

Putting Young Carers on the Map!

Ella Amir PhD
AMI-Quebec
514 486 1448
www.amiquebec.org

Who is a Young Carer?

A young carer is anyone (typically under the age of 25) providing substantial unpaid caregiving to a family member with an exceptional need. Short or long-term, including an illness, disability, mental health issue, addiction, language or cultural barrier, or other unique situations.

Prevalence

1.18 million youth (15-24 years old) were providing some level of unpaid care to family members with a chronic illness, disability, mental health or substance use issue and/or problem related to old age in 2006; representing a 13.5% increase from 1996

(Statistics Canada census data, 2012) (Stamatopoulos, 2015)

What have **we** done?

Despite the central role young carers occupy in public policy and social service programming in other countries, very little attention has been paid to these youth in Canada, with no dedicated policies acknowledging their care-work

International Perspective

- 2007 Global Analysis on national levels of young carer awareness ranges from *emerging* to *advanced* (Becker, 2007)
- **The UK the only country that holds an ‘advanced’ position**
- Canada would fall in the ‘preliminary’ stage due to very little national awareness and no dedicated legislative supports

(Stamatopoulos, 2015)

The Young Carer movement in the UK

Foundational body of research on youth-based caregiving emerged in the late 1980's and has grown to constitute the most advanced young carer movement in the world (Becker, 2007)

What did the UK do that others have not done?

1. Widespread national awareness and recognition of young carers (public, professionals, policy makers)
2. The breadth of nationally dispersed social service programming (whole family approach, >350 dedicated YC projects serving aprox. 30,000 Ycs)

3. Support from the national legislative body (Carers Act: assess a carer's needs based on *appearance* of need; refer YCs to support services in their area or direct payments in lieu of services)

What Holds Canada Back?

- * No mention in any official or legal documentation regarding the role youth play in supporting their families
- * Lack of wider public awareness
- * Lack of dedicated young carer supports (1 in 14 YC receive support in the UK; 1 in 944 in Canada)

The Current Canadian Experience

- * The origin of the Canadian initiative traced to a small group of service providers recognizing the unmet needs among youth in vulnerable families
- * The wider national approach still revolves around the illness or disorder (and care-recipient's needs) without paying sufficient attention to the caregiving aspect of the children's lives.

3 Young Carers groups in Canada

- Niagara – Young Carers Initiative: Powerhouse Project (2003)
- Toronto – Hospice Toronto's Young Carer Program (2007)
- Vancouver Island – Cowichan Family Caregivers Support Society (2010)

(Waterloo Region – Young Carer Project)

Goals of Young Carer Support

- Assistance-based services (information, coping, strategies, counseling, mostly focused on supporting YC in their caregiving role)
- Mitigation-based strategies (reducing caregiving responsibilities, intensity, respite, including education, training and employment assistance, financial support).
- Preventative strategies (avoid entrenchment of the caregiving role and associated negative outcomes in school, employment, health and well-being)

Barriers

- Sufficient Funding
- Collaborative partnerships with school boards

Young Carer's challenges

- Identity , Emotions, Stress, Self-care
- Relationships: Family, Friends & Others
- World: School, employment, Healthcare
- Unsupported, young carers are at high risk of social, academic, and mental and physical health difficulties *(Marshall, 2010)*

“If we continue to look the other way and not address the impact caregiving has on these youth *now*, we will have to deal with it down the road as secondary users of a physical or mental health care system.”

- Programme Director of Hospice Toronto's YCP (*Stamatopoulos, 2015*)

What can we do?

- Recognize the importance of the issue
- Identify interested stakeholders
- Create a working group to brain storm possible course of action?
- Recognizing the importance of engaging YCs in the process

- * What do you think Young Carers need the most?
- * What gets in the way of identifying and supporting young carers?
- * How can you find the young carers you work with?
- * What steps can you take to better support young carers?
- * What can your organization offer young carers?