

# EPISODIC CAREGIVER SUPPORT INITIATIVE

## 2014 Final Report



Canadian Working Group on HIV and Rehabilitation  
Groupe de travail canadien sur le VIH et la réinsertion sociale



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## EXECUTIVE SUMMARY

The Episodic Caregiver Support Initiative (ECSI) was launched in the fall of 2013 as a yearlong developmental grant funded by the Ontario Trillium Foundation to explore the needs of family / friend caregivers of individuals with episodic disability in Ontario. An important aspect of this work was also to increase awareness of episodic disability throughout the province. This report provides an overview of the work and the lessons learned by the project partners.

The ECSI activities began with understanding the needs of those caregivers who support individuals with an episodic disability. The activities involved a review of the literature, a survey of caregivers and persons with episodic disabilities, and in-person focus groups in order to get a deeper understanding of the challenges unique to this subset of family / friend caregivers. The goal of the one-year developmental grant was to develop a preliminary model / framework that responds to the support needs of caregivers of people living with episodic disabilities in Ontario with the intent to encourage policy makers to consider and implement the next steps to improve caregiving in the province.

We are grateful to the many people who came forward to share their experiences - through the survey, focus groups, and key informant conversations. While the stories are not of hardship, they illustrate how caregiving often places additional and unimaginable burdens on people. The family / friend caregivers we met were always interested in enabling caregiving to continue, believing the variety of caregiving activities to be human, personal and essential.

Words are important and we found many different interpretations to words and assumptions as to meaning. The following are definitions of several key terms.

**“It’s not all about more services, rather a shift in social values.”**

Survey respondent

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*Individuals living with episodic disability and their caregivers have remained largely invisible and absent from current policy developments despite evidence that more than 1 million Canadians have an episodic health condition.*

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Episodic disabilities encompass a variety of “complex chronic illness conditions with different trajectories: **Episodic Stable** conditions are characterized by periods of relative wellness interspersed with unpredictable and fluctuating periods of acute illness, such as severe migraines, **Episodic Degenerating** conditions are similar to Episodic Stable conditions early on, but over time there is progressive decline, such as with Parkinson’s Disease, and **Episodic Remissive** conditions may start as Episodic Stable, but in some instances the person experiences full recovery / remission, such as with some mental health conditions” (Whitehead and Lero 2014b, p1).

The onset of episodic disabilities in young adulthood or midlife and the long-term, unpredictable and fluctuating nature of these illnesses yields challenges for caregivers that are both similar and different to those experienced by those who care for a person with a long-term disability or aging-related conditions. Caregivers can face distinct challenges in being called on to care by virtue of their age (young caregivers), gender (male), other caregiving responsibilities (usually women with children) and the difficulties of balancing paid work or school with caring. Caregiving may be very different for episodic stable conditions, with care needs that are fluctuating and unpredictable, but possibly lasting for decades. For those managing a degenerating episodic disability, the overall trajectory of decline may eventually lead to high care needs and associated higher caregiver burdens.

Caregiving in the context of episodic disability changes the nature of personal relationships, including the addition of stress and altered communication patterns. Additionally caregiving responsibilities may interfere with paid employment, compromise the parenting of children, or inhibit the ability to plan for the future, including saving for retirement.

Individuals living with episodic disability and their caregivers have remained largely invisible and absent from current policy developments despite evidence that more than 1 million Canadians have an episodic health condition. 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.

Drawing on the lessons learned from this project a model was developed to depict how caregivers need to be supported to address the life domains most impacted by their caregiving of a person living with episodic disability: education / information; job security and flexibility; income adequacy and security; health services; emotional wellness; and social supports. The outcomes are realized when we, as a society, have shifted our behaviours – those areas that need to be strengthened - in order to better support family / friend caregivers of people living with an episodic disability.

The importance of caregivers as a resource to the people they care about and within our health care system is clear. Some of the needs of caregivers to individuals living with episodic disabilities are very similar to those who care for the elderly. As such, this group of individuals needs access to information, emotional support and practical resources in their communities in order to sustain their capacities and maintain the quality of family / friend care. But there are unique characteristics that must be considered when setting policy and practice in order to be inclusive of all family caregivers.

## KEY RECOMMENDATIONS

There is a role for everyone in improving the supports for all family / friend caregivers. **On behalf of family / friend caregivers of people living with episodic disability** we make the following recommendations to policy makers, caregiving advocates and others who are supportive of moving this work forward:

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### WELLNESS

- Acknowledge that family / friend caregiving is a distinct circumstance for which physical, mental and emotional wellbeing should be regularly assessed. The assessment should be used to build the person's capacity through education and access to services, which are available as needed.
- Provide increased respite opportunities in order to address assessed need and recognize that the need could be as simple as providing support with household chores to providing hands on care.
- Recognize the need for individually-tailored emotion-focused caregiver supports.

### EDUCATION

- Improve education and awareness regarding caregiving as an activity of younger persons for people living with an episodic disability that often means that the needs are minimal and other times intensive and can fluctuate unpredictably.

- Provide better access to information about how to get help to deliver care and to learn about services and care options.
- Introduce family caregiving as part of the primary school curriculum.

### FINANCIAL

- Improve caregiver access to financial resources, including financial and tax incentives, that are currently restricted to only those who provide care to the elderly or people living with a permanent disability.
- Consider tax incentives such as allowances and refundable credits that recognize families / friends who provide care at home.

### HEALTH CARE

- Facilitate access to needed extended drug and health care supports to help caregivers maintain a high standard of physical and emotional health.
- Provide increased training to workers within the health care

system to facilitate early identification of caregiver needs and intervention in times of caregiver strain.

### EMPLOYMENT

- Increase flexible work options to recognize the fluctuating and unpredictable needs of caregivers of people living with episodic disability.
- Consider implementing caregiving leaves and employee assistance plans that address the caregiving issues of those caring for people living with an episodic disability.

### SYSTEM COORDINATION

- Reduce the barriers to programs and support services by improving and stabilizing program funding for caregivers and addressing obstacles such as hours of operation, location, disease specific requirements and age restrictions.
- Reduce the number of individual assessments required to access public and community-based services.

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While we have not ascribed responsibility to any particular level of government or sector, it is our hope that the champions of family / friend caregivers and those working in the areas of episodic disability will build on and incorporate our findings and recommendations in order to advance the policy agenda. As a society, we need to work collectively toward creating an environment where family / friend caregivers are honoured for their contributions. We encourage policy makers, professionals connected to caregivers in the diverse array of circumstances and the broader public to adopt these recommendations within their sphere of influence.

# BACKGROUND

*Nearly half of Canadians aged 15 years and older have provided care to a family or friend with a long-term condition, disability or aging need. The support of family and friends reduces the demands on health care and social systems and allows people with various conditions, including episodic disabilities, to remain at home.*

## THE BIG PICTURE

Caregiving has become a major focus on the public policy agenda in Canada as the large cohort of boomers undertakes responsibility for aging parents and anticipates their own needs for care. Acknowledging this imperative, the federal government announced in the 2014 budget the Canadian Employers for Caregivers Plan to better support employees balancing both work and caregiving responsibilities. In Ontario, the government passed the 'Leave to Help Families' Act which provides working Ontarians up to eight weeks of unpaid time away from work in order to provide care of a family member.

Nearly half of Canadians aged 15 years and older have provided care to a family or friend with a long-term condition, disability or aging need (Sinha 2013, p3). The support of family and friends reduces the demands on health care and social systems (Sinha 2013) and allows people with various conditions, including episodic disabilities, to remain at home.

The purpose of the Episodic Caregiver Support Initiative (ECSI) was to understand the needs of those caregivers who support individuals with an episodic disability. The activities involved a review of the literature, a survey of caregivers and persons living with episodic disabilities, and in-person focus groups in order to get a deeper understanding of the experiences unique to this subset of family / friend caregivers. Specifically, the goal of the one-year developmental grant was to develop a preliminary model that responds to the support needs of caregivers of people living with episodic disabilities in Ontario.

## TERMINOLOGY

Words are important and therefore necessary to address up front. We found many different interpretations to words and assumptions as to meaning. A full list of definitions relevant to this initiative is at Appendix A.

**Episodic disability** is a term used to describe a variety of different chronic illness conditions such as HIV / AIDS, severe migraines, multiple sclerosis, lupus, diabetes, Parkinson's disease, and certain forms of arthritis, cancer, and mental health conditions (Furrie 2010). Almost half of working adults with a disability have at least one of these conditions (Furrie 2010). Features that distinguish episodic disabilities from traditional disabilities include the unpredictable trajectory,

1. A complete list is found in Appendix B



Focus Group participants expressed varying degrees of comfort with the term caregiver. *“Like a lot of people in my community I had to hide what is going on in my household.”*

alternating episodes and degrees of illness and wellness, the invisibility of illness-related symptoms and the general ambiguity of the disability. People with episodic disabilities are often young and middle-aged adults and can live for 50 years or more with the disability, which in turn impacts the length of time, nature, and demands of caregiving (Canadian Working Group on HIV and Rehabilitation 2012).

The significant variation in symptoms and illness progression that may occur means that these illnesses have unique disease-dependent trajectories that can be classified into three categories: **Episodic Stable** (have periods of relative wellness interspersed with unpredictable and fluctuating periods of acute illness; **Episodic Degenerating** (early on the illness shares the same features as an Episodic Stable condition, but over time there is a progressive physical decline; and **Episodic Remissive** (starts as Episodic Stable, but in some instances the person experiences full recovery / remission such as with some mental health conditions) (Whitehead and Lero 2014b, p1).

**Caregiving** involves the actions taken to provide care for their family member or friend. These tasks may include providing transportation, housework, house maintenance and outdoor work, scheduling and coordinating appointments, managing finances, helping with medical treatments, providing personal care, social and emotional support, and mediation with formal organizations and service providers (Sinha 2013).

**Caregivers**, who may also be referred to as “informal caregivers”, “primary caregivers” and “carers”, are the family members and friends who provide care and assistance for spouses, children, parents and other extended family friend members and friends who are in need of support because of age, disabling medical conditions, chronic injury, long-term illness or disability (Canadian Caregiver Coalition 2008).

Many caregivers do not identify with the term “caregiver” but may still be experiencing challenges related to episodic disability and caregiving. Other possible terms may include ‘family’ or ‘support’. It is important to note that although these terms are used by health and social service systems, family and friends may or may not identify themselves as caregivers (MacCourt and Krawczyk 2012). For the purpose of this initiative these individuals are referred to as **family / friend caregivers**.

Participants repeatedly told us that people do not understand caregiving until they have “walked in those shoes”. As a result, the caregiving experience can be isolating, frustrating, and painful. As one participant said, it is a “wildly busy financially and health challenging time”. Prior to each focus group, one or more participants inquired to learn if their circumstances were a fit with the type of ‘caregiver’ outlined in the project description.



.....  
*People do not understand caregiving until they have “walked in those shoes.”*  
.....


### **LINKING EPISODIC DISABILITY & FAMILY / FRIEND CAREGIVING**

The nature and extent of care and assistance that is required may be linked to the type of episodic disability (including the type of associated medical, physical and emotional needs), as well as the trajectory of the illness. Some illnesses fluctuate from better to worse and back to better (Episodic Stable), while other illnesses typically progress to a stage involving more intensive caregiving (Whitehead and Lero 2014b, p2).

*Family / friend caregivers’ ability to meet the demands of caregiving is influenced by three aspects:*

- 1) The personal resources of the caregiver, including financial, personal skills and qualifications, and time invested to deliver caregiving supports.
- 2) The characteristics of the care receiver including severity of the symptoms of the disability, living arrangements and personal attributes.
- 3) The health, social, legal and tax systems and connected policies, procedures and practices that may be more or less inclusive of the caregiver with individual needs (Whitehead and Lero 2014b, p2).

**Concerns about the resilience of caregivers arise when the demands of caregiving exceed the caregiver’s emotional, physical and financial resources and ability to access support.** (Lero et al. 2007; Turcotte 2013)



**The needs of the care recipient dominate discussions and responses of family / friend caregivers and are linked to the needs of the caregiver. When asked about *their* needs, caregivers always spoke about the need for care, service, assistive devices, medication and so on for their family member.**

# IMPLEMENTATION

In order to work towards the development of a useful model of caregiving in the context of episodic illness for the province of Ontario, consultation focused on three communities in Ontario. These communities, Thunder Bay, Toronto and Guelph, provided a representation of the diversity of geographies and communities sizes across the province.

## **ENVIRONMENTAL SCAN**

The environmental scan consisted of a literature review (Whitehead and Lero 2014c) and through a review of existing programs (Whitehead and Lero 2014a), the identification of best practices in current programs, services and policies. This work showed that there are unique aspects of episodic disabilities that have implications for family members and friends who provide support, including those who become caregivers.

The nature and extent of care and assistance that is required may be linked to the type of episodic disability (including the type of associated medical, physical and emotional needs), as well as the trajectory of the illness. Some illnesses fluctuate from better to worse and back to better (Episodic Stable), while other illnesses typically progress to a stage involving more intensive caregiving (Whitehead and Lero 2014b).

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 2013; Health Council of Canada 2012). "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

## **NEEDS ASSESSMENT**

The needs assessment served to validate and / or clarify findings from the environmental scan and consisted of two parts: an online survey and focus group discussions.

### **ONLINE SURVEY**

The purpose of the survey was to understand the experiences of family / friend caregivers of people with episodic disabilities either in the past or currently. Respondents were asked to provide personal perspectives and experiences and invited them to comment on system improvements to better address their needs. A total of 130

individuals opened and initiated the survey. Eighty-nine chose at least one of the five categories of respondents:

- A caregiver (past or present)
- A person living with an episodic disability
- A provider of health or social services
- A provider of services specific to individuals with episodic disability
- Other

Many chose more than one category, which is reflective of the prevalence of complex, multiple roles present in the lives of caregivers.

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 individually-determined psychosocial supports in the form of counseling and information about how to cope with the stressors and strains associated with caregiving” (Whitehead and Lero 2014a, p 13).

“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” (Whitehead and Lero 2014a, p13) that meet standards for accessing supports by the time that many feel a need to reach out for help, circumstances are often quite challenging.

## WHAT WE LEARNED

Participants were generous with their time and in sharing their experiences and thoughts about how to make things better. Through the research and the stories, we came to understand a little better the breadth of challenges that family / friend caregivers address. We witnessed motivation rooted in compassion, caring and duty. The suggestions for a better future were thoughtful and typically modest - a caregiver recognition day, a thank you, a little flexibility. There was much more however. We learned that there was much that the broader social systems and we as a society could do in order to better demonstrate the value we intrinsically place on caregiving.

## FOCUS GROUPS

The focus group sessions allowed a deeper discussion with family / friend caregivers as heard through their experiences and recommendations. Sessions were held in each of the identified communities - Thunder Bay, Guelph and Toronto. The primary question for the sessions was: ‘*What if Ontario offered the best supports in the world to family / friend caregivers of people living with episodic disability?*’ A total of 21 participants drew on their experiences to discuss what would need to happen to realize a vision of an Ontario where family / friend caregivers of people living with episodic disability felt well-supported and understood.

Other project activities also included conducting an evaluation of the project; and, increasing awareness about caregiving of those with episodic disabilities. The *logic model* detailing the work of the initiative is at Appendix D. Model development was an iterative process involving feedback from key informants, building on the learnings from the *environmental scan and needs assessment*.

## UNIQUE ASPECTS OF CAREGIVING IN THE CONTEXT OF EPISODIC DISABILITY

“The nature and extent of care and assistance that is required is closely linked to the type of episodic disability (including the type of associated medical, physical and emotional needs), as well as the trajectory of the illness. Some illnesses fluctuate from better to worse and back to better (Episodic Stable), while other illnesses typically progress to a stage involving more intensive caregiving” (Whitehead and Lero 2014b, p1). Additionally the characteristics of episodic disabilities have implications for family members and friends who provide support, including those who become caregivers. The unique aspects of episodic disability include the following:

- **“Early onset** - Often conditions become evident in early adulthood to mid-life” (Whitehead and Lero 2014b, p1).
- **“Traumatic** - The diagnosis of an episodic disability often marks a sharp and sudden demarcation in the life-course – before and after diagnosis” (Whitehead and Lero 2014b , p1). The change in family roles and responsibilities coupled with uncertainty are prime reasons that caregivers believe counseling and peer support programs to be important services that would support them in their roles.
- **“Fluctuating periods of acute illness / flare-ups** - The illness is punctuated with times of flare-ups that may require acute medical care and periods of recuperation until eventually settling into a new ‘normal’ or plateau until the next flare-up” (Whitehead and Lero 2014b ,p1).
- **“Unpredictable trajectory** - Uncertain future: Many episodic disabilities follow an uncertain and unpredictable trajectory. Both caregivers and service providers may not be able to forecast when specific types of care and assistance will be required” (Whitehead and Lero 2014b, p1). Many of respondents identified this as a key challenge impacting their ability to plan for the future.
- **“Invisible and ambiguous disability** - In many instances, the person living with an episodic disability will exhibit few overt symptoms. Employers, friends and family may be unaware of the illness or may not be sympathetic to reports of fatigue or other ‘vague’ symptoms associated with illness” (Whitehead and Lero 2014b, p1). Family / friend caregivers reported feeling stigmatized and considered to be abusing time off work in order to care.
  - **“Off-time caregiving** - An episodic often leads to caregiving that is not part of the normal expected life course pattern because onset is during young adulthood or middle age. Consequently, caregiving is more likely to involve care and assistance provided by a young carer (under 18 years); a young adult enrolled in post-secondary education or starting work; and / or by a partner during the period of adulthood when one is still also working, paying a mortgage, planning for retirement and / or raising children. Financial support and assistance with financial

“During my sister’s big episode, I wasn’t able to work for a couple of weeks. I was too stressed out, too emotional – huge toll emotionally and very stressful. Returning to work was pretty bad too. Nobody really understood that and it wasn’t something anybody wanted to talk about.”

Focus group participant



planning were identified as a key need by caregivers” (Whitehead and Lero 2014b, p1).

- **“Ongoing adaptations** - The unpredictable, fluctuating and possible degenerating aspects of episodic disabilities require that the individual, the caregiver and other close members of the family system continually adapt, sometimes over many decades, to the physical, emotional, cognitive and financial changes that the illness generates” (Whitehead and Lero 2014b, p2).
- **Variability of caregiver needs** - differences from person to person and community to community.
- **Long-term** - caregiving which often spans years or decades.

## THE IMPACT OF EPISODIC DISABILITY ON DIFFERENT CARE RELATIONSHIPS

The impacts that episodic disability caregiving has on the caregiver is **influenced by the type of relationship** that the caregiver shares with the person living with the episodic disability, as well as the intensity of support required. Typically, the most intensive caregiving typically provided by a spouse / partner (Whitehead and Lero 2014b, p2).

**Women** continue to provide more hours of care, are more directly involved, and are often assumed to be the primary caregiver, whether as a spouse / partner, daughter, or mother. Women also are more likely to experience employment and longer-term financial consequences, as well as potential costs to their own health and social well-being (Whitehead and Lero 2014a, p2).

The interconnected emotional, physical and financial ties of a partnered relationship can result in big changes for a **spouse / partner**: emotionally, financially and potentially, the loss of a co-parent. Partners will face having to redefine the couple relationship and make accommodations for the illness. There are also more immediate as well as long-term financial implications that the episodic disability will generate. Some of these aspects resemble those experienced by caregivers for seniors (e.g., taking time away from work), but are more intense and complicated



for caregivers of an episodic disability because of the impact over a much longer period of the life course which can leave many feeling alone and disconnected from their social systems and communities for unknown periods of time (Whitehead and Lero 2014b, p2).

**Men** are increasingly active in caregiving however, statistically less likely to be caregivers than women. Society’s expectations of men in many cultures can create acute role strain due to unfamiliarity with the tasks and intensity of the caregiving role. “Men are also less likely to reach out for support. While the research is mixed, there is evidence that there are higher rates of partner separation / divorce when the ill partner requiring care is female. Men have unique needs in adapting to the caregiving role and require a careful assessment of required supports, including peer supports and counseling” (Whitehead and Lero 2014b, p2).

The timing of an episodic disability means that **children and youth** are more likely to be pressed into caregiving duties. Depending upon the extent of their caregiving responsibilities, young caregivers can experience hindered growth and development, and limited time for interactions with peers and extra-curricular activities. Caregiving duties can also interfere with school, homework, and opportunities to attend post-secondary education, and can potentially compromise the transition to adulthood. Health and related service agencies need to be sensitive to the needs of young caregivers and acknowledge their

efforts with the goal of addressing their needs for tailored supports (Whitehead and Lero 2014b, p3).

“Generally, **friends and extended family** tend to provide less time and less intensive caregiving than close family members, but can provide important social support, both to the person with an episodic disability and to caregivers. They are less likely to be impacted financially” (Whitehead and Lero 2014b, p3).

## ACCESS TO SUPPORTS

Resources are often targeted to caregivers of the elderly. “The general assumption when searching for care resources is that one is an **adult child** caring for an aging parent or a spouse caring for an ill and aging partner. 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” (Whitehead and Lero 2014a, p2).

“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 for care themselves, never mind their family / friend caregiver” (Whitehead and Lero 2014a, p2).

There are many disease specific programs for care recipients and family caregivers. For many, a generic or linking of programs would improve access that can

be compromised by distance, hours of operation, technology or diagnosis. Family / friend caregivers were mixed as to the merits of support using technology such as chat rooms, remote monitoring, and webinars, with some emphatically preferring face to face contact to access professional supports.

Excessive bureaucracy can compromise good programming. Caregivers reported having to repeatedly tell their story, complete paperwork and lose important gains because of short-term programs and staff turnover. While acknowledged as somewhat unavoidable, greater efforts to communicate information at times of transition between programs or staff and the support of a navigator were seen to be potentially useful in improving access to support for family / friend caregivers.

## THE NEED FOR UNDERSTANDING

Many hesitated over the term ‘caregiver’ as a role in need of support as they saw it as their human responsibility. The boundaries of normal family support and family caregiving can be difficult to distinguish. Some expressed that culturally to seek help for family matters was not comfortable. Others reported extensive caregiving responsibilities and yet being excluded from the ‘circle of care’ and as a result not directly informed on care issues.

Notwithstanding the hesitancy in role definition, most family / friend caregivers recognize that they were not prepared for their caregiving responsibility. Not surprisingly, the needs caregivers typically seek to have addressed are information and education about how to support the health and well-being of the care recipient and the types of services that are available. Many feel guilty seeking respite and mental / emotional health supports.

Repeatedly, family / friend caregivers said that they wanted to be recognized, their work affirmed. A ‘caregiver awareness day - like mothers’ day’ was suggested. All participants said they were encouraged that the discussion was happening.

## THE IDEAL SYSTEM

Participants acknowledged a need to (re)create a more humane system that makes allowances for the health vicissitudes that happen with episodic disability illness episodes. The ideal system would offer practical supports, including emotional support to help manage the emotional strain resulting from ongoing long-term caregiving. The caregiver experience can be traumatic and necessitate professional support. However, caregivers tend to forego their needs, feeling guilty if they take time away and not wanting to spend their very limited (and uncertain future) emotional resources on themselves.

In a perfect system, caregivers, who are typically isolated, would benefit from outreach services in person, the merits of web-based support being mixed amongst the participants. The approach would be more proactive thereby addressing barriers such as language, time, culture, awareness of resources and reluctance to self-advocate, before a crisis occurs.

There would be effective triaging and access to care for the caregiver and the care recipient. As participants stated, "If you don't know anybody, then you don't know anything". In Waterloo-Wellington region, the mental health providers have coordinated access to service through one intake system with live 24 hour telephone support. This is a promising practice that is intended to improve access, triaging and service.

Ongoing financial support was a common priority need identified as financial insecurity can further destabilize strained family dynamics and increase the experience of stress. It was suggested that temporary, low cost accommodations be provided for caregivers who relocate to support a family/friend; that subsidies for housecleaning, meal preparation, transportation service be provided; that immigration be fast tracked so family caregivers who have relocated from another country are not compelled to return home.

Education and awareness to sensitize people to family caregiving was identified as highly important to an ideal system for family caregivers. Recognizing that people need to care for one another as part of the human context, it was suggested that there needs to be a shift from the typical crisis based approach. This approach means that when family caregivers struggle - they may access primary care for symptom relief, i.e. call on EMS for assistance in the home when other services would be appropriate or they isolate themselves.

*"Redefine the criteria [for access to financial / employment support]. They could have a very bad year and then they could have a really good year. The fact is, it's up and down. If they need financial help, they are going to be precluded from it because in our case they aren't disabled 365 days in a row. It just doesn't make sense."*

*Survey respondent*

**"Everyone of us here could fall into that role, right?"**

Focus group participant





It was suggested that children sense that their family dynamic is altered and are not inclined to speak about their circumstance. The school system could introduce programming that increases awareness, fosters discussion and normalizes caregiving - "it's not if you will become a family caregiver, it is when."

## STAGES OF CAREGIVING

The trajectory for the person living with episodic disability is not predictable and as such the caregiving role fluctuates from less to more intensive and back again. The visual on the next page demonstrates **stages of caregiving**: infrequent, intermittent, chronic, transitional, and end-of-life.

As we learned, depending on the stage of caregiving, the needs and supports vary. For example,

**when caregiving is infrequent**, family / friends are more likely to benefit from proactive outreach (wellness), regular hours and understanding (employment), access to tax credits (financial) and information about services that are available (education).

At the other end of the caregiving continuum, **end-of-life, caregiving is more intense**. Family / friend caregivers need respite (wellness), protected leaves / compassionate care benefit (employment), financial planning support (financial), and understanding (education).

"Caring for a family member is part of what it means to be a family member. It is not interference. There are many life experiences that influence work and studies, caring and caregiving is just one type."

Survey respondent

While general in nature and cognizant that each caregiver has unique experiences and needs, the visual on the next page shows how different services become more important as the family / friend caregiver moves through the caregiving stages. Awareness about caregiving transcends all stages of caregiving and speaks to the need for broader understanding, acceptance and honoring this important role as a normal part of life.



# FRAMEWORK FOR SUPPORT PROGRAMS FOR FAMILY / FRIEND CAREGIVERS OF PEOPLE LIVING WITH EPISODIC DISABILITIES



EPISODIC STABLE	STAGE 1 INFREQUENT CAREGIVING	STAGE 2 INTERMITTENT CAREGIVING	STAGE 3 CHRONIC CAREGIVING	STAGE 4 TRANSITIONAL	STAGE 5 END-OF-LIFE CAREGIVING
EPISODIC DEGENERATING EPISODIC REMISSIVE	Few needs - care integrated into routines	Care demands can be intense for short periods	Daily care needs - more predictable routine	Full-time caregiving & /or more professional support	Full-time caregiving
NEEDS	<b>1. WELLBEING</b>				
ACCESS TO HEALTH CARE	<b>Primary Care Support</b> <ul style="list-style-type: none"> <li>Proactive outreach</li> <li>Regular caregiver checkups - physical, mental &amp; emotional</li> </ul>		<b>System Navigator / Coordinator</b> <ul style="list-style-type: none"> <li>Advocate</li> <li>Individualized caregiver assessment</li> <li>Referrals to caregiver support group &amp; services for both and each of caregiver &amp; person with episodic disability</li> </ul>		
SUPPORT	<b>Responsive Services</b> <ul style="list-style-type: none"> <li>24x7 response to crises - of caregiver &amp; / or person with episodic disability</li> <li>Equipment &amp; supplies</li> <li>Address eligibility to supports</li> </ul>				
SOCIALIZATION					<b>Respite</b> <ul style="list-style-type: none"> <li>As an outcome</li> <li>At home to allow caregiver to go out</li> </ul>
<b>2. EMPLOYMENT SUPPORTS</b>					
Maintain employment	<b>Capacity</b> <ul style="list-style-type: none"> <li>Regular hours</li> <li>Competency</li> </ul>	<b>Flexible employment practices</b> <ul style="list-style-type: none"> <li>Job sharing</li> <li>Flex hours</li> <li>Remote work stations</li> </ul>		<b>Protected Leave</b> <ul style="list-style-type: none"> <li>Family Caregiver Leave in Ontario</li> <li>Compassionate Care Benefit at EOL</li> </ul>	
Supportive work environment	<b>Understanding</b> <ul style="list-style-type: none"> <li>Awareness</li> <li>Genuine belief in person's situation</li> </ul>	<b>Caregiver Friendly Policies &amp; Practices</b> <ul style="list-style-type: none"> <li>Knowledgeable staff</li> <li>Compassionate work environment</li> <li>Leave sharing practices</li> <li>Caregiving leave benefits</li> </ul>			
<b>3. FINANCIAL / LEGAL</b>					
Economic security	<b>Funding</b> <ul style="list-style-type: none"> <li>Tax Credits / allowances to offset cost supplies, home modifications, lost time at work, lost CPP, RRSP contributions</li> </ul>				
Support for altered life course	<b>Financial Planning</b> <ul style="list-style-type: none"> <li>Support to manage change in family income</li> <li>Scenario planning considering altered life span projections &amp; / or change in needs</li> </ul>				
Health care preparedness	<b>Care Planning</b> <ul style="list-style-type: none"> <li>Wills</li> <li>Advance Care Planning / Substitute Decision Maker</li> </ul>				
<b>4. EDUCATION / INFORMATION</b>					
Confidence	<b>Information</b> <ul style="list-style-type: none"> <li>Services - what's available, entitlements</li> <li>Training on delivering care</li> <li>Understanding how &amp; when to empower person with episodic disability</li> <li>Disease specific resources</li> </ul>				
Fear, Stigma	<b>Awareness</b> <ul style="list-style-type: none"> <li>Normalize caregiving in society - schools, work, communities</li> <li>Changing social values</li> <li>Cultural sensitivity</li> <li>Political leadership</li> </ul>				

# DEVELOPING A MODEL / FRAMEWORK

*“Redefine the criteria [for access to financial / employment support]. They could have a very bad year and then they could have a really good year. The fact is, it’s up and down. If they need financial help, they are going to be precluded from it because in our case they aren’t disabled 365 days in a row. It just doesn’t make sense.”*

Survey respondent

## IDEAL MODEL FOR FAMILY/FRIEND CAREGIVER SUPPORT

This initiative worked towards the development of an ideal model of supports for caregivers of people with episodic disabilities. Summing it all up in a picture was an iterative process that involved reviewing what caregivers told us, what we found in the literature and pulling it together. The model below shows how caregivers need to be supported to address the life domains most impacted by their caregiving of a person living with episodic disability: education / information, job security and flexibility; income adequacy and security, health services, emotional wellness and social supports. The outcomes are realized when the work is done, when we have shifted our behaviours as a society. In the middle are the system behaviours toward family / friend caregivers that need to be strengthened including:

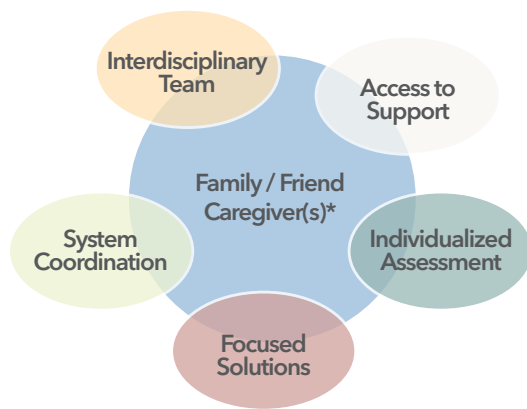
- 1. Interdisciplinary Team** - includes health, social and community members as determined by the caregiver. Examples include primary care, a system navigator, caregiver support services (disease specific and general), employer human resource staff, faith-based practitioner, or counsellors.
- 2. Individualized Assessment** - a regular check up is envisioned whereby the physiological, psychosocial and mental needs of the caregiver are assessed as distinct from the person with episodic disability.
- 3. Focused Solutions** - that address the diversity of needs recognizing the unique circumstances of the caregiver. This includes publicly funded programs that

flow through Local Health Integration Networks (LHINs) and third party insurance / benefit programs.

- 4. System Coordination** - caregivers need services that are timely and responsive. Assessments, services and resources that are used or have been accessed need to be coordinated in order to avoid duplication by those supporting the caregiver and unnecessary repeating of background information by the family / friend caregiver.
- 5. Access to Supports** - 24x7 access, in person or online. Distance needs to be minimal recognizing that caregiver time may be limited. Supports need to be continuous and yet recognize that caregiver participation will be as episodic, fluctuating according to the caregiving needs. Consideration must be made for backfilling responsibilities so the caregiver can attend and support travel to and from services.

Guiding the behaviours are principles of integration, cultural sensitivity, effective communication and client-centredness. Applying the Model for Ideal Support for Family / Friend Caregivers of People Living with Episodic Disability.

The image on the top of the next page shows the types of services that may be required by caregivers depending on their circumstances and stage of caregiving. The shape is intended to convey that various services will be needed to a greater or lesser extent as needs change.



### MODEL FOR IDEAL SUPPORT FOR CAREGIVERS OF PEOPLE WITH EPISODIC DISABILITY

#### Key Caregiver Life Domains

- Education / Information
- Job Security & Flexibility
- Income Adequacy & Security
- Health Services
- Emotional Wellness
- Social Supports

#### Guiding Principles

- Integration
- Cultural Sensitivity
- Effective Communication
- Client-centred

#### Outcomes

- Confident caregivers
- Caregiving recognized as valid and normal part of life
- Ability to maintain education / employment trajectory
- Adequate Respite
- Proactive & Responsive supports
- Consistency of caregiver support

\* Family / Friend Caregivers are closely linked to the needs of the person with episodic disability whose needs change over time and who have unpredictable and episodic care trajectories. These can be classified as episodic stable, episodic degenerative and episodic remissive.

## CONCLUSION

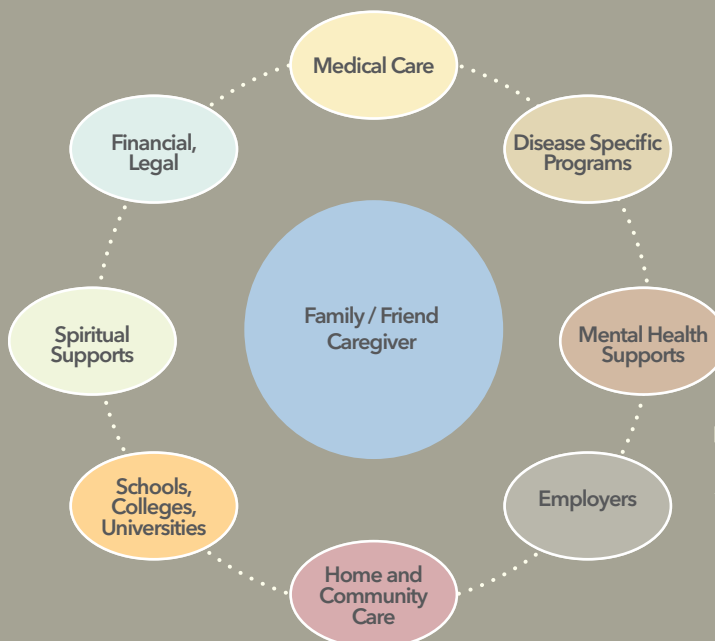
There is no doubt that well-supported family caregivers can play a facilitative role in the journey of their ill relative and in the improvement of their quality of life (MacCourt, Family Caregivers Advisory Committee, and Mental Health Commission of Canada, 2013). For those supporting people living with an episodic disability, the life course can suddenly and dramatically change **from day to day**. As a society we need to acknowledge this important caring role and do what we can to mitigate the stressors.

While we have not ascribed responsibility to any particular level of government or sector, it is our hope that the champions of family / friend caregivers and those working in the areas of episodic disability will build on and incorporate our findings and recommendations in order to advance the policy agenda. We encourage policy makers, professionals connected to caregivers in the broad and diverse array of circumstances to undertake to advance these recommendations within their sphere of influence.

As a society, we need to work collectively toward creating an environment where family / friend caregivers are honoured for their contributions. There is a role for everyone.

### APPLYING THE MODEL FOR IDEAL SUPPORTS FOR FAMILY/FRIEND CAREGIVERS OF PEOPLE LIVING WITH EPISODIC DISABILITY

The image below shows the types of services that may be required by caregivers depending on their circumstances and stage of caregiving. The shape is intended to convey that various services will be needed to a greater or lesser extent as needs change.



### POTENTIAL INTERDISCIPLINARY TEAM SUPPORTS FOR FAMILY / FRIEND CAREGIVERS OF PEOPLE WITH EPISODIC DISABILITY SUPPORTS IN ONTARIO

In concert with the Model for Ideal Support, a multiplicity of persons, determined to meet the unique and changing needs of the caregiver(s), functions as a team providing an accessible, coordinated approach, and offering solutions based on individualized needs determined through a caregiver assessment.

The support of family/friend caregivers must be guided by principles of integration, culturally sensitive practice, effective communication and client-centeredness.

The approach to support is in the context of the life domains and intended to achieve the listed outcomes.

Support needs and services will be required uniquely and will fluctuate and intersect with caregivers as each caregiver circumstances dictate.

#### SERVICES FOR CAREGIVERS COULD INCLUDE:

- CCAC • Counsellors • Guidance Counsellors • Hospital
- Human Resources / EAP • Illness-Specific Programs • Legal Aide Clinics • Nurse Practitioners • Physician(s) • Public Health • Self-Help Groups • Specialists • System Navigator • Teachers

# APPENDIX A

## DEFINITIONS

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**Advisory Committee:** includes seven organizations and other members as agreed to by those identified in the proposal (Canadian Working Group on HIV and Rehabilitation 2012) The role is to provide overall direction, guidance, partnership opportunities, support with dissemination of results, identify new resources and strategies for sustainability. (Canadian Working Group on HIV and Rehabilitation 2012).

**Caregiving:** involves the actions taken to provide care for their family member or friend. These tasks may include providing transportation, housework, house maintenance and outdoor work, scheduling and coordinating appointments, managing finances, helping with medical treatments, providing personal care, social and emotional support, and mediation with formal organizations and service providers. (Sinha 2013).

**Caregivers:** are the family members and friends who provide care and assistance for spouses, children, parents and other extended family friend members and friends who are in need of support because of age, disabling medical conditions, chronic injury, long-term illness or disability (Canadian Caregiver Coalition 2008).

**Episodic Disability:** used to describe a variety of different chronic illness conditions such as HIV / AIDS, severe migraines, multiple sclerosis, lupus, rheumatoid arthritis, cancer, diabetes, Parkinson's disease, and certain mental health conditions (Furrie 2010). Features that distinguish episodic disabilities from traditional disabilities

include the unpredictable trajectory, alternating episodes and degrees of illness and wellness, the invisibility of illness-related symptoms and the general ambiguity of the disability. People with episodic disabilities are often young and middle-aged adults and can live for 50 years or more with the disability, which in turn impacts the length of time nature and demand of caregiving (Canadian Working Group on HIV and Rehabilitation 2012).

**Family:** relatives, friends and significant others whom the person with episodic disability defines as family, including same-sex partners (MacCourt and Krawczyk 2012).

**Key Informants:** individuals identified by the project team as having knowledge or expertise relevant to the work of the initiative.

**Local Health Integration Network (LHIN):** LHINs are 14 not-for-profit organizations responsible for planning, integrating and funding local health services in 14 different geographic areas of Ontario. LHINs were founded base on the idea that community-based care is best planned, coordinated and funded locally by the people living in the communities.

**Partners:** generic term for an individual, group or organization active in the provision of health and / or social care to individuals with episodic disabilities and / or their family / friend caregivers

- **Local Community Partners:** e.g. CCAC, service organizations, family caregiver groups

- **Provincial Partners:** organizations with a provincial mandate and interest in serving individuals with episodic disabilities and family / friend caregivers.

**Project Participants:** individuals and organizations that actively contribute to the initiative by participating in activities including responding to surveys, participating in focus groups or interviews, disseminating information.

**Project Team:** staff and / or consultants retained by the organizations identified in The Ontario Trillium Foundation proposal, The Canadian Working Group on HIV and Rehabilitation (CWGHR), the Centre for Families, Work & Well-Being at the University of Guelph; the Ontario Home Care Association; the Ontario Episodic Disability Network; and, Health Gateway.

**Rehabilitation:** Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination (GTA Rehab Network 2014).

**Staff:** individuals employed by the members of the Project Team.

**Stakeholders:** beneficiaries of the project that can include people living with episodic disabilities, caregiver networks, employers, policy makers and others (Canadian Working Group on HIV and Rehabilitation 2012).

2. A complete list is found in Appendix B A complete list is found in Appendix B.



# APPENDIX B

## LIST OF 27 EPISODIC DISABILITIES

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*ALS (AMYOTROPHIC  
LATERAL SCLEROSIS)*

*ARTHRITIS*

*ASTHMA*

*CANCER*

*CHRONIC BRONCHITIS*

*CHRONIC FATIGUE SYNDROME*

*DIABETES*

*EMPHYSEMA*

*EPILEPSY*

*FIBROMYALGIA*

*GUILLAIN-BARRE SYNDROME*

*HEPATITIS B*

*HEPATITIS C*

*HIV/AIDS*

*LONG-TERM PAIN*

*LUPUS*

*MAJOR DEPRESSION*

*MENIERES DISEASE*

*MOOD DISORDERS*

*MULTIPLE SCLEROSIS*

*MUSCULAR DYSTROPHY*

*PARKINSON'S DISEASE*

*PERSONALITY DISORDERS*

*REPETITIVE STRAIN INJURY*

*SCHIZOPHRENIA*

*SEVERE MIGRAINES*

*TUBERCULOSIS*

# APPENDIX C

## PROJECT PARTNERS

---

**Canadian Working Group on HIV & Rehabilitation (CWGHR)** - national multi-sector and inter-disciplinary organization that brings together a broad range of stakeholders with an interest in HIV, episodic disabilities and rehabilitation within Canada and internationally. <http://www.hivandrehab.ca/EN/>

**Centre for Families, Work & Well-Being** - University of Guelph - an innovative, interdisciplinary research and educational centre responding to dramatic changes in family patterns, paid work, and broader economic and political structures. <http://www.worklifecanada.ca>

**Home Care Ontario** - non-profit membership association representing providers of quality home care

services from across Ontario. OHCA is a founding member of the Ontario Caregiver Coalition (OCC) and partner of the CCC. Supports the advocacy to help raise awareness of family caregivers. <http://www.homecareontario.ca/public/>

**Ontario Episodic Disability Network (OEDN)** - a coalition of organizations interested in issues facing people in Ontario living with episodic disabilities. The OEDN facilitates information sharing among participant organizations and people living with episodic disabilities at the provincial level to promote coordinated initiatives and strategies. This network collaborates on research, advances public policy, and promotes broad integration to strengthen episodic disabilities activities in the province.

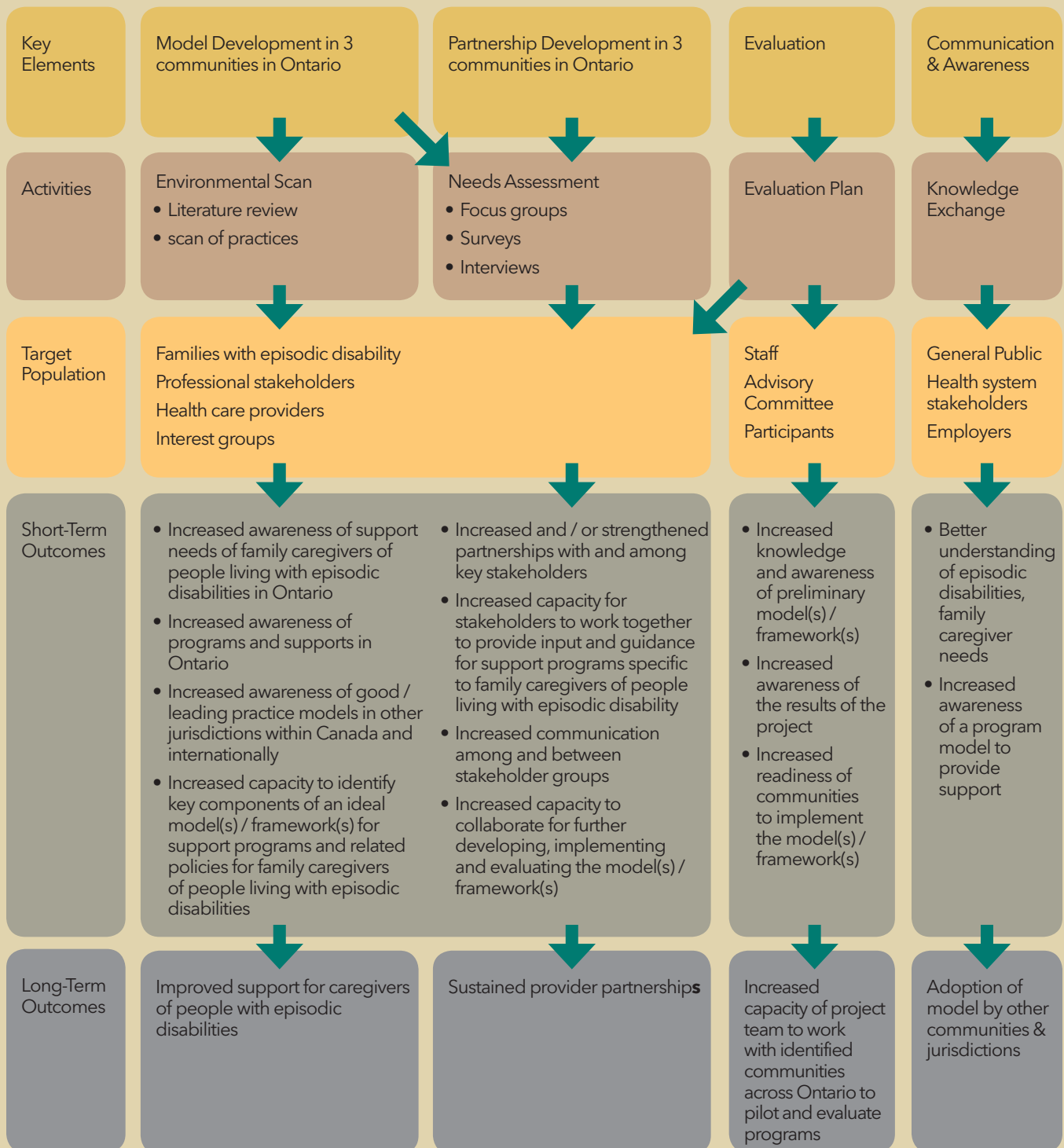
CWGHR is in the secretariat position for this network. [http://www.hivandrehab.ca/EN/episodic\\_disabilities/episodic\\_disabilities\\_network.php](http://www.hivandrehab.ca/EN/episodic_disabilities/episodic_disabilities_network.php)

**Health Gateway** - an e-library that facilitates access to important information that people need to manage their health and daily living needs including housing and employment information, income support, equipment, services, support and funding. It links users to a broad range of information from vetted and approved websites. Health Gateway is the product of collaboration between Bridgepoint Health and CWGHR and was initially funded in part by the Ontario Trillium Foundation and Sun Life Financial. <http://www.healthgateway.ca>

# APPENDIX D

## EPISODIC CAREGIVER SUPPORT INITIATIVE LOGIC MODEL

**Mandate:** To establish a model to address the needs of caregivers of people living with episodic disabilities in Ontario.



# APPENDIX E

## ADVISORY COMMITTEE & KEY INFORMANTS

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### ADVISORY COMMITTEE

**Tammy Yates**, CWGHR

**John Stapleton**, Open Policy

**Donna Lero**, University of Guelph

**Sue VanderBent**, Home Care Ontario

**Denise Whitehead**, University of Guelph

**Marg McAlister**, MMC Consulting

**Allie Peckham**, University of Toronto

**Melissa Popiel**, CWGHR

**Wendy Porch**, CWGHR

The Advisory Committee greatly acknowledges the in-kind support provided by Epilepsy Toronto, Woodgreen Community Services and Revera Home Health

### KEY INFORMANTS

**Molly Carpenter**, Caregiver Advocate, Home Instead Senior Care

**Rhonda Feldman**, Ph.D., C.Psych. Mental Health Clinician The Cyril & Dorothy, Joel & Jill Reitman Centre for Alzheimer's Support and Training & the Outpatient Geriatric Psychiatry Clinic Mount Sinai Hospital

**Lisa Levin**, Vice President, Communications and Development, Circle of Care and Chair Ontario Caregiver Coalition

**Neil Pierce**, President Alberta & Northwest Territories Division & National Vice-President, Government Relations & Volunteer Engagement, MS Society of Canada

**Bonnie Schroeder**, MSW, RSW

**Sherri Torjman**, Vice President, Caledon Institute of Social Policy

**Linda Cook**, BSN, MN, PhD, RN, CPMHN(C), Nursing Faculty, MacEwan University

# APPENDIX F

## REFERENCES

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Canadian Caregiver Coalition. 2008. A Framework for a Canadian Caregiver Strategy. Ottawa, Ontario: Canadian Caregiver Coalition.

Canadian Working Group on HIV and Rehabilitation, "Ontario Trillium Foundation (OTF) Grant Application" Toronto, Ontario, 2012.

Furrie, A. 2010. Towards a better understanding of the dynamics of disability and its impact on employment.

GTA Rehab Network. What is rehabilitation? 2014 [cited 01/05 2014]. Available from <http://www.gtarehabnetwork.ca/what-is-rehabilitation>.

Health Council of Canada. 2012. Seniors in need, Caregivers in distress: What are the home care priorities for seniors in Canada? Toronto, Ontario: Health Council of Canada.

Lero, D., N. Keating, J. Fast, G. Joseph, and L. Cook. 2007. The interplay of risk factors associated with negative outcomes among family caregivers: A synthesis of the literature. Available from <http://www.worklifecanada.ca>

Local Health Integration Networks. Frequently asked questions. 2014 [cited 08/20 2014]. Available from <http://www.lhins.on.ca/faq.aspx>.

MacCourt, P., Family Caregivers Advisory Committee, and Mental Health Commission of Canada. 2013. National guidelines for a comprehensive service system to support family caregivers of adults with mental health problems and illnesses. Calgary, Alberta: Mental Health Commission of Canada.

MacCourt, P., and M. Krawczyk. 2012. Supporting the caregivers of seniors through policy: The caregiver policy lens. Vancouver, British Columbia: British Columbia Psychogeriatric Association.

Government of Canada. The Road to Balance: Creating Jobs and Opportunities. 41st Parliament, 2nd sess. Budget 2014 (2014).

Legislative Assembly of Ontario. Family Caregiver Leave in Ontario, an Act to Amend the Employment Standards Act, 2000 in Respect of Family Caregiver, Critically Ill Child Care and Crime-Related Child Death

Or Disappearance Leaves of Absence. Chapter Number: S.O. 2014 C.6. Parliament 41, 1st sess., Leaves to Help Families (2014).

Sinha, M. 2013. Portrait of caregivers, 2012. Ottawa, Canada: Statistics Canada, Catalogue no. 89-652-X.

Turcotte, M. 2013. Family caregiving: What are the consequences. Ottawa, Canada: Statistics Canada.

Whitehead, D., and D. Lero. 2014(a). An environmental scan and commentary of caregivers supports for people living with episodic disabilities. Toronto, Ontario: Canadian Working Group on HIV & Rehabilitation.

Whitehead, D. and D. Lero. 2014(b). Executive summary: Supporting caregivers of persons with episodic disabilities. Toronto, Ontario: Canadian Working Group on HIV and Rehabilitation.

Whitehead, D. and D. Lero. 2014(c). Supporting caregivers of people living with episodic disabilities. Toronto, Ontario: Canadian Working Group on HIV and Rehabilitation.





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FOR MORE INFORMATION ON THE  
EPISODIC CAREGIVERS SUPPORT INITIATIVE  
PLEASE CONTACT THE CANADIAN WORKING GROUP  
ON HIV AND REHABILITATION (CWGHR)

1240 BAY STREET, SUITE 600  
TORONTO, ON M5R 2A7  
+1 416 513-0440 OR AT [INFO@HIVANDREHAB.CA](mailto:INFO@HIVANDREHAB.CA)  
[WWW.HIVANDREHAB.CA](http://WWW.HIVANDREHAB.CA)