

An Environmental Scan and Commentary of Caregiver Supports for People Living with Episodic Disabilities

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This environmental scan focused on two objectives: 1) Compile an inventory of existing programs and supports available to family/friend caregivers generally and for caregivers of people living with an episodic disability; and 2) Identify best practices for family/friend caregivers of people with an episodic disability, nationally and internationally.

This environmental scan complements the literature review, *Supporting Caregivers of People Living with Episodic Disabilities*, that was completed by the above authors as part of the *Episodic Caregiver Support Initiative (ECSI)*. In addition to the literature review and environmental scan, this initiative also included key informant interviews and a needs assessment utilizing an on-line survey and focus groups with caregivers, people with episodic disabilities and service providers to learn more about the realities of caregiving needs.

In compiling the inventory of existing programs, the mandate of the environmental scan was two-fold: 1) To examine organizations, services and programs that may provide support to caregivers regardless of geographical location; and 2) To focus on three distinct geographical catchment areas in Ontario (Toronto, Thunder Bay and Guelph) that would be the target of the focus groups. These catchment areas have unique demographic and health profiles that are described at Appendices A (Toronto Central), B (Thunder Bay), C (Guelph) & D (health comparisons). Furthermore, the identification of programs and services specific to these catchment areas were also identified and are itemized in the inventory below.

Ultimately, the information gathered through the literature review, environmental scan, key informant interviews, surveys and focus groups was examined to help identify areas of convergence regarding service availability, as well as gaps.

¹ The ECSI partners gratefully acknowledge funding provided for this project by the Ontario Trillium Foundation.

General Comments About the Importance of Supporting Caregivers in Policy and Planning Agendas

Caregiving has increasingly been identified and acknowledged for the central role it plays in supporting the growing population of aging individuals and those with disabilities who require some care and services in order to live comfortably in their own homes and community (Sinha, 2012²). A fairly recent set of studies is bringing recognition to the particular social, emotional, financial and well-being needs associated with the role of being a caregiver (see the Literature Review).

The current reality is that the challenges of caring for aging seniors, particularly those with serious impairments such as dementia, dominates the political and resource landscape regarding family caregivers (Sinha, 2012; Health Council of Canada³). This project presents a unique and important opportunity to recognize and respond to the needs of people with episodic disabilities and their caregivers and to highlight those caregiving challenges that are common to other populations and those that are uniquely associated with episodic disabilities.

When conducting the environmental scan of available programs, it was evident how often resources are targeted to caregivers of the elderly. The general assumption when searching the Internet for care resources was that one is an **adult child** caring for an aging parent or a **spouse** caring for an ill and aging partner. The environmental scan revealed that there are many supports and provisions targeted to seniors that vary by program and service, but generally target individuals age 60 or older, with some granting provisions to individuals 55 or older. Younger people with episodic *degenerating* illnesses, as opposed to episodic *stable* conditions (see literature review for further discussion), may find that their disease trajectory warrants access to the types of caregiving services that are typically associated with elder care. Similarly, their caregivers are more likely to be “understood” and their needs recognized when they provide care that it is daily, intensive, and required.

Occasionally, there was recognition that caregivers may be assisting individuals with severe disabilities, typically children or family members with mental health conditions. Entitlement to supports, however, is often adjudicated by government funded service providers, such as Community Care Access Centres in Ontario, and is a function of the **degree** of disability. Persons with episodic disabilities, particularly in the early years, appear to reside in a gap where there are few or no services (other than those that are disease-specific) due to not being “disabled enough” to qualify.

² Sinha, S. K. (2012). Living Longer, Living Well: Highlights and Recommendations. Ontario: Ministry of Health & Long-term Care.

³ Health Council of Canada (2012, March). Seniors in need, caregivers in distress: What are the homecare priorities for seniors in Canada. http://www.carp.ca/wp-content/uploads/2012/04/HCC_HomeCare_2d.pdf

Both the fluctuating nature of symptoms and the uncertain trajectory of the condition for a particular individual can result in a form of “partial disability” that, in all likelihood, has kept the needs of those with episodic disabilities (for services, employment accommodations, and income security) and their caregivers off policy and planning agendas. These needs must be addressed by those, whose current attention is highly focused on the aging population -- needs that are better researched and understood and hence resourced.

The Canadian Caregiver Coalition (CCC) has identified five key domains for addressing the needs of caregivers:

1. **Educational** supports about the illness and about resources
2. **Employment and Education** supports to facilitate the dual work of earning and caring
3. **Financial** supports and supplementation when caregiving compromises paid work and to offset the additional costs typically associated with caring for someone with a disability
4. **Well-being** brings a focus to caring for the caregiver’s emotional and physical needs and the challenges associated with the benefits and burdens of providing care to others.
5. **Research** to support evidence informed decision-making

This commentary utilizes the first four of the five domains identified by the Canadian Caregiver Coalition to frame further discussion.

Comments about Educational Supports About the Illness

The Internet has transformed accessibility to information for much of the public. Access to disease-specific information is easily located by accessing disease-specific societies such as those for Multiple Sclerosis, Lupus, Huntington’s, Parkinson’s Disease or Rheumatoid Arthritis (see Inventory below). These sites provide information about the illness including the nature of the disease, likely prognosis and links and resources to further information.

The catchment areas under investigation all have disease-specific resources, primarily in the form of local support groups focused on the individual with the illness. Support groups for caregivers were not readily identified. Accessing care resources for family caregivers is a patchwork at best. The creation of regional Community Care Access Centres in Ontario has likely made things better than before their inception, but a focus on government funded services results in lack of a more comprehensive, clearinghouse approach as a link to all types of services (both government funded and private fee-for-service), particularly those that serve caregivers.

One option would be a provincial clearinghouse that coordinates the availability of services specifically for caregivers with links to local resources. Some attempt at this exists via thehealthline.ca, an Internet based search engine for community-based

resources, but most of the services are primarily aimed at the person with an illness. Similarly, modeled after 9-1-1 services, Ontarians can access the 2-1-1 service⁴ both by telephone and the Internet to find information about services. This requires some level of competence to navigate the multi-tiers of offerings and the ability to be able to have some knowledge to target one's search.

Information on Caregiving

In contrast to the disease-specific information discussed above, our scan of on-line resources tailored to help caregivers understand and cope with their role typically assumed that the caregiver is either an adult child caring for an aging parent or a spouse caring for a quite disabled, usually aging partner (e.g., Baycrest's Koschitzky Centre for Innovation in Family Caregiving; Mount Sinai Hospital's Reitman Centre CARERS Program).

Some organizations recognize the caregiver role and offer electronic resources and other materials specifically tailored to help caregivers understand their role and the stressors they face. The information in these resources is quite general, and highlights issues around the need for self-care, and finding ways to reach out for supports that may include fee-for-service paid care and/or from a wider network of family and friends.

Even within episodic disability-specific websites this environmental scan found virtually no information for caregivers in the **early years** or stages of living with an episodic disability. Consequently, available resources generally presuppose a more advanced level of disability and lack an acknowledgement of the physical, emotional and cognitive changes that a person living with an episodic disability may face, long before the advent of 'total' disability. Indeed, the period immediately after receiving a diagnosis has been identified as a critical time for providing information and support to the patient and their family/caregivers.

Similarly, most websites fail to acknowledge or orient potential caregivers viewing their site to the range of physical, emotional and financial challenges they will likely encounter. There was one notable exception. The MS Society of Canada warrants special recognition as a "best practice" for its intensive and active focus on caregivers. Their website provides a guide to caregiving, a newsletter, a caregiver network and numerous other resources.

Employment Supports

Employment supports, such as flex-time, reduced work hours, paid leave days, etc., generally come about in two ways: 1) through government legislation that requires employers to provide support and accommodations; or 2) by employers voluntarily recognizing employees' caregiving needs and accommodating them – either through company-wide policies and practices or as a result of individual managers making decisions on a case-by-case basis.

⁴ <http://www.211ontario.ca/>

Employers may find useful information for their workplace and caregiving employees in the *Toolkit for employers: Resources for supporting family caregivers in the workplace*, developed by the B.C. Family Caregiving Network Society.⁵ The toolkit provides two types of information: 1) information for employers, such as the impact of caregiving on the workplace, how to create a caregiving-friendly workplace and developing an action plan; and 2) resources to support caregiving employees such as types of care, on-line resources and developing a care plan. Caregivers are also supported when supportive workplace practices keep individuals with episodic disabilities actively employed, thereby increasing engagement and facilitating income. ESCI partner, The Canadian Working Group on HIV and Rehabilitation (CWGHR), has been at the forefront in making the business case for hiring practices that actively recruit and retain people living with episodic disabilities.⁶

Internationally, “right to request” legislation is also gaining traction. First implemented in the UK, the city of San Francisco recently passed the *Family Friendly Workplace Ordinance*, effective January 1, 2014. These “right to request” legislative initiatives usually require that employers make reasonable efforts to accommodate employees’ requests for flexibility to address caregiving needs, whether for young children or for aging or disabled family members. Furthermore, such legislation prohibits discrimination based on family/caregiving responsibilities and generally protects employees from being dismissed for having requested accommodation. Such initiatives may be limited to employers that have a certain number of employees (e.g., the San Francisco ordinance applies to employers with 20 or more employees). In Canada, the Canadian Human Rights Commission and the Ontario Human Rights Tribunal have affirmed the rights of employees to appropriate accommodations (non-discriminatory practice) based on family status, including caregiving responsibilities. Several recent court cases have been adjudicated in favour of employees, setting case law precedents.

In 2006, the federal government introduced **Compassionate Care Benefits** through the Employment Insurance system to enable family members to receive partial income replacement if taking leave to care for a gravely ill family member. On April 29th, 2014 Ontario gave royal assent to **Bill 21: The Ontario Family Caregivers Bill** (Employment Standards Amendment Act -- Leaves to Help Families). This legislation extends current provisions to allow 8 weeks of unpaid, job protected leave for individuals caring for a family member, 37 weeks for the caring of a critically ill child and 104 weeks following the crime related death or disappearance of a child. Importantly, Bill 21 recognizes the need for leave in cases when a family

⁵ <http://www.fcns-caregiving.org/wp-content/uploads/2013/11/Employer-Toolkit-Digital-Version-FINAL.pdf>

⁶ A win-win proposition: The business case for actively recruiting and retaining people with episodic disabilities. http://www.hivandrehab.ca/EN/episodic_disabilities/documents/The-Business-Case-for-Actively-Recruiting-and-Retaining-People_with_Episodic_Disabiliti.pdf

member is seriously (but not gravely) ill, and is more appropriate for a wider range of caregiving situations, including those involving a family member or close friend who may have an episodic disability.

Financial Supports

The challenges associated with the provision of government funded financial supports for those with an episodic disability and their caregivers were addressed in considerable detail in the literature review. The discussion focused on the general lack of income replacement and refundable tax credits associated with medical needs and care for those who are living with an episodic disability that is not considered to be a significantly severe and lasting impairment. The literature review also raised concerns about the impact that episodic disabilities can have on the ability to save for retirement, particularly noting the impact that this can have on the caregiver.

In Canada, a number of provinces have developed legislative responses to meeting the needs of caregivers. Nova Scotia provides a **Caregiver Benefit** of \$400/month to caregivers of low-income adults who have a high level of disability or impairment. This is unlikely to serve the needs of most caregivers addressing the needs of a person with an episodic disability, give the requirement of “high level of disability,” but may meet the needs of some caregivers who have reached that stage of care.

Since 2011, caregivers in Quebec may claim a refundable tax credit equivalent to \$775/year where they have provided unpaid care for a relative or person with whom they live and who is unable to live alone.

Caregiver Well-being

The environmental scan generated an abundance of resources. One of the on-going challenges in conducting the scan was distinguishing between whether a service or program is primarily designed to support the ill or aging individual or whether the program or service was designed primarily for the *caregiver*. Often times, the reality is that the provision of appropriate and responsive care services that support the ill individual can ‘indirectly’ reduce or eliminate some of the burdens on the caregiver (e.g., homemaking, nursing care, transportation etc).

Respite

When it comes to caring for the elderly and other profoundly disabled individuals who require daily intensive care, provisions for some respite care have risen to the fore as a highly available service. Numerous organizations in all three catchment areas have many respite services available. Cost is another issue, but one that is largely not discussed on the organizational websites. This gap leaves a caregiver to have to further to determine if respite would be covered through public health insurance or is a fee-for-service that must be funded directly by the caregiver/care recipient.

In the context of caring for someone with an episodic disability the topic of “respite” requires more nuance. Not all episodic disabilities require intensive caregiving. Yet, the added responsibilities of coping through various stages of an episodic disability may mean that there are many years in which an individual with an illness requires some support, but may not require constant vigilance/supervision or assistance with the tasks of daily living. This is not to say that caregivers do not feel the stress and weight of being available, worrying about the ill individual, or carrying out household tasks that may be beyond their strength or fatigue level. Simply stated, individuals with episodic disabilities may require accommodations and assistance, but the care needs are not such that respite in the form of “time away” is always necessary because the caregiver is unable to have undisturbed sleep, recreational time on their own or pursue work and leisure activities.

Certainly, if the illness progresses and care needs intensify, access to “time away” respite may be required. This scan suggests, however, that when the need arises these supports are available through numerous community resources, including funded assistance through Community Care Access Centres and numerous fee-for-service agencies that are widely available in all three catchment centres.

Conceptualizing respite as something more than “time away” (e.g., adult day programs, overnight care or in-home care) was the focus of an innovative three-year pilot project funded by the JW McConnell Foundation in 2003. This pilot project provided funding to eight organizations to explore and implement programs of respite. Conceived as a part of the larger project, *Care Renewal: Reaching out to Caregivers*, these organizations implemented various initiatives around building respite knowledge (see Building Respite Knowledge⁷).

The Meaning of Respite: This pilot project provided this: “Respite refers to caregivers’ physical, emotional, psychological, social and/or spiritual relief or renewal which results from anything intended to help them maintain their own health and achieve greater balance in their lives” (p. 8)

The MS Society of Canada was one of the eight service provider organizations to receive funding as part of this project. One of key features of the MS initiative was to recognize and fund “respite of choice” as defined by the caregivers. Small sums of money (usually only a few hundred dollars) were provided to caregivers to address what they needed: a subscription for theatre tickets, the purchase of plants, or a small inflatable pool for the backyard to serve both a healthy child and the ill parent for whom mobility was a challenge.

⁷ Building Respite Knowledge: A Knowledge Series on the Milestones of the Care Renewal Projects. Available at <http://www.von.ca/carer renewal/eng/pdfs/CareRenewalBuildingRespiteKnowledge.pdf>

Counseling for the Caregiver: Adjusting to the Trajectory of the Illness

There are numerous service organizations identified in the environmental scan that note the provision of counseling services. The literature review identified the work of Rolland (1999)⁸ who was at the forefront of discussing the impact that episodic disabilities have on the family system. One of his key recommendations was the importance of connecting the ill individual and their family/support network to counseling. It was identified that this should start at the time of diagnosis to help the individual and the “family” system (including ‘biological’ kin as well as ‘chosen’ kin) navigate the emotional, physical and relationship adaptations that will be necessary. Most critically, it was identified that counseling should not wait until a crisis stage, but rather be a resource that starts at diagnosis and is continually available “as needed” throughout the years as the disease progresses and on-going adaptations continue.

As discussed in the literature review,⁹ counseling for those facing episodic disabilities should not be treated in the same way as traditional “relationship counseling,” but rather should address the distinct challenges that the person living with the episodic disability and their close family and friends may face in coming to terms with the short and long term implications of their condition.

Counseling was identified by numerous organizations as a service that is provided. Usually only noting “individual, family or couples counseling;” it is unclear at this juncture whether these counseling services offer the therapeutic interventions identified as effective for episodic disabilities. This would require direct inquiry with the service providers in the next phase of this study.

Support for Specific Populations***Young Carers: The Need for Emotional and Educational Supports***

Young Carers are children under 18 years of age who are providing care to someone who is their usual “natural” caregiver (such as a parent or grandparent), but who is unable to do so because of illness or incapacitation (Miller, 2012, p. 8). Recognition of Young Carers is an emerging area of concern as they have typically been invisible and the consequences of their caregiving unacknowledged (Charles, Stainton & Marshall, 2012).

Canadian data identified that 12% of Canadian youth are stepping up to care; the data does not differentiate to what extent these children and youth are specifically assisting a parent or another adult who is living with an episodic disability, versus assisting a disabled sibling or aging grandparent. It is reasonable to speculate that episodic disabilities, due to their earlier on-set in the life-course, likely means that young carers are performing caregiver duties, both light and more intensive care.

⁸ Rolland, J. S. (1999). Parental illness and disability: A family systems framework. *Journal of Family Therapy*, 21, 242-266.

⁹ See page 13 of the Literature Review re Baucom et al’s. (2012) approach and Tompkins et al. (2013) “Relationship matters”

The needs assessment survey may not adequately reveal the extent to which this is taking place as Young Carers are often viewed as secondary to the primary adult carer (Baago, 2005).

The environmental scan identified several programs that have been developed to address the needs of Young Carers. This scan did not confine inclusion of resources solely by whether they were available within one of the three catchment areas.

Young Carers often have two critical sources of need: 1) Supporting them during their years of growing up when they are managing school, friends, extra-curricular activities and caring; and 2) Supporting young carers through young adulthood as they transition to post-secondary school, work and living on their own. Two notable initiatives in Canada address the unique needs of Young Carers by providing them support and time-away respite (e.g., summer camps): the *Young Carers Initiative* (Niagara) and the *Youth Caregivers Program* (BC). It is also worth acknowledging the proactive initiative of the UK wherein legislation was introduced requiring that care assessments include an analysis of need and provision of supports to Young Carers.

Supports for Education

Young Carers requires support with regards to education so they can succeed in school. Family Action UK¹⁰ has specifically researched this area of concern and has identified the invisibility of young carers in schools and amongst teachers. Furthermore, the lack of supports, policies and procedures to address their need for different expectations around attendance, behaviour, anxiety, fatigue, concentration and homework completion are not always well addressed, even within the UK that has made young carers a priority.

The 2013 Young Carers Action Canada Task Force has also identified the need for educational supports for Young Carers including¹¹:

- Creation of training workshops and educational packages for teachers and other educational professionals to better understand and address the needs of Young Carers in school
- Allocating a designated support person in every Canadian school
- Support programs to help teenagers transition from high school to post-secondary

Young carers also need supports for post-secondary education as they plan for their adult life. One of the concerns addressed in the literature review was the potential

¹⁰ Family Action. (2012). *Be bothered! Making education count for young carers*. United Kingdom. <http://www.family-action.org.uk/uploads/documents/Be%20Bothered!%20Make%20Education%20Count%20for%20Young%20Carers.pdf>

¹¹ *Who cares about young carers: Raising awareness for an invisible population*. <http://www.scribd.com/doc/124089317/Who-Cares-About-Young-Carers-Raising-Awareness-for-an-Invisible-Population>

for a compromised ability for a family to meet the financial needs of post-secondary education for their children when one or both parents have reduced their paid employment or left the work force – either as a direct result of illness or in order to provide care. The lack of transition to post-secondary education or inability to comfortably afford further education can hinder a young adult's transition to financial security and independence. An analysis of government programs with respect to disability usually focuses on income replacement. For children and their parents it is important to make them aware of opportunities to fund post-secondary in the event of low household income. The *Registered Educational Savings Plan* (RESP) and accompanying *Savings Grant* furnishes families with up to 20% per year for each \$2500 contribution made by the individual/family. For very low income families, the *Canada Learning Bond* contributes up to \$2000 over 15 years with no required contribution. These can be important savings tools when families know about them. To access these plans the child requires a Social Insurance Number and the RESP plan can be opened through most financial institutions.

There are also additional programs for funding post-secondary including provincial loans (e.g., Ontario's Student Assistance Plan), Ontario's 30% off tuition, and various federal tax relief initiatives, such as tax credit on loans, the Education Tax credit and textbook tax credits. It is suggested that ensuring that families are aware of their options is a key for helping Young Carers plan for their future.

Men as Caregivers

The challenges that men experience as caregivers are largely unacknowledged. As the literature review outlined, men are often reluctant to share their personal feelings about the challenges they face when assuming the caregiver role. Men may find that they simply don't have the necessary skills around laundry, cooking or housekeeping. They may also struggle with the changes in their spouse/partner and yet not know how to, or be able to easily reach out to express their own grief and frustration. This inability to reach out may also compromise their willingness to seek out services and supports that can relieve their caregiver burden, but most importantly allow them to access the emotional and relationship supports they need for their own social-emotional well-being. It has been advocated that men need distinct types of supports that meet them within their own levels of comfort. There were few services specifically tailored for men. The Alzheimer's Society of Toronto offers a cooking class for men. One noteworthy on-line resource was the *Male Caregiver Community*, a US based forum geared to men and their caregiving experiences. In addition the "Caring" website included an article on male caregiving.¹²

¹² <http://www.caring.com/articles/the-male-caregiver>

BEST PRACTICES

Recognizing caregivers' needs and making various supports easily accessible should be the primary objective of supportive caregiver practices. A critical oversight in understanding the needs of caregivers has been that the health system and social service agencies have tended to only identify the care recipient as their client, overlooking the central and equally important role of the caregiver (Keefe, Guberman, Fancey, Barylak, & Nahmiash, 2008¹³).

Manitoba recently enacted *The Caregiver Recognition Act* (effective December 5, 2013) legislating that caregivers need to be acknowledged, researched, and supported. The purposes of this Act are:

- (a) To increase recognition and awareness of caregivers;
- (b) To acknowledge the valuable contribution they make to society; and
- (c) To help guide the development of a framework for caregiver recognition and caregiver supports.

The first Tuesday of April in each year is proclaimed as Caregiver Recognition Day. Most critically, this legislation mandates that an inventory, description and analysis of caregivers' needs in regards to existing government and other caregiver supports be conducted and made available to its citizens. This is similar to efforts in the UK and Australia, which have focused on "caring for the carer." In Vermont, the *National Family Caregiver Support Program* was legislated into effect under the Older Americans Act Title III E. It is funded and administered through the Vermont Department of Disabilities, Aging and Independent Living and local Area Agencies on Aging. Access to respite resources and other supports is limited to those caring for individuals who are 60 years or older or under 18 years of age and meet criteria regarding severity of disability. While innovative, there would be a gap in addressing the needs of those with moderately disabling episodic disabilities.

Evidence-Based Practice

At the forefront of evidence-based practice is the Rosalynn Carter Institute for Caregiving (RCI)¹⁴ located in Georgia, U.S. The focus is on researching and utilizing evidence-based practice for offering counseling and ***tailored*** support programs for caregivers, both family and professional.

Tailored programming is also the hallmark of the *Reitman Centre for Alzheimer's Support & Training Centre* at Mount Sinai Hospital, Toronto. Focusing on the behavioural challenges associated with various types of dementia, the program's cornerstone premise is that the tasks and coping associated with caregiving have

¹³ Keefe, J., Guberman, N., Fancey, P., Barylak, L., & Nahmiash, D. (2008). Caregivers' aspirations, realities, and expectations: The CARE Tool. *Journal of Applied Gerontology*, 27(3), 286-308. doi: 10.1177/0733464807312236

¹⁴ <http://www.rosalynncarter.org/>

similarities, but also differences due to the ways in which dementia presents. The CARERS Program (Coaching, Advocacy, Respite, Education, Relationship, & Stimulation) seeks to address a wide array of needs and supports by offering one-on-one training sessions.

Similarly, the *Koschitzky Centre for Innovations in Family Caregiving*, associated with the Toronto Baycrest Centre for Aging, is at the forefront of providing care and resources to caregivers. Limited primarily to caregivers of the elderly, it stands as a model for linking supports for the person in need of care and supports for the caregiver within an organization that more proactively responds to, and facilitates access to resources.

Caregiver Assessments

Caregiver assessments are increasingly being identified as a necessary component of providing care to the individual. In many jurisdictions, particularly in the UK, caregiver assessments are mandated as part of the overall strategy in providing care. These assessments are designed to assess the physical, emotional and financial resources of the caregiver with the aim that supports and resources can be targeted to ameliorate caregiver stressors and strains (including for Young Carers).

A well-established instrument that has been used widely in Canada and worldwide is the *Resident Assessment Instrument-Home Care* (RAI-HC). In addition to assessing the needs of the care recipient, the RAI-HC is also used to identify caregiver distress, defined as “the overall impact of physical, psychological, social and financial demands of caregiving.”

The RAI-HC identifies caregiver distress if one or both conditions exist:

- i) A caregiver is unable to continue in caring activities, for example due to decline in the caregiver’s health; and/or
- ii) The primary caregiver expresses feelings of distress, anger or depression.

One of the gaps for those caring for individuals with episodic disabilities may be that assessments, such as the RAI-HC, are administered only when the person living with an episodic disability is severely disabled enough to be “in the system.” One of the biggest gaps is that caregivers of people with an episodic disability may only be acknowledged when the illness/disability reaches a significant threshold. In other words, until such time as the need for care services reaches a sufficient level of intervention, it is unlikely that most caregivers are likely to be surveyed about their needs.

CONCLUSIONS

Caregivers are no longer invisible. Certainly, in response to the foreshadowed crisis that is expected with our rapidly aging population, there has been a more concerted effort in Ontario and elsewhere to move caregiving to the forefront of supports and services agendas. As a result, there are many services available locally, nationally and internationally that can provide supports for caregivers and recognize the role of caregiving more broadly. Respite, in the form of time-away, is an example. But certainly innovative programs are also recognizing that caregivers need tailored training to meet the needs of the care recipient, particularly in the face of complex needs and dementia. There is also recognition of the need for psycho-social supports in the form of counseling and information about how to cope with the stressors and strains associated with caregiving.

There are, however, significant limitations when it comes to addressing the needs of caregivers of people living with episodic disabilities, particularly when they are not quite disabled “enough” and/or are not yet considered to have reached the threshold of a senior (anywhere from 55+ to 65+). These caregivers, and it is argued, the individual with the episodic disability, are largely absent from the way in which most caregiving supports are currently constructed, advertised and allocated. There is no doubt that once the person living with an episodic disability reaches both age and severity thresholds that supports are available, but what happens before that time is largely unknown.

Appendix A: Toronto Central LHIN¹⁵

The Greater Toronto Area (GTA) is a vast area to inventory. For the purposes of this Environmental Scan, the Toronto Central LHIN was selected as the area of focus. As a medical hub for Ontario, Toronto Central has the unique distinction of serving many patients who reside in other LHINs. It also has the distinction of being the LHIN with the most educated population as well as the LHIN with the greatest proportion of low-income residents.

- 1.195 million people live within the Toronto Central (TC) LHIN – 8.9% of the population of Ontario
- 54% of patients in TC LHIN hospitals and 55% of patients who see family physicians in the TC LHIN **reside in other LHINs**
- Immigrants: 41% of residents are immigrants; 8.3% arrived between 2001-2006
- Visible minorities: 32.5% in 2006
- 170 languages and dialects are spoken in Toronto
- 4.5% of the population reports no knowledge of either official language
- Aboriginal Identity: 19,265 - one of the largest Aboriginal populations in Canada. Aboriginal people in the city tend to have poorer health at a younger age than the general population
- Highest **educated** population in Ontario: 70% have completed post-secondary
- Highest **low-income** population in Ontario: 24% (considerably higher than rate for all of Ontario at 14.7%)

Toronto Central LHIN Boundary Map



¹⁵ Toronto Central LHIN. (2013). Partnership in action: Building a loyal health system for all: Annual Report 2012/13. Available at [http://www.torontocentrallhin.on.ca/uploadedFiles/Home_Page/Report_and_Publications/Annual%20Report%202012-2013%20English\(3\).pdf](http://www.torontocentrallhin.on.ca/uploadedFiles/Home_Page/Report_and_Publications/Annual%20Report%202012-2013%20English(3).pdf)

Appendix B: Thunder Bay -- North West LHIN¹⁶

The North West LHIN serves a diverse, and geographically sparse population outside its largest regional centre, Thunder Bay, which contains 52.6% of the population served by this LHIN.

- Large Aboriginal population: 19% (Highest of the LHINs)
- Small population of visible minorities: 1.9%
- Higher than average Francophone population: 3.5%
- Completed post-secondary: 55% (Lowest of the LHINs)
- Relatively low rate of low-income: 11% (3rd lowest of the LHINs)
- Higher than average rates of diabetes and mental health/addiction issues
- Highest rate of Chronic Conditions of Ontario LHINs (42%) (see Appendix D)
- Serves evacuees from more northern, isolated communities that have faced inhospitable conditions due to flooding or forest fires.

North West LHIN Boundary Map



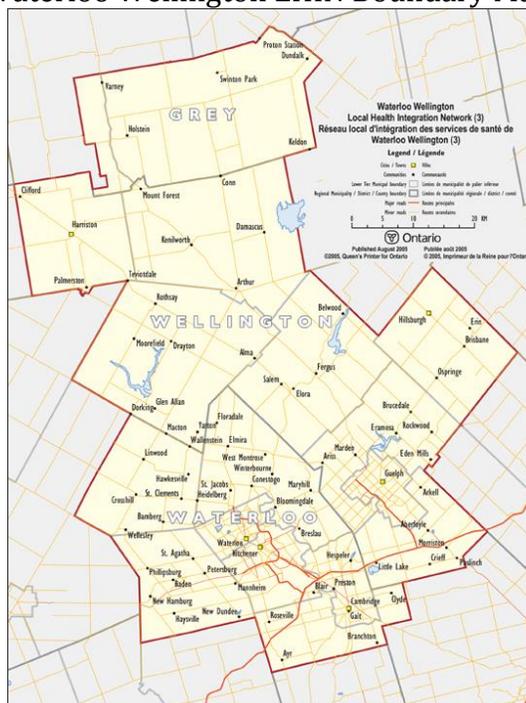
¹⁶ North West LHIN. (2013). Creating healthy change: 2012-2013 Annual Report. Available at http://www.northwestlhin.on.ca/uploadedFiles/Home_Page/Report_and_Publications/Annual_Reports/20131210-Creating-Healthy-Change-2012-2013-Annual-Report%20ENGLISH.pdf

Appendix C: Guelph -- Waterloo Wellington LHIN¹⁷

The City of Guelph, with an approximate population of 120,000, is part of the much larger Waterloo Wellington LHIN (See boundary map at Appendix C) that serves 775,000 residents¹⁸.

- Guelph has a well educated population – 62% completed post-secondary
- The city has an economic base that is served by both business and post – secondary educational institutions
- 65+ years: 13.4%
- French first language: 1.6%
- Immigrants 26,825 (20.2%)
- Self-identify as Aboriginal: 1,355
- Unemployment rate is 5.1% (below the provincial average of 6.4%)
- Live below the Low-Income Cut-Off: 7.6%

Waterloo Wellington LHIN Boundary Map



¹⁷ Waterloo Wellington LHIN. (2013). Leading a high quality, integrated health system for our residents: Annual Report, 2012-2013. Available at http://www.waterloowellingtonlhin.on.ca/uploadedFiles/Public_Community/Accountability/Home_Page/Board_of_Directors/Annual%20Report%202012_2013_FINAL.pdf

¹⁸ Population Health Profile: Waterloo Wellington LHIN (n.d.). Available at http://www.waterloowellingtonlhin.on.ca/uploadedFiles/Public_Community/Accountability/Home_Page/About_Our_LHIN/Population%20Health%20Profile_December%202013.pdf

APPENDIX D: Health Condition Comparisons for the Catchments**Rates of Illness and Chronic Conditions for Ontario and Three LHINs (%)**

<i>Condition</i>	<i>Ontario</i>	<i>Waterloo Wellington (incl. Guelph)</i>	<i>North West (Thunder Bay)</i>	<i>Toronto Central</i>
Arthritis	17.0	14.0	22.2	14.7
Cancer	1.9	1.4	1.1	1.7
Asthma	8.0	7.7	7.3	9.0
Diabetes	6.9	7.0	7.3	5.8
Chronic Conditions	37.0	33.0	42.0*	32.6
Multiple Chronic Conditions	15.0	13.9	18.0	13.6

* The highest rate for chronic conditions in Ontario