



Young Carers' Movement in Toronto

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"This group seems to be such a good match for them as it is not so much focused on the illness, but on them in their caring role. Meeting other kids who "get it" has been a really significant connection for them"

— Parent of two young carers from the program at Hospice Toronto.

Children and youth who are caregivers for family members in Canada are beginning to discover they have a name and they are not alone.

The term 'young carers' is still very new to Canadians (Charles, Marshall, & Stainton, 2010). Health care and social service professionals working to help families dealing with illness and disability have primarily concentrated on the individual with the condition, or the parent of a child with a condition, but have tended not to address the unique needs of the other children in the home that play a role in supporting the family (Baago, 2005; Frank, Tatum & Tucker, 1999). While many positive aspects

come out of being a caregiver, for many of these young carers the role consequently affects their emotional, physical, academic, and social well-being, placing significant strain on their future successes (Aldridge & Becker, 1993). With the right supports in place, children who are young carers can thrive. Research has shown that positive interventions can make all the difference in a young carers' life (Dearden & Becker, 2002; Rose & Cohen, 2010).

Hospice Toronto's Interest

Hospice Toronto is a non-profit organization whose primary service is a volunteer-based, in-home hospice and palliative care program. Through the work done with families in providing home hospice palliative care over the last 22 years, Hospice Toronto recognized years ago that the needs of young people were often overlooked. This led to the development of the first-ever home hospice children's support program in Toronto: the Kits for Kids program to help children address grief and loss, bereavement, and trauma. Hospice Toronto's experience working with children who are young carers is significant, and it has motivated the investigation and ultimately implementation of its current Young Carers Program.

In 2007, Hospice Toronto's Executive Director attended the LHIN Innovation presentations and connected with Sylvia Baago, who initiated the Young Carers Initiative in Canada, which derived out of studying young carers aiding relatives with Alzheimer's. Inspired by the model, and the opportunity to further test and develop a Young Carer's support program in an urban setting, an application was made to the Federal Government's (Caregiver focused) Social Development Partnership Program. In January 2010 Hospice Toronto received three-year contribution funds to set up an urban demonstration project with a

focus on developing a 'tool kit' for replication across the country.

With mentorship from Sylvia Baago and Jenny Frank (Programme Manager at The Children's Society UK), Hospice Toronto has implemented their Young Carers Program. A literature review and the toolkit will be completed in the fall of 2012. The Advisory Committee (representing disability, mental health, chronic and palliative care, substance abuse and children's support services) assists in creating referrals, offering space to run programs, and providing input on the toolkit.

The Key Objectives of the Young Carers Program are to:

1. Increase integration of child/youth and adult services through a cross-sector approach to optimize outcomes, with increased access of non-traditional partnerships in both private and public sectors to maximize service provisions and resources.
2. Create greater public awareness through strategic outreach and engagement of the needs and strengths of young carers so that they will be seen, recognized, acknowledged and supported within the context of the caregiving family unit.
3. Promote and increase young carers' academic performance through

advocacy with schools, and help and support with homework.

4. Reduce 'compassion fatigue' and feelings of 'hopelessness' in young carers through peer support and access to information that better prepares them to understand and respond to illness and disability, personal care responsibilities, and the impact of 'parentification' through naturally occurring role reversal in caring for older family members.
5. Empower young carers to have enhanced self-esteem and reduced anxiety through the validation of the vital role they play in caring for a family member, while reclaiming some of their lost childhood by providing enhanced social support networking opportunities through peer-to-peer social/recreational activities, 'just to be a kid'.
6. Increase knowledge transfer and integration with health and social child/youth and adult agencies and services using a sharing, cross-sector approach to develop more effective and coordinated responses that address the needs of young carers and their families.
7. Develop and sustain a network of youth mentor young carers (for peer-to-peer support) and



specially trained volunteers, with the support of 'host sites' to establish a viable and sustainable Young Carers program.

8. Create a national Young Carers initiative in Canada.

The Young Carers Program

The Young Carers Program of Hospice Toronto is an age appropriate, children and youth support program based upon the highly successful model from the UK. The project supports children and youth, who out of necessity have assumed a significant caregiving role for a family member (i.e., parent, grandparent or sibling) coping with a life threatening or chronic illness, a mental illness, a physical disability, a substance addiction, or a language barrier.

The program is an inter-agency strategy developed to meet the needs of young carers (18 years old and younger) who are finding that their caregiving role is impacting their well-being. It is designed to help those young carers whose responsibilities have negatively affected their emotional, social or physical state with particular emphasis on social relationships, educational success, and self-esteem. These particular young carers are at risk for social isolation and bullying, under-achievement, absenteeism from school, and physical and mental health problems (Aldridge, 2006,

Charles, Stainton, & Marshall, 2008, 2009, 2010; Cree, 2003; Frank, Tatum & Tucker, 1999). The primary purpose of the program is to work towards providing the necessary supports to the family (through advocacy and referrals) so that the child's caregiver role is both age-appropriate and positive.

The program facilitates a variety of weekly activities, workshops and special events (at no cost to families) throughout Toronto that provide recreational, social, educational and skill development opportunities for young carers. Young people are given the opportunity to meet new friends, gain practical and social skills, and be recognized for their caregiving role. Through programs, young carers build resilience and self-esteem, and most importantly are given time 'to be a kid'. Programs include sports, group activities, expressive arts, drama, movies, games, fieldtrips, homework assistance, coping skill development, leadership, cooking and nutrition, medical education and more. Programs are hosted through partner agencies and organizations.

The program provides a safe space for kids to talk about what it is like to be a young carer. Children and youth are free to share their personal caregiving story, which lets them know they are surrounded by others who understand what it means to care for a family member. Conversation that occurs during programming is always dictated by the

participants, and although staff may help facilitate topics, the exchange is led by youth for youth. Ice breakers and familiarizing games, which typically start off the activities, assist in building rapport amongst new members. Depending on the type of program, more specific games and activities ensue that promote self care and peer connection.

For example, in the SIBS program (a program for siblings who take care of their brother or sister) there are activities that help children understand some of the challenges they may be having with the person they care for. Communication Charades is an activity whereby a participant must communicate a concept to the rest of the group, but with certain verbal and physical restrictions. This helps to promote empathy for some of the challenges their siblings may face. The group then shares some of the frustrations they may have in either trying to deliver the message or decipher it. The group also shares similar experiences they have had at home and brainstorm creative ways they can deal with their more difficult feelings. The focus is always on the young carer's experience and building upon positive coping strategies. The goal is not to perpetuate the caring level, but instead to give them the tools to better care for themselves and their needs in relation to their caregiver role and as individuals.

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The program strives to empower young carers by creating opportunities for friendship, fun and learning, which will help strengthen the youth as well as their families. For many it is the first time they have opened up and expressed their feelings and worries. The program facilitates an outlet for self-expression and discussion. As one young carer stated, "I learned there are other people that feel the same way as me". Expected outcomes of participating in the program include: reduced stress and a more balanced lifestyle, stronger family support, better communication and social skills, improved self-care, enhanced peer support, higher self-esteem, improved schooling, and increased coping skills and empathy.

A recent addition to the program is the creation of its Youth Champions Committee. This committee engages current or prior young carers between the ages of 16-24, with an interest in helping to raise awareness of young carers in their schools and communities. This group will also be using their personal experience to help guide the development of the program, which will help shape supports for young carers nationally.

The Young Carers Program consists of a small but robust staff including a Program Manager, Coordinator, and Community Engagement Worker; supported with the help of student interns and a team of trained volunteers.

Hospice Toronto's clinical team, fund development, and administration all contribute to supporting the program and the Executive Director guides the program.

The Young Carers

Currently there are over 70 young carers registered with the program. They vary in age from 5-18, and are representative of the broad diversity in the city of Toronto. Some care for siblings while others care for parents; some have family members who have a disability, some an illness, an addiction, and others mental health challenges. Some of Toronto's young carers take on practical, personal and emotional caregiving tasks. These tasks can include helping with mobility, housework, shopping, translating, cooking, babysitting siblings, washing, toileting, feeding, dressing, administering medication, and providing emotional support. Each young carer is affected differently and each requires different kinds of support; all of them seek to connect with other young carers. The majority of the members display typical young carer qualities such as increased maturity, a compassionate character, and insightfulness (Rose & Cohen, 2010). Many have bonded immediately to each other since often their similarities outweigh their individual differences in family circumstances. They worry – they are "adults" before their time – and they are all dealing

with a stressful situation that many of their peers at school cannot relate to.

Next Steps

Supported by the very positive feedback from parents and youth, the program plans to continue to promote awareness and advocate for young carers to be seen, heard, understood, and validated in their experience of providing care. The relative lack of awareness of the concept of "young carers" in Canada is a significant challenge. There is a real need for more holistic models to be adopted by service providers to facilitate both identifying and providing services to support young carers, who are often reluctant to identify that they need help (Charles, Marshall, & Stainton, 2010). Often they fear that their family structure may change and their privacy will be compromised (Charles, Marshall, & Stainton, 2010). Trying to convince families that parenting skills aren't being judged can be a challenge. One of the goals of the project is to develop communication and assessment tools to make this conversation with families easier to have, and to help them to understand that the real issue is often the absence of supports that can ease the burden of care for all members of the family, including young carers (Baago, 2005).

On a national level, Hospice Toronto's executive director Dena Maule is the co-chair of Young Carers Canada; a newly



formed steering committee currently taking the necessary steps to become incorporated. This committee will be monumental in bringing together interested partners to increase awareness and stabilize supports for young carers across Canada. Together with our colleagues across the country we are moving forward the agenda of young carers. This is an important step in ensuring that they will get the supports and services they need to thrive as young people in special circumstances.

References

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Dena Maule is Executive Director of Hospice Toronto. She is a Board member at OCSA, Co-Chair of the TC CSS Network, and Co-Chair of Young Carers Canada, as well as a past member of the Toronto Central LHIN Senior's Advisory Council as the Palliative Care representative.

