ACCESS Health

Volume Two, Issue One

Winter 2011

Aging With a Disability

Aging With a Disability is NOT the same as Disability as a Result of the Aging Process.

The Issues:

Isolation
Depression
Fear of the ‘unknown’
Anger
Lack of housing
Lack of supports
Acquiring secondary disabilities
Aging at Home versus Institutionalization

What Needs To Be Done?

- An extensive literature review.
- A consumer survey designed to find out what aging consumers want and need.
- A survey for service providers to find out what they are doing in this area.
- Education for funders, consumers and health care providers.
- Create more programs/supports to meet the aging needs of consumers (i.e. workshops, adapted fitness programs, etc.)
- PEER SUPPORT

Aging With a Disability: What’s It Like?

People living with lifelong disabilities are now living longer than expected, and are now embarking upon another life transition - the aging process. They should be able to do so with dignity; this includes having access to all information and resources, having the choice of living at home with appropriate supports and services versus living in long term care facilities, accessing educational programs on health and nutrition, fitness programs and those designed to decrease social isolation as it relates to aging with a disability.

In the past getting older was a not as large of an issue for people with disabilities as it is now, so how well will we live as we age? Now, people with disabilities are asking questions about the quality of our living and the quality of our aging. It is important that we keep ourselves as informed as possible on wellness, self care, health care, exercise and advocacy.

Secondary medical conditions such as respiratory illness, renal failure, accidents, infections, and depression, coupled with a general lack of adequate primary medical care, prevented most persons from experiencing their true life expectancy.

The “AGING WITH A DISABILITY WORKING GROUP” is comprised of consumers and representatives from the cross-disability community who want to be able to anticipate the type, severity and course of age-associated changes focusing on experiences of aging. Through a consumer approach, we want to help identify what to expect, what preventative steps can be taken to ease the effects of aging on disability, how to translate living longer into living better and actively, how to prevent losing our achieved independence, and what to do to delay new conditions and increasing disability. We want to support aging consumers in mitigating risk factors (including effective use of assistive technology), accessing helpful resources that will offer knowledgeable review, assessment and intervention, and find options and choices regarding fitness, physical, social and financial options.

We intend to produce and promote change in civil society including government to integrate improvements and implementation of supports and services to ease the aging process for persons living with disabilities. This will be done through conducting a literature review of existing research, conducting consumer and service provider surveys, and raising awareness with a view to develop an action plan.

The Aging Advocacy Team: Centre for Independent Living in Toronto (CILT), Access Apartments, Anne Johnston Health Station, ARCH Disability Law Centre, Birchmount Bluffs Neighbourhood Centre, CPA Ontario, Ethno-racial People with Disabilities (ERDCO), Huntington Society, MS Society, Muscular Dystrophy Canada (MDC), North Yorkers for Disabled Persons (NYDP), Ontario Federation for Cerebral Palsy (OFCP), Tobias House Attendant Care.

News From the Direct Funding Program: Integration With the LHIN System

By Sandra Carpenter

With the advent of the Local Health Integration Network (LHIN) system, attendant services and other Ministry of Health and Long Term Care (the Ministry) funded community-based programs are now under the same authority as all other “health” and hospital programs. An exception to this, up until now, has been the Direct Funding Program.

We do know that this change has made it harder for people with disabilities, who view attendant services as critical to maintaining community participation and who have also spent the last 40 years distancing themselves from terms like “patient”, to feel any sense of confidence in this development.

LHINs were born in response to the problem that too much money was being spent on the administration of health care and not targeted towards the delivery of health care. Early Bulletins from the Ontario Ministry of Health, in 2006 illustrated the inefficiencies of a health system by pointing out the number of agencies, councils and government administrative structures that were all involved with health service planning or allocation. On the other hand, individuals were waiting for unacceptably long periods of time for certain health services.

From the beginning, the Ontario Liberals were interested in “transforming” health care. However, as history shows, systems cannot be “transformed” through top-down initiatives. Community development cannot occur unless there is true community based bottom-up development. The LHIN initiative did involve intensive community consultation and development but it was highly controlled and key decisions regarding strategy and direction were already decided. These decisions came from the “top”. Examples of this are numerous including the process and delineation of boundaries, the elimination of decision and planning centres, the consultation process and who would be included, and the very idea of a regional health planning and allocation structure.

Community Consultations

The initial consultations were based on “open space technology”, itself a misnomer. How it worked was like this:

In Toronto in December 2004, four staff at the Centre for Independent Living in Toronto, were among 600 individuals invited to attend an all day meeting held at the Metropolitan Trade Centre at the CNE. Groups were selected based on which LHIN area the group was in and this was decided through their postal code address. LHIN areas – boundaries – were determined through an analysis of hospital discharge patterns that were used to create a map of each LHIN area.

Based on this and a mailing list of organizations funded by the Ministry, the invitation to attend a consultation meeting was issued. Because this consultation was made up of representatives from groups that were already funded by the Ministry, groups such as ours were vastly outnumbered by more traditional health care groups such as doctors, hospital admin-istrators, nurses, therapists, counselors, addictions and mental health services staff, staff from Community Care Access Centres, and so on.

In a group of 600 people, it rapidly became a numbers game. Firstly, all the participants, if they were interested in leading a workshop, had to scribble a brief explanation of the topic down on a piece of paper and tape it to the wall. Those of us who were in wheel-chairs (four of us) were highly disadvantaged even in this exercise because of the following:

1. We couldn’t run up to the front to grab a piece of paper from the floor;

2. We had no where to write and couldn’t use the floor like everyone else; and

3. None of us had the ability to tape anything on a wall.

Luckily we had one of our staff who was not in a wheelchair do these three steps for us.

The next step was that “volunteers” from among the 600 went around and put similar sounding topics together. Once that was done, the 600 went around and using cards, voted by putting their cards in the envelope describing the workshop. The next step was to count the votes that each one received. Only the top 20 were picked.

The rest of the day was spent in workshops and when those results were shared, there was another voting process so that only the top 5 of the 20 would be priority areas for that LHIN to work on. In other words, the majority ruled and it is a well known fact among equity seekers that majority decisions often disadvantage minority groups.

The Initial Commitment for DF to Remain Outside LHINs

By February 2005, the Centre for Independent Living in Toronto and the Attendant Consumer Action Coalition received confirmation that Direct Funding (DF) would not be rolled into the LHINs. This was important for a few reasons. First, as supporters of DF have seen with other similarly structured programs in other provinces, the key issue of portability within the Province was lost. A person who lives in one region cannot move to another unless he or she is willing to start all over again. The dollars do not follow the person. Supporters did not want to see DF carved up into 14 areas. One of the program's key principles was that by having one program which blanketed the Province, the significant barrier of portability (within Ontario) was eliminated. This was important to enable people to move for employment, education or personal reasons and not be a prisoner to 'remaining in place' because that's where the resources were. A second key reason is that by carving DF up people who wanted to move would be at the mercy of whatever the priorities of a particular LHIN were at the time and if, in fact, there were resources to access. For all of these reasons DF was kept outside the LHINs.

By March 2006, Bill 36 - legislation that would enact LHINs and spell out the relationship between LHINs and CCACs – passed third reading and was proclaimed later that year.

Fast forward to 2011

Although we felt that there was a significant win on our side to keep DF out of the LHIN structure, and in spite of the assurances we received in 2005 from the Ministry, the primary barrier for the Ministry was that DF was a Provincial program and there was no mechanism to deal with that. But since then, the Ministry was thinking about a mechanism to deal with province-wide programs through the LHIN system.

In January 2011, Ministry staff received senior level management approval to implement something called "a Lead LHIN model" whereby provincial programs could remain intact but be administered through the LHIN system which by design, is a local level structure. Lead LHINs would have a contract with the Ministry to administer the program, but the LHIN would have a contract with the agency to administer the program.

Needless to say, there were a lot of questions that we had for them. On January 20th we met with representatives from the Ministry followed by another meeting on February 11th, with representatives both from the Toronto Central LHIN (TCLHIN), which will have Lead LHIN responsibility for DF.

We wanted assurances that the program would remain intact, that CILT would continue to manage the waitlists and acceptance onto the program, that our relationship/partnerships with the other Independent Living Centres in Ontario would continue and that the key principles of the Independent Living Philosophy would be respected.

The first step will be the transfer, as is, of the contract we now hold with the Ministry to the TCLHIN. We will then, over the next year be working with TCLHIN to hammer out more specifics.

Good News or Bad?

At this point it is hard to say whether this is good news or bad news for us. The concerns, of course, point to the original fears we had regarding LHINs; that they are still too focused on the medical model - something we have been fighting to get away from for nearly 40 years. The drive towards standardization, equity and efficiency, often have the unintended result of severely curtailing the development of personalized support packages that can effectively and creatively meet individual needs. When you have a life-long or very long-term disability, the individualization of personal supports is paramount. On the positive side, however, we do have the opportunity to educate LHIN staff about the essence of DF and the real solutions it creates for participants across the Province. Perhaps, down the road, it might result in more funding for the program.

ODSP and Addictions: Eligibility Update

http://www.archdisabilitylaw.ca/sites/all/files/Update%20-%20Dec%202010.doc

People with addictions to drugs and / or alcohol can now be found eligible for benefits from the Ontario Disability Support Program.

Background:

Until recently, people whose only disabling conditions were drug and / or alcohol addictions have not been eligible for Ontario Disability Support Program (ODSP) benefits. That's because there is a rule in the ODSP Act that specifically excludes people from ODSP if their only significant disability is their addiction.

People with addictions could only be eligible for ODSP benefits if they had another disabling condition that met the ODSP test for disability. A court decision in 2009 changed this.

Ontario legal clinics challenged this rule in the court on behalf of two people. The court decided that the provincial government was violating the rights of people with addictions and said that the rule could no longer be applied.

The government appealed that decision. But, in September 2010, the Ontario Court of Appeal upheld the original decision. The deadline for filing another appeal recently expired. The government did not file an appeal, so the original decision is now the law in Ontario.

Why is this important?

The fact that the government did not appeal the decision means that the rule denying benefits to people with addictions can no longer be applied. This is an important victory for people with addictions because:

1. It means that people with addictions may be able to get ODSP benefits. This is especially important for people whose only disability is their addiction. It will mean that they can get benefits if they qualify as "a person with a disability" and meet the other eligibility tests. This does not mean that people with addictions will automatically get ODSP. But it does mean that they are no longer automatically denied. For people who have other disabilities, the impact of their addiction can also be taken into account when deciding if they meet the disability test.

2. It means that people with addictions who got ODSP benefits after the court decision in 2009, who were told that they might lose their benefits because of the government's appeal, no longer have to worry.

3. It also means that addictions are now being thought of as medical

conditions that can cause a disability, instead of as a moral failure of the person with the addiction.

I have an addiction. What does this mean for me?

If you haven’t applied for ODSP because you were told you weren’t eligible because of your addiction:

- You should apply for ODSP. Remember that you will have to meet the ODSP test for disability and the financial test.
- If you are currently on OW, ask your caseworker for an ODSP application.
- If you are not on OW, get an application from your local ODSP office. You can find out where they are and how to contact them at this website: http://www.mcss.gov.on.ca/en/mcss/programs/social/odsp/contacts/index.aspx.
- You might want to get help with the application process. Contact your local Community Legal Clinic, Community Health Centre, or other social service agency for help.

If you were recently granted ODSP but were told that your eligibility for benefits might be reviewed because of the court case:

- The government has said that you will be contacted directly by the Disability Adjudication Unit (DAU).
- The DAU will send you a letter to let you know that your benefits will not be reviewed because of the court case.
- The government is reminding people of one other thing. The court’s decision does not affect any decision about medical review dates. People who were given medical review dates will still have their disabilities reviewed.

- The government is reminding people of one other thing. The court’s decision does not affect any decision about medical review dates. People who were given medical review dates will still have their disabilities reviewed.

If you have an addiction and were turned down for ODSP, but you have filed an appeal at the Social Benefits Tribunal (SBT):

- We recommend that you get legal advice to help you with this process. To find your local Community Legal Clinic and how to contact them, go to www.legalaid.on.ca/en/locate/default.asp.

Your Action Plan: Strategies for Managing Your Illness By Gloria Troyer;

http://www.abilities.ca/health_activity/2010/05/05/_managing_illness/

Living with a chronic illness or disability presents many challenges. There are so many strong emotions to cope with, and so many life decisions to make. We often need to make adjustments to our daily routines, our homes, and our careers. We must deal with reactions from family members, friends and society at large. We have to take stock of our finances and navigate the maze of government systems.

We may also face physical challenges such as sleeping problems and nutritional issues. Add to that having to deal with chronic pain, medication, doctors and other health-care providers, and life can seem over-whelming.

The key is to take charge by taking positive steps. Essentially, you should try to manage your chronic condition in much the same way that you would a business.

"Whenever people are contemplating change in their life, there are well-researched stages that people go through," says Judy McKague, a physiotherapist with the Arthritis Society of Kitchener in Ontario. "Self-management requires readiness for change; those people that can work through these stages will be more successful in making the changes. Sometimes consultation with a health-care professional will assist people in moving forward through the stages of change."

You can wallow in self-pity or try to make the best of a bad situation by trying something different. Working with professionals and becoming more proactive in your own health care is a good way to go. "In order for someone to take charge of their chronic illness, education is of primary importance.

Learning about what is going on inside their body, what is known about that process and how to ameliorate it is the first step," says McKague. Fortunately, she adds, there is growing recognition in our health-care system of the benefits of the self-management approach.

Michael Sausser, 47, of Palm Springs, Calif., says, "It took me a long time until I was able to 'self-manage' my chronic illness. I was too busy being angry and depressed about it, especially when I realized that I was never going to get better."

Sausser started his self-management by getting as much information as he could about his physical condition from his doctors and health-care workers. "Once I understood my illness and disability and its progression, I began listening to my own body. I worry less about the appointment that I had a month ago and deal with what I am feeling in the moment. I no longer let my illness consume me. I am moving forward regardless of it. "

SET GOALS: Write down your goals. Choose one and ask: What do I want to achieve? What are alternative ways that I might accomplish my goal?

Whatever your goal is, don't assume it isn't possible or that options don't exist – thoroughly investigate, and ask for help from your family, friends and health-care professionals. Community organizations may be able to offer help.

"The two most effective strategies I've observed from leading the Stanford Chronic Disease Self-Management program are problem-solving and goal-setting," says Shelley Murphy, registered dietitian and co-leader of the 'Take Charge!' Program at the Guelph Community Health Centre in Ontario. "There are many different tools, such as communication skills, healthy eating, exercise and stress management, that help support and direct problem-solving and goal-setting. These are the foundation to move knowledge into action. Furthermore, having good support in place, like family, friends and health professionals, is an important way to keep on track with managing our health."

CREATE AN ACTION PLAN: For each goal, decide on a short-term plan. You need to decide how much you are going to do, when you are going to do it, and how many times. For example:

“This week, my goal is to go to the pool for water therapy (what). I am going to go for 30 minutes (how long) after breakfast (when) twice this week (how many times)."

PROBLEM SOLVING: If you’re having trouble achieving a goal, don’t give up immediately – explore what you can do, and ask others for advice. Try these steps: - Identify the problem. - List ideas that may resolve the issue.

Select an idea. Try the idea. Assess the results. If one idea doesn’t work, try another. Utilize other resources – call on friends, family, health-care professionals or organizations.

Identify the problem: Let’s say you want to eat more healthfully, but you’re not sure what dietary changes to make. Also, due to your level of fatigue, you are not eating enough and therefore not getting enough nutritional value from what you do eat.

List ideas: Talk to your doctor or a dietitian to learn how to meet your specific nutritional needs. (Find a dietitian by visiting the Dietitians of Canada website at dietitians.ca. In Ontario, you can speak to a dietitian for free by calling 1-877-510-5102. Bring a list of questions, take notes and ask about resources. To prepare healthful food while respecting your limited energy, you could get your teenage kids more involved, plan ahead by “batch cooking” soups and sauces and freezing them, or make smoothies with protein and brown rice powders.

Select an idea: Next weekend when the kids are home, you are going to cook.

Try the idea: Together, you make a pot of spaghetti sauce, chicken soup and a mixed vegetable casserole. The food is divided into smaller containers and frozen.

Assess the results: The frozen meals are handy when you are home alone and are not up to cooking. Also, the kids realize the importance of helping out with food preparation and become more active on a day-to-day basis.

Utilize other resources: If this plan does not work, explore other options, such as occasionally ordering take-out or inquiring about Meals on Wheels in your area. Get a copy of Canada’s Food Guide to Healthy Eating (healthcanada.gc.ca/foodguide) to self-manage the nutrients that you need to stay healthy.

REWARD YOURSELF: Reward yourself for reaching your goals – you deserve it! It could be as simple as lighting an aromatherapy candle and listening to your favourite music. Enjoy a cup of tea, have a bubble bath or go out for coffee with friends. Give yourself a pat on the back.

BE PERSISTENT: You will not always achieve your goals right away. Acknowledge the setbacks and move on – this is part of self-managing a chronic condition. “Life is unpredictable and ever-changing. We all have ups and downs, and self-management is a journey rather than an end point,” says Murphy. “I believe everyone has the capacity to self-manage…There are times when we are better self-managers than others. Keeping a positive outlook, setting goals for ourselves and finding solutions to our challenges will contribute to weathering life’s ups and downs a little better.”

Gloria Troyer is a freelance writer who lives in Guelph, Ont. She wrote an article about creating a medical resumé titled “Paging Dr. You” for the Fall 2009 issue of Abilities.

Arthritis Information for Those of Us Who Are Aging By Public Health Agency of Canada; Division of Aging and Seniors - www.phac-aspc.gc.ca/seniors-aines

There are many forms of arthritis. Osteoarthritis is the most common form and the most frequent joint disorder in seniors. It is also one of the major reasons why seniors limit their activities.

What is arthritis? Arthritis is due to the wearing down of cartilage, which is the material that cushions the ends of the bones. Some researchers believe that when the joints are unable to react properly to stress, the cartilage is damaged. This leads to the development of arthritis. The joints most commonly affected by arthritis are weight-bearing joints, such as feet, knees, hips and spine. Other joints, such as finger and thumb joints, may also be affected. While approximately the same percentage of men and women have arthritis when all ages are considered, it affects them in different ways. The disease seems to affect women’s hands, knees, ankles and feet, whereas in men, the symptoms are more likely to appear in the hips, wrist and spine. Also, women are more likely to experience symptoms in more than one joint than are men.

What are the warning signs? The warning signs of arthritis include: pain in or around a joint; stiffness or problems moving a joint; swelling (sometimes) in a joint.

Many people with arthritis do not experience any symptoms in the initial stages of the disease. It often takes a long time for the disease to progress and the condition can remain stable for long periods of time.

Risk factors: The key risk factors for the development of arthritis are age, excess weight, injury and complications from other conditions, heredity and lack of physical activity.

Age: While age is not a cause of arthritis, this disease affects a very large number of seniors. You can’t stop the years from adding up, but you can improve the way your body ages by adopting a healthy lifestyle and making exercise a part of your everyday life.

Excess weight: Many studies have identified a link between obesity and arthritis. Excess weight puts extra stress on weight-bearing joints, especially the knees. A 10-15 lb. weight loss can reduce pain in the knees.

Injury and complications from other conditions: Arthritis can develop because of previous joint injuries or joint inflammation, hereditary joint conditions, or diseases that affect the joints (such as diabetes). Joint injury can also occur when joints are put under repetitive, high impact stress for long periods of time. Some specific exercises, sports or occupations may increase the likelihood of arthritis. For example, hand arthritis is more frequent among boxers, and elbow arthritis is more likely to develop in pneumatic drill operators.

Heredity: Some very specific types of arthritis can result from hereditary factors. Some families may pass on the tendency for defective cartilage; others may pass on slight defects in the way joints fit together.

Lack of physical activity: Arthritis symptoms such as pain, stiffness, fatigue and fear of harming oneself often lead people with arthritis to avoid exercise. Ironically, inactivity can worsen arthritis problems.

Prevention: While we are unable to change some of the factors which make one susceptible to arthritis, such as age, sex and heredity, it is possible to reduce the likelihood of developing this disease by adopting a healthy lifestyle that includes exercise (such as walking, cycling and swimming) to strengthen supporting muscles and maintain joint mobility. Weight control can also help reduce stress on the joints and spine.

Coping with arthritis

Alleviating pain: Medication can sometimes be used to alleviate pain. The application of heat can help relieve some of the joint pain and soreness, and the application of cold can help reduce swelling. Severe, advanced arthritis may be treated with surgery.

Reducing risk and progression: Protecting joints by avoiding excess mechanical stress in daily life is important. This can be accomplished by pacing tasks, using assistive devices such as canes, grab bars and larger handles, and by proper joint positioning.

For more information contact: The Arthritis Society; 1-800-321-1433; www.arthritis.ca Information is also available via Internet: www.canadian-health-network.ca; www.hc-sc.gc.ca www.phac-aspc.gc.ca; www.agenet.com.

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Stepping It Up: Moving the Focus from Health Care in Canada to a Healthier Canada By The Health Council of Canada; 2010 www.phac-aspc.gc.ca/seniors-aines

Determinants of health:

- Our health is affected by a broad range of factors called the determinants of health.

- These determinants include our income, our level of education, what kind of work we do, our relationships, our early childhood experiences, the safety and quality of our housing and communities, and other environmental factors.

- These factors which are outside the health care system have a strong impact on our health outcomes.

Income as a key determinant of health:

- Health care spending is expected to reach $192 billion in 2010. An estimated 20% of total health care spending may be attributable to income disparities.

- Canadians with the lowest incomes are more likely to suffer from chronic conditions such as diabetes, arthritis and heart disease, to live with a disability, to be hospitalized for a variety of health problems, to suffer from mental distress, and to die earlier.

- The rates of diabetes and heart disease among the poorest 20% of the population are more than double the rates of the richest 20% of the population.

- Low income people are twice as likely to use healthcare services as those with the highest incomes.

- A Saskatoon study found that low income residents consume 35% more health care resources than middle and high income residents.

- A Winnipeg study found that eliminating the gap between the poorest and wealthiest neighbourhoods would reduce heart attacks by 22% and hip fractures by 20%.

- International research indicates that to reduce the gaps in health, the health of the poorest 30%-40% of the population must be improved at a faster rate than the health of the rest of the population.

- Living with the chronic stress of disadvantage can have an effect on cardiovascular and immune systems. Over time this can leave people more vulnerable to chronic diseases and infections and mental health conditions like depression.

- The poverty rate in Canada is estimated at 11%, with rates being much higher for specific sectors of society lone-parent families (26%), work-limited people (21%), recent immigrants(19%), and off-reserve Aboriginal people (17%).

Child health issues are an important marker for overall population health:

- Research shows that supportive policies and programs that help to shape better living conditions can reduce the incidence of infant mortality and low birth weights.

- Infant mortality and low birth weight is worse in Canada than in many other developed countries such as Sweden, Norway, and Denmark.

- Infant mortality rates per 1000 live births: 5.3 in Canada, 2.4 in Sweden, 3.1 in Norway, and 4.4 in Denmark.

- Low birth weight infants per 100 newborns: 5.9 in Canada, 4.2 in Sweden, 4.8 in Norway, 4.9 in Denmark.

- Countries like Sweden, Norway, and Denmark are well known for their poverty-reduction policies and supportive programs such as extended parental leave, employment policies for parents who need retraining and support, a social safety net, and early childhood care and education.

International examples of successful health promotion programs and policies:

- Canada is falling behind other industrialized nations in categories such as poverty levels, the degree of inequality between the rich and the poor, and investments in social programs.
- United Kingdom: National goals set in 2002, included a reduction of inequalities in health outcomes by 10% by 2010 as measured by infant mortality and life expectancy at birth.
- There has been some success in reducing child poverty as a result of government's tax and benefit reforms.
- Norway: A key focus that emerged from the 2007 National Strategy to Reduce Social Inequalities in Health in Norway was the relationship between income and better health.
- Sweden: With a history of pursuing equality-oriented health and social policies, Sweden has focused on strengthening democratic participation, promoting security and well-being of families and reducing health inequalities. Its approach to public health based on social determinants of health is consistent with long-standing approaches to public policy. Sweden has low mortality rates, high life expectancy and favourable health indicators across all socio-economic groups.
- Australia: A world leader in addressing health inequalities,
- Australia has adopted a whole of government approach to health promotion. Activity, which includes ongoing health impact assessments, occurs primarily at the state level.

ACCESS Health is a publication of the Centre for Independent Living in Toronto (CILT) Inc. To become a member of the Peer Support Program or to submit an article to ACCESS Health, contact CILT at:

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ACCESS Health is also available in large print, on audiotape or by e-mail.

Funded by The United Way of Greater Toronto.