

EPISODIC CAREGIVER SUPPORT INITIATIVE

2014 Executive Summary



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



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Fondation Trillium de l'Ontario

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.

A photograph of a man with short brown hair, wearing a brown crew-neck sweater over a white t-shirt. He is smiling broadly, showing his teeth, and looking down at a document he is holding. The background is a soft-focus indoor setting.

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

Survey respondent

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.

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:

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.

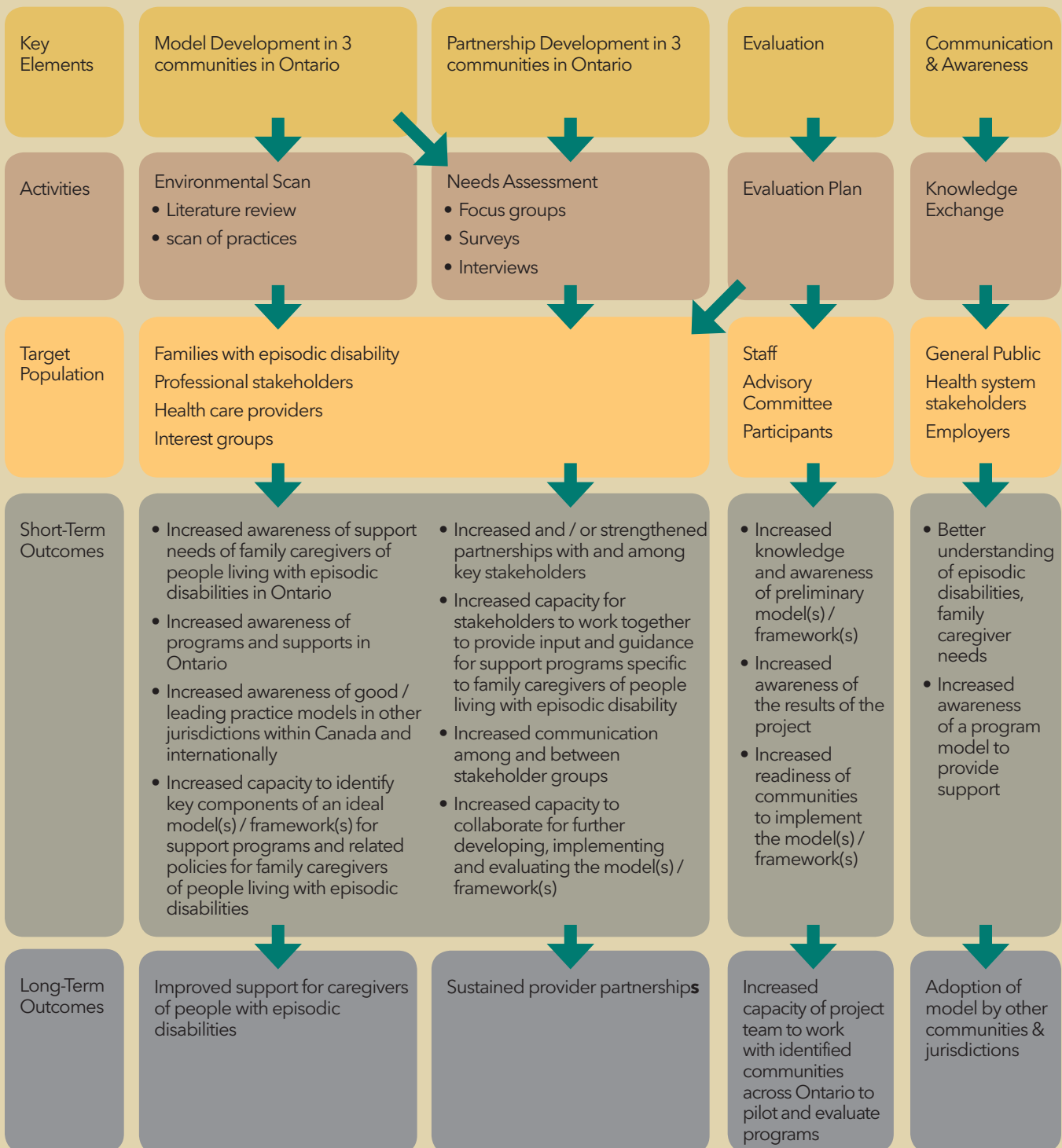
SYSTEM COORDINATION

- 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.

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.

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.



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REFERENCING

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