a sunny Friday afternoon, and they tried to pull the used car salesman trick. They said, ‘Look how beautiful it is. Wouldn’t you like to be out there?’ I had to exercise all my best recovery skills and diplomacy skills to refrain from asking them, ‘Wouldn’t YOU like to be out there?’ I resented them trying to sell me on leaving.

That’s when I started to worry about discharge – when I realized they had a private agenda to get me out. I panicked, and started to cry. Nobody ever asked me, ‘What are your plans when you get home?’

It was my Housing Support Worker who intervened. It was a condition of my discharge that I would need constant monitoring for the next two or three days. He said, ‘We don’t provide that service. And there’s no-one here on weekends anyway.’ So they had to backtrack. They said, ‘We weren’t aware this would be an issue.’

By Monday they had pulled their shorts up. The hospital social worker met with me. I told her I was frightened about going home and wanted to see a counselor. She kinda hesitated, and I said, ‘Don’t tell me I should have panicked on Friday. I’m an out-patient, aren’t I?’ And that’s what had happened. I’d been discharged before the weekend.

I’m not much of a worrier. I’m a planner. But if you don’t provide me with any information, it’s kinda scary. I get apprehensive. Before they discharged me, they gave me a folder. When I was feeling better I could sit up and read it, and got a wealth of information about my heart and what to do. But I would have liked some personal contact – someone who would talk to me.”
– Tenant

Lack of aftercare

“They shipped me home in an ambulance, tied to a board, and right into bed. I couldn’t walk. My building doesn’t have an elevator. It took me ten days before I was ambulatory. I had a friend come in to help – I don’t know what I would have done without him – but no home care.” – Tenant

“A resident in our housing was in hospital for mobility problems. Before he was discharged the hospital promised they’d give us notice and provide a walker. Instead, he was dropped off outside our front door in a taxi with no walker, and no supports. How are we going to make sure he’s cared for? There is no funding for this stuff, or budget flexibility to address this.”
– Working group member

“One guy had been in ICU after an assault. A rib had speared his spleen. He had major abdominal surgery, but was sent home with only ibuprofen for pain. They handed him a staple remover and that was it. This man doesn’t have a doctor. He has nowhere to get help. I pushed together two tables at the Good Neighbours Club and took the staples out myself.”
– Working group member

It is
time
to act

When the hurdles aren't cleared

“It’s always terminal when it’s discovered.”

– Working group member

Failing to clear the six hurdles described in this report leads to:

- Missed prevention opportunities
- Late or incorrect diagnoses
- Poor care
- Serious illness and death

Here’s just one example of the cumulative impact on our clients, tenants and members:

“We’re seeing it more and more: people dying way ahead of their time. Take a woman who died of cancer in her 40s. Sixteen months ago, I was just starting my sick leave, and confided to her I had uterine cancer. I had an operation, chemo, radiation, and am back on the job. She found out she had ovarian cancer while I was on leave. I’m here. She’s gone. It wasn’t that she didn’t get good care. It’s just she was diagnosed so late.

I asked my doctor at Princess Margaret, “How many people with mental illness do you treat, and how do they get on?” He said, ‘It’s very sad. They’re too far gone by the time they get to us.’ They haven’t had regular pap smears. They don’t get annual check-ups or regular bloodwork.

I just visited one of our members at Princess Margaret. She has Stage 4 cervical cancer. It was diagnosed 10 days ago. It’s heart-breaking.” – Direct Service staff

And when they are

Although we have heard and witnessed many unhappy stories, we have also heard success stories where the system is working well. Here’s one example:

“Toronto East General had just opened a clinic across the road, and said they were taking new patients. I phoned them, got an appointment, and took my Housing Support Worker to see him. She helped me prepare my questions.

When I went to the appointment I interviewed the doctor, to find out whether he was versed in mental health issues. He had good answers. He was connected to Mt. Sinai, and knew what he was talking about.

Last year I was ill three times. They took me once to St. Mike’s, once to St. Joe’s and once to East General. St. Mike’s kept me a couple of days. I got good treatment there.

St. Mike’s got me hooked up with a nurse through the CCAC who visits me once a month. I get behavioral therapy through VHA. I have a COPA worker every couple of months. I’ve got my Housing Support Worker.

I was begging – pleading, pleading – for this kind of support for years. Now I’ve got it. I’ve got a doctor, a psychiatrist and a nurse. I’ve had three psychotic breakdowns, but only was in hospital a couple of days at most. Before this, I was in CAMH for a year. I’m just healthier. Things are just better.

I see my family doctor monthly. He only gives me prescriptions for one month’s medication, and I get it in weekly amounts, because I have a history of over-dosing. My doctor understands mental health. Between my doctor and the psychiatrist they’ve got me on proper medication. It makes me happy.” – Tenant

3. The way forward

“You know how everyone knows a street corner is dangerous, but nobody builds the crosswalk until somebody dies? Well, a lot of people have already died. And now we’ve got to act.”

– Working group member

As a working group of practitioners, we do not feel equipped to make firm recommendations to either the Toronto Central LHIN or the Ministry of Health and Long Term Care. But we do see the way forward.

We propose the Toronto Central LHIN name early-onset illness and mortality a dimension of the TC LHIN priorities in its strategic plan.

We have been inspired by the results the Toronto Central LHIN achieves when it identifies a priority.

For example, when it made emergency wait times a priority, within one year 9 out of 10 patients waited 20% less time to be treated in ER. When it made Aging at Home a priority, the percentage of ER visits by CCAC clients plummeted in 10 months.

We believe the time has come to make early-onset illness and mortality itself a priority. The groundwork is already in place:

- **The Toronto Central LHIN has committed itself to health equity** by addressing disparities in access to needed health care services for poor and marginalized individuals.
- **International and Canadian research** shows that people with serious mental illness are dying 25 years earlier than others – and that these deaths could be prevented.
- **TC LHIN’s own pilot projects** have highlighted the unmet needs of people under the age of 65 with mental illness. For example, the Virtual Ward initiative notes the most challenging Virtual Ward patients have one or more chronic diseases and a mental health or addiction diagnosis.³⁶ When the Crisis Outreach Service for Seniors allowed people under 65 to be served in exceptional cases, it found that fully 42% of COSS consumers were between the ages of 55 and 64.
- **There are models in other jurisdictions to guide the way.** For example, US Department of Health and Human Services’ “10 x10” *Wellness Campaign* has been designed to increase life expectancy among people with mental illness by 10 years over the next 10 years.³⁷ Launched in 2010 by the Substance Abuse and Mental Health Services Administration, this multi-pronged strategy includes data collection, policy development, education and training and advocacy. So far, over 2000 organizations and individuals have signed the “wellness pledge” to take action.

³⁶ Irfan Dhalla et al, *The Toronto Central LHIN Virtual Ward: A New Model of Collaboration to Reduce Hospital Re-Admissions*, (Toronto: Toronto Central LHIN, 2011).

³⁷ Substance Abuse and Mental Health Services Administration Center for Mental Health Services (SAMHSA), *10 X 10 Wellness Campaign*, SAMHSA, 2011.

It is time to act

We propose a Think Tank on Early-Onset Illness and Mortality. The Think Tank would bring together policy makers, administrators, educators, researchers, and practitioners from the health sector, and consumers and front-line housing and agency staff, to:

- Raise the profile of this important topic
- Facilitate the exchange of information and knowledge among experts, practitioners and consumers
- Identify and change practices that perpetuate discrimination and stigma
- Identify successful models and the potential for their expansion or replication
- Create an opportunity for potential partners to meet and move forward together.

We believe this approach will give this issue the profile it deserves; identify projects that will help enhance an integrated health care system; give participants ownership over both the definition of the issues and the solutions; and help advance the TC LHIN's goals.

In this section we look at some of the topics we would like the Think Tank to explore.

Topic 1: Service co-ordination

“Structures force people to work in ways that aren't helpful for people who are in mental health”
– Direct Service staff

“We are integrated, we are holistic beings – our environment plays a big role too.... Everything is part of our world – you cannot cut it, and when you do, we live in isolation.” – Tenant

The Toronto Central LHIN already knows the value of co-ordination and collaboration.

For example, its Integrated Care for Complex Populations Task Force has led the way on integrated care for seniors. Many of the task force's strategies could be adapted for the people we serve: a strong care team, intensive case management, more face time with clients, and regular case conferences, leading to reduced hospitalization and other costly care.

We also see many models that already serve people with similar needs to our members and clients: the Virtual Ward, the Crisis Outreach Service for Seniors, and The Inner City Access Program, to name a few.

Each of these models contains the elements we believe are essential to our tenants and clients:

- Multi-disciplinary teams offering wrap-around support
- Services delivered to people where they live
- Health care professionals able to take time to address complex needs.

However, these initiatives have weaknesses too.

Eligibility is limited to people in a specific age range, neighbourhood or even those housed by a single housing provider. They stop and start, undermining the continuity and trust that are the hallmarks of good care. And they are often not well advertised, so even people working in the field do not know they exist.

As one Working Group member said, *“What we have here is health care by lottery.”*

At a Think Tank, we would like to:

- Hear not just success stories, but learn which elements are essential to that success
- Meet individuals and organizations willing to collaborate and build on these models
- Identify sources of ongoing funding for these initiatives, so we can stop “reinventing the wheel” and build on our investments
- Identify ways the CCAC could break the compartmentalization of physical and mental health
- Identify ways to integrate these specialty services into the overall health delivery system.

Topic 2: Bringing health care to the home

“Just getting up energy to go to the doctor, it's a huge effort so they don't go. If only the service came to them.” – Direct Service staff

“Home visits are a wonderful thing. It helps for so many people: someone who has agoraphobia or a social disorder; someone who is ashamed to go out. It deals with transportation issues, or having the money to get to an appointment. And instead of having to make and remember an appointment, they can just come by.”

– Housing supervisor

How do you reach people who cannot, or do not, seek help? Bring health care to the home.

Many people we interviewed cited home visits, or periodic on-site clinics, as the best way to make health care accessible to isolated people. (Ironically, people in shelters can have better access to health care than people who are permanently housed, thanks to shelter-based clinics.)

At a Think Tank, we would like to:

- Discuss the elements of a successful on-site clinic, including staffing, scheduling, outreach and privacy
- Explore ways to fill gaps typically left by on-site clinics, including the capacity to diagnose complex cases and follow up with screening, referrals and treatment.

Topic 3: Expanding access to one-stop clinics

“I first went to the Adelaide when I was in the Fred Victor Centre shelter. They have one nurse and one doctor – they are so supportive. You don’t need an appointment. It’s first come, first-served. They’re really friendly. I go there every week.” – Tenant

When we asked tenants, clients and Direct Service staff where they got the best care, here’s what we heard: Community Health Centres; hospital-based Family Practice Teams; the Centre for Addiction’s Primary Care Clinic; specialty clinics such as the Adelaide Centre for Women; private clinics like the Albany Clinic.

These clinics may have different structures and mandates. But each of them offers the features that are important to our tenants and clients:

- An expectation that their patients will have complex needs
- Salaried physicians who are able to take time to listen before diagnosing or prescribing; and do not restrict patients to “one issue per visit”
- A variety of health care professionals on site for one-stop care
- A commitment to continuity, monitoring and follow-up.

The only real problem with these clinics is that many are working at capacity and cannot take new patients.

At a Think Tank, we would like to:

- Learn about Ontario’s plans to expand access to “one-stop clinics”
- Identify practices that could inform care offered in emergency rooms, doctors’ offices and other care venues.

Topic 4: Providing training for health care professionals

“In Ontario, family physicians provide up to 80 per cent of all mental health care, and an even greater proportion of addiction care.”³⁸

“I’ve been asking if medical students could focus on mental health. If they could volunteer some time with the community – like five hours a week. This should be constant, every year.” – Focus group participant

“I’m happy with my doctor. He does a routine physical every three months. He does all my blood work, and looks at my blood sugar. He’s very thorough. I like him”.
– Tenant

We have observed that many family doctors are reluctant to provide care for the people we serve. The doctors may feel inadequately compensated by the fee structure, or as importantly, that they are operating outside their area of competence.

The Ontario Medical Association agrees. Noting that “too many people with mental illness are not getting the care and support they need,” the OMA has called for educational initiatives for family physicians to help them better support patients with serious mental illness.³⁹

We have been inspired by an initiative by the General Practice Services Committee, established by the BC Government to respond to declining interest among GPs in practicing family medicine. The committee organized training led by GP champions to help GPs increase their skills and confidence. A separate program for medical office assistants focused on booking practices, interpersonal skills with patients with mental disorders, and billing procedures for fee codes related to mental health. (The program’s learning modules, videos and tools are available online.)

³⁸ Anne Hoelscher. *Mental Health and Addictions in Primary Care Project Report*. (Toronto: CAMH, 2007), 5

³⁹ Ontario Medical Association, Better Care. *Healthier Patients. A Stronger Ontario*, (Ontario Medical Association, August 2010), 24, <https://www.oma.org/Resources/Documents/InsightsAndRecommendations.pdf>.

As of August 2010, 30% of the province's GPs had enrolled. Although it's too soon to evaluate patient outcomes, over 90% of participants said the training had improved their practice, enhanced their diagnostic and treatment skills, and improved patient care – and 78% said it had increased their job satisfaction.⁴⁰

At a Think Tank, we would like to:

- Learn what family doctors see as the chief obstacles to providing good health care for this population
- Hear about initiatives in Ontario and other jurisdictions to provide the training *most* helpful to family doctors
- Learn about other tools, such as checklists or standard protocols, that would facilitate good treatment for vulnerable people
- Discuss ways doctors (both students and experienced) and consumers can learn from each other.

Topic 5: Improved communication among care providers

“The systematic separation of mental health and general medical care has left severely mentally ill patients with unrecognized medical concerns.”⁴¹

“I have a family doctor who's there for me 24 hours a day. I have a heart specialist, and a mental health worker. They all talk to each other. I signed a permission paper saying they could. Then they don't give me medication that's not good for me. – Tenant

The need for improved communication among health care professionals is not new. Nonetheless, we would like to highlight two communication gaps that are of particular concern to the people we serve:

- Communication between psychiatrists and family doctors and other specialists
- Communication between support workers and medical professionals.

We believe an approach that has been used extensively in the UK would be a particularly good fit for the people we serve. The CARE Program features a semi-annual case conference, where an individual is joined by their family doctor, psychiatrist, housing workers, relatives, or anyone else involved in the “circle of care.” During these 1/2-hour sessions, the group develops a care plan, signed by everyone at the meeting.

These conferences, co-ordinated by the family doctor, overcome many of the concerns around client consent by ensuring clients are present while they are the subject of discussion.

At a Think Tank, we would like to:

- Survey the status of current efforts to improve communication within the care team
- Identify outstanding barriers to good communication, and identify ways to overcome them
- Identify and propose specific remedies to miscommunication that leads to inappropriate medication.



40 Rivian Weinerman et al., “Improving Mental Healthcare by Primary Care Physicians in British Columbia,” *Healthcare Quarterly* 14, iss.1 (2011), 36-38.

41 Mary Ann Nemcek and Elizabeth N. Austin, “A Psychiatric-Cardiac Case: Analysis for Education and Clinical Practice,” *Issues in Mental Health Nursing* 30 (2009), 393.

4. Being part of the solution

The health care system has primary responsibility for the health of Ontario's citizens, but it is not a responsibility it shoulders alone.

As community-based organizations, we are willing to do our part to improve the health of our tenants. In this section we look at four measures that could directly improve the health of people now living in supportive housing and those to come.

We would like to talk further with the TC LHIN about the potential savings yielded by these measures, and the best way to move forward.

Measure 1: Making physical health a supportive housing priority

"Just hiring a nurse from a mental health setting is not going to cut it. The model you use, no matter what one, has to be about respect, hope, dignity." (WOTCH interview)

In the past, supportive housing has focused on successful tenancies and creating strong communities – not physical health. However, recent deaths tell us the physical health of our tenants cannot be ignored.

We have been impressed with the success of WOTCH, a mental health housing and case management organization in London, Ontario. WOTCH made a commitment to the physical health of its clients. They re-organized staff; hired nurses to fill some case management positions; introduced a foot clinic and diabetes screening; and taught other case managers about nutrition, diabetes, and other health matters. WOTCH also made a concerted effort to match its clients with family doctors.

The results: WOTCH has observed increased foot care and client mobility, and increased use of local diabetes services. They have also seen markedly improved access to primary care. In 2006, 72% of clients had a doctor, 26% no doctor, and 2% no doctor by choice. By 2009, 96% had a doctor, 2% no doctor, 2% no doctor by choice.⁴²

We believe we too can have a role in helping our tenants live healthy lives and receive the care they need. Explicitly naming physical health as a supportive housing priority is the first step.

To move forward, we need:

- Opportunities for WOTCH and other organizations that have taken this step to share their experiences

New resources needed:

None in the short term. Learnings can be shared through existing networks and conferences. However, additional and ongoing funds would be needed to hire staff with health training.

⁴² Christine Sansom et al., "Introducing Primary Health Care Services into Community Mental Health Settings" (presentation, WOTCH Community Mental Health Services, London, ON, November 2009).

Measure 2: Training for supportive housing staff

Some people have suggested that supportive housing staff take more responsibility for asking health-related questions – “Have you seen a doctor? Do you have a doctor? Did you get that prescription filled?” – and helping tenants as needed. Others felt the role should be limited to “healthy living” issues: “Have you been eating? Did you get a chance to go out for a walk today?”

Supportive housing staff already assist tenants through individual counseling. Some organizations have the resources to provide staff accompaniment to medical appointments. But we believe there are opportunities to take this work to another level, by training case managers and clients to be partners in primary healthcare advocacy.

We are inspired by Brooklyn’s Integrated Collaborative Care Management Protocol, which uses a collaborative approach, rooted in a commitment to make the pursuit of primary health care a key service plan goal. The program provided an eight session, 16-hour program, led by health care professionals. The sessions focused on:

- the adverse effects of medications, the use of Metabolic Syndrome Monitoring Protocol (MSMP)
- diabetes and cardiac disease – helping clients to ask questions and get answers

The protocol was field tested with 11 case managers and 24 consumers, and later expanded to another 33 case managers and 58 consumers. Although it is too early to test the impact on longevity, consumers in the program improved their scores at double the rate of non-participants for:

- improved quality of healthcare
- increased use of the Metabolic Syndrome Monitoring Protocol by family doctors and psychiatrists
- remedies ordered to address problems made evident by the MSMP
- psychiatrists and family doctors informed of these remedies
- satisfaction with their psychiatrists and family doctor’s responses⁴³

To move forward we need:

- To determine whether the Brooklyn model is suited to a Canadian context, and if there are better models available
- To identify an organization to develop and pilot training among its own staff, drawing on the materials and processes developed for the Brooklyn project or similar initiatives
- To extend the training to other supportive housing providers both within and beyond the TC LHIN

New resources needed:

Funds to research the Brooklyn and other training models, and to develop, pilot and roll out training. Experts to evaluate training models for their suitability to a Toronto context.

Measure 3: Promoting healthy living

“We had a dietician come and do a very good presentation. She brought a pancreas that inflated – you could see how everything worked. I learned so much. A diabet[es] nurse came to talk to us about our diets. I learned to limit myself to three servings of fruit a day – things like that. She gave her phone number so we can call for advice.” – Tenant

“One of the most important things [my housing provider] has is a group membership with the YMCA. The Y has been essential to my recovery. It’s the relationship with a personal trainer who encouraged me. It’s having allies and mentors who have seen me change from a shell of a man and are now celebrating my success.” – Tenant

“I tell everyone: I see my doctor every year for a check-up. That’s what everyone should do to stay healthy. That, and try to cut down on the smokes, the alcohol and the dope.” – Tenant

Many of the people we interviewed saw the circular relationship between mental and physical health. It is the relationship cited in the US “10 x 10 Wellness Campaign” – defining wellness as social, environmental, physical, emotional, spiritual, occupational, intellectual and financial wellness.

43 Jack Carney, “Helping consumers add years to their lives,” *Behavioral Healthcare* (2011).
<http://www.behavioral.net/ME2/dirmod.asp?sid=&nm=&type=Publishing&mod=Publications%3A%3AArticle&mid=64D490AC6A7D4FE1AEB453627F1A4A32&tier=4&id=2570E67741024603B106066E8B3D46C7>

We are also inspired by the Recovery Movement that promotes alternatives to more costly and intrusive health care. We have seen our tenants, members and clients develop their own Wellness Recovery and Action Plans; take charge of their own medications; draw on their peers for support; and take advantage of self-help opportunities that have reduced their use of the formal health care system.

This is an area where supportive housing has already had many successes. Many tenants cited the multiple benefits of community kitchens. These communal meals created affordable and nutritious meals; introduced new foods and helped shift eating patterns; cultivated shopping and cooking skills; and broke down isolation. They were also venues for presenting nutrition and other health information.

Many people also cited supportive housing's potential as a venue for health education and advocacy. Some pointed to guest speakers on diabetes management and other health topics. They also noted the benefits for hearing "healthy lifestyle" information from peers who had learned through experience and could offer very practical advice.

To more forward we need:

- Opportunities to share ideas and approaches among community-based organizations
- Opportunities to identify new partnerships and collaborations
- Models for peer-to-peer education
- Staffing to form partnerships, train and support peers educators, and co-ordinate community kitchens and other direct services
- Research to measure the effectiveness of these programs in reducing other health care costs and promoting health

New resources needed:

Additional staff time – a topic for further discussion with the TC LHIN to determine where savings and synergies are possible.

Measure 4: **Addressing accessibility issues**

"I notice we're ill equipped to deal with our large aging population. We only have two buildings with elevators. We don't have accessible units, baths or toilets to suit people with major mobility problems. Retrofitting is prohibitively expensive. We also need more programs – the usual geriatric activities, but for people who are 45."
– Direct Service staff

"Just being able to live on the main floor can help. Or an accessible kitchen and bathroom. Otherwise, people end up in long-term care facilities. It would be nice to have more nurses checking in – and a lot of support from neighbours and housemates. Being told to live in a more institutional setting can push people over the edge too." – Tenant

One growing concern, mentioned by both tenants and staff, is unit accessibility. Most supportive housing units are not wheelchair accessible, and units are often too small to accommodate scooters or other mobility devices.

This is an extremely complex issue, touching upon supportive housing's mandate, the expectations set by the *Accessibility for Ontarians with Disabilities Act*, and the physical limitations of the supportive housing stock. We would therefore like to work with others to find a solution for tenants who want to grow old in supportive housing, but are already, in their 40s and 50s, finding they need a more accessible home than we can offer.

To move forward we need:

- To convene a working group comprised of supportive and other social housing providers, tenants, long-term care providers, accessibility experts and funders
- To identify the current barriers to accessibility, including building configurations, unit sizes, etc.
- To explore the options for tenants who need accessible housing and supports, but otherwise do not need long-term care
- To develop a plan to address the accessibility needs of current and future supportive housing tenants.

New resources needed:

Unknown, but could be substantial depending on the recommended plan.

Conclusion

As community-based agencies and housing providers, we do not pretend to be medical experts, researchers or health systems designers. What we bring are our deep knowledge of, and commitment to, the people we house and serve, and a readiness to join with others to take action.

We, the members of the Early Onset Illness and Mortality Working Group, are convinced that:

- the “perfect storm” of mental illness, poverty and housing instability leads to early physical illness and early deaths.
- that helping the people we serve will advance many of the Ministry of Health’s and Toronto Central LHIN’s goals: reducing hospitalizations and re-admittances; reducing emergency room use; addressing diabetes; integrating services and promoting health equity.
- that many solutions are within reach, tested by initiatives already funded by the Toronto Central LHIN.
- that the costs of doing nothing include higher emergency room use, more hospitalizations, and more unsuccessful treatments.

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