Supporting young carers: a qualitative review of young carer services in Canada

Vivian Stamatopoulos*

Department of Sociology, York University, Toronto, ON, Canada

(Received 5 April 2015; accepted 9 June 2015)

In Canada, a growing number of young people (i.e., young carers) provide an increasing level of unpaid care to family member(s) with a chronic illness, disability, mental health or substance use issue and/or problems related to old age. Despite young carers occupying a central role 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 and only a handful of non-profit organisations struggling to support their needs. This article provides the first known qualitative review of existing young carer programmes in Canada, using interview data with staff at each operational site to: (1) review the range of services offered to young carers and, (2) document barriers to improving their scope and reach. Findings show that available support services are in a preliminary assistance–mitigation phase, with various constraints related to funding and reach that impede their movement to a model of prevention.

Keywords: young carers; unpaid caregiving; Canada; qualitative interviews; young carer support services

Introduction

Young carer is the term given to young people, typically under the age of 25 years, who provide substantial unpaid caregiving to a family member often because of a long-term illness, disability, mental health or substance use issue and/or problems related to old age. Recent socio-demographic changes have also seen additional groups of youth drawn into caregiving resulting from parental absence (e.g., divorce, desertion or overseas military service) and language difficulties that restrict the parents’ ability to communicate effectively with the dominant culture (Charles, Stainton, & Marshall, 2012). As it relates to the Canadian incidence of young caring, additional factors including an ageing population (Cranswick & Dosman, 2008), the rise in lone-parent and skip-generation families (Statistics Canada, 2011) and a shrinking pool of potential family carers due to women’s increased employment and the retrenchment of policies enabling early retirement (Armstrong, 2003) have set the stage for a steady increase to the number of young carers.

While little is known about these youth within Canada, the same cannot be said of other countries, with a 2007 global analysis characterising national levels of young carer awareness and policy response on a scale from emerging to advanced (Becker, 2007). At that point only four countries occupied a position in the typology, with Sub-Saharan Africa holding an ‘emerging’ position characterised by an embryonic awareness of young carers as a distinct social group within the ‘vulnerable children’ population, contrasted
with the USA’s ‘preliminary’ position marked by a larger (albeit limited) research base coinciding with a handful of dedicated local services. Moving up the scale we find Australia that holds an ‘intermediate’ placement marked by an even greater level of national awareness and recognition of young carers among public, policy makers and professionals corresponding with partial legal rights and increasing young carer-specific interventions (Becker, 2007, p. 42). The UK, on the other hand, continues to represent the only ‘advanced’ country in the typology in addition to being the founding nation of the young carer movement.

While Canada had yet to make the list at the time, it may currently be characterised as holding a ‘preliminary’ position, marked by very little in the way of national awareness of young carers coinciding with no dedicated legislative supports. It does, however, edge past an ‘emerging’ position due to a small but developing research base (Baago, 2004, 2005; Chalmers, 2011; Chalmers & Lucyk, 2012; Charles, 2011; Charles, Stainton, & Marshall, 2008, 2009, 2010, 2012; Stamatopoulos, 2015; Toporas, 2003) and a handful of dedicated, albeit locally driven, young carer services. Interesting to note, however, is how the current lack of awareness and recognition remains unrelated to their incidence, with Statistic’s Canada census data revealing over 1.18 million youth between the ages of 15–24 years (28.2%) were providing some level of unpaid child and senior care in 2006, representing a 13.5% increase from 1996 (Stamatopoulos, 2015). As a point of comparison, the UK census data revealed close to 175,000 youth under the age of 17 years who were providing some level of unpaid caregiving in 2001, a figure that triggered a massive media spotlight on the issue (Becker, 2007, p. 27).

From a policy analysis perspective, various factors inhibit the development of a more advanced young carer movement within Canada. First, the current mandate of Canadian health and social services is to ‘provide support either for the care recipient solely, or for the care recipient/primary caregiver dyad, but not to other members of the family in a holistic sense’ (Baago, 2005, p. 6). Underpinning this mandate, of course, are the series of changes beginning in the late 1970s (later identified as ‘neoliberalism’) whereby the federal government radically changed the system in place by reducing healthcare funding but also removing the conditions on how the provinces and territories could spend those funds (Gindin et al., 2005). Second, cuts to the areas of nursing and child care and the attendant shift from hospital to home-care have resulted in the transfer of an increasing amount of health and human services from the public to the private sector, which brings with it an associated increase in the amount of social support and caring required by (unpaid) family workers and volunteers (Armstrong, 2003; Pupo & Duffy, 2012). Third and concomitantly, additional programmes once publically provided now off-loaded onto the non-profit and voluntary sector suffer due to a non-commensurate increase to their human and financial resources (Scott, 2003) with almost half of Canada’s 161,000 non-profit and voluntary organisations reporting problems obtaining funding (NSNVO Factsheet, 2006).

Appreciating that Canadian research and awareness on young carers is still in a developmental phase, we can and should look to those most advanced young carer movements for the adoption of best practices relating to how we may better identify and support these youth. Consequently this article will: (1) review the origins and current state of the young carer movement in Canada; (2) provide a summary of best (young carer) practices operating in the UK – the most advanced model of young carer social programming and policy provisioning and, (3) draw on qualitative data with frontline staff at each of the three existing young carer programmes in Canada to review the current range of services available while documenting those barriers to improving their individual scope and reach.
The young carer movement in Canada

Similar to other developed nations with young carer movements, the origin of the Canadian movement can be traced to a small group of social service providers recognising an unmet need among youth in vulnerable families. Specifically, during home visits with clients and their caregivers, staff with the Alzheimer Society of the Niagara Region (ASNR) began to identify upwards of 70 children and youth taking on caregiving roles for a parent, grandparent or other relative suffering from progressive dementia. Quickly becoming clear that many of these children struggled with stress and anxiety, or other emotional problems (Baago, 2005, p. 6), the ASNR branched out to form the Young Carers Initiative of Niagara (YCIN) in 2003. Consisting of 14 concerned community agencies in the Niagara Region of Southern Ontario, their mission was to promote awareness of these youth and to alert member agencies (representing a wide range of community services for children, youth and adults, covering diverse health conditions, such as HIV/AIDS, multiple sclerosis, brain injury, dementia and autism) on ways they may better detect and provide referrals services for these youth.

Despite momentum building to better identify young carers among these organisations, there is still very little targeted programming to assist them in their caregiving roles. Moreover, outside of this select group of non-profit service providers in Southern Ontario, the wider national approach to health and social services delivery still revolves around the illness or disorder without paying sufficient attention to the caregiving aspect of the children’s lives. Instead, it is only when the young person becomes viewed as ‘parentified’ or deemed a ‘problem’ (by becoming depressed, suffering from an eating disorder, skipping school, acting out, being aggressive or manifesting a variety of other anti-social behaviours) that mental health and/or other social service agencies are called in to provide assistance (Baago, 2005; Charles et al., 2008).

Currently, only three dedicated young carer programmes exist across Canada and each operate under the umbrella of larger non-profit organisations. The first programme developed as a special project of the aforementioned ASNR in 2003, the second under Hospice Toronto (a palliative care programme) in 2007 to service those youth across the Greater Toronto Area (GTA) and the final in 2010 under the Cowichan Family Caregivers Support Society (CFCSS), which serves youth residing on Vancouver Island.

The longest running young carers programme (formerly the YCIN but now called the Young Carers Initiative: Powerhouse Project) can be classified as the most advanced of the three, currently providing a mix of predominantly individualised but emerging whole-family programming. With a total of six paid staff covering the Niagara and Haldimand–Norfolk regions and approximately 20 volunteers, services are provided at no charge to the 700 youth registered with the programme since its inception.

Hospice Toronto’s Young Carers Program (YCP) credits its start to the initial communicative efforts of the Niagara YCI with a 2007 Local Health Integration Network Innovation Presentation connecting those spearheading the Niagara YCI with the executive director of Hospice Toronto. A working relationship began and resulted in the development of an urban model that was up and running by the end of that same year in Toronto. Similar to the impetus behind the Niagara-based YCI formation, Hospice Toronto employees were increasingly identifying youth taking on ‘active and often age inappropriate caregiving duties where, in many cases, they were the only able-bodied family member available to assist a loved one’ (Hospice Toronto). With a total of three paid staff on hand and a handful of volunteers, services have been provided at no charge to the approximately 500 young carers having utilised its services since 2007.
The final programme operates out of Vancouver Island under the auspices of the Cowichan Family Caregivers Support Society (CFCSS) – a registered not-for-profit organisation dedicated to supporting family caregivers. The programme started as a 3-year project in January 2010 and like the other programmes, its development was motivated to due increasing staff encounters with youth in substantial caring roles. Currently, the programme includes two paid staffers and a handful of youth and adult volunteers working to primarily create awareness for young carers in the Cowichan Valley and surrounding First Nations communities. Although the exact number of young carers served is not known, staffers approximate the number to be around 50 since 2010.

On the national level, three elements currently prevent Canada from moving past its current ‘preliminary’ position. First, there is no mention in any official (governmental) or legal documentation regarding the role youth play in supporting their families in these circumstances, let alone the provision of designated legal rights akin to those found in the UK. This lack of awareness that youth may be both providers and not merely receivers of care is also evident in the current federal supports available to Canadian caregivers, with the caregiver credit and the compassionate care benefit geared exclusively towards working adults in the form of tax credits and limited paid work leave (Service Canada, 2014). Second, and related to this, is the lack of wider public consciousness on the issue, with slim to no focus of these youth in the public media and the term ‘young carer’ remaining a virtual unknown. Third, compared to the roughly 30,000 youth receiving dedicated young carer supports across the UK, only three young carer projects exist in Canada, having served roughly 1250 young carers since their collective launches.

If we approach the issue in terms of a current unmet need, the most recent national census data documented 432,250 young carers aged 5–25 years who provided some level of unpaid care in England and Wales in 2011 (Association of Directors of Adult Social Services Association of Directors of Adult Social Services, 2014) compared to over 1.18 million Canadian youth aged 15 to 24 years providing some level of unpaid child and senior care in 2006 (Stamatopoulos, 2015). While the statistics are generally meant to serve as minimum values due to various issues surrounding underreporting and methodological limitations of the survey instruments employed, they nevertheless amount to roughly 1 in 14 youth receiving caregiver supports in England and Wales compared to 1 in 944 receiving comparable supports in Canada.

The young carer movement in the UK

The earliest literature on young carers can be traced to the UK, where the development of what is still considered the foundational body of research on youth-based caregiving emerged in the late 1980’s to early 1990’s (Aldridge & Becker, 1993; Bilsborrow, 1992; Brown, 1989; Meredith, 1991, 1992). Over the past three decades, research, policy and social programming for young carers has grown to constitute the most advanced young carer movement in the world, in large part attributed to the work of early researchers who were ‘critical in raising awareness among UK policy and practitioner networks on the experiences and needs of young carers and their families’ (Becker, 2007, p. 35). With that said, reviewing the national level of awareness and recognition of young carers, the breadth of dedicated young carer programming, and the legal supports afforded to these youth can clarify what separates an ‘advanced’ model from all others. A caveat to note is that while these three elements can be discussed as separate entities for the purposes of documenting the progression of an emergent to advanced young carer model, in practice
they are not mutually exclusive and arguably reflect a key underpinning concept of recognition.

First, advanced young carer movements involve widespread national awareness and recognition of young carers, both in the public as well as among professionals and policy makers. In the UK, an extensive research base exists and young carers (i.e., as a distinct social category) were ‘well and truly on the map of child welfare services’ by the early 1990s (Newman, 2002, p. 614). The term ‘young carer’ is also part of everyday vernacular, with a Google search for ‘UK Young Carers’ drawing over 4.8 million hits, over a dozen TV documentaries dedicated to the issue, and various celebrity endorsements for young carer charities, ranging from Helen Mirren to Ortise Williams to Jaime Oliver.

Moreover, widely circulated public information exists across the UK, with a host of print and digital documentation detailing those rights currently available to young carers. For one, registered young carer projects are housed on the National Health Service (NHS) website, with an online directory of all those young carer centres searchable by postal code to provide a greater ease of access. Second, an online ‘carer self-assessment’ tool enables youth to see what kinds of resources and (legal) rights exist for them and which are best suited to their individual needs as indicated by their results to a short online survey tool. Third, information for two government-funded help phone lines is provided, with ‘Childline’ offering youth under the age of 19 years a free and confidential telephone helpline to speak to a counsellor about any issue they wish, in addition to the ‘Carers Direct’ line that provides advice and support with carer-specific issues.

Second, the breadth of nationally dispersed social service programming for these youth remains unmatched by any other country, with more than 350 dedicated young carer projects servicing approximately 30,000 young carers and employing hundreds of workers and volunteers (Joseph, Becker, & Becker, 2009). Most programmes run through the voluntary sector and are funded from statutory agencies, such as local regional health authorities. The supports offered vary but are typically child-centred and aim to both assist youth in managing their caregiving load while alleviating some of the negative consequences incurred from it. Among these targeted interventions are leisure and respite-based activities, such as group outings and summer camps (with a nationwide ‘Young Carers Festival’ organised by the Children’s Society attracting over 1000 young carers, government and policy makers since 2000) to more help-based, assistive workshops designed to counter some of the educational and emotional difficulties faced by young carers, including one-to-one support, counselling, assistance with school work and liaison within schools. Moreover, strategies seeking to prevent youth’s entrenchment in caregiving are on the rise, with ‘Family Conferencing’ (Ofsted, 2013) being one such technique that engages relevant social service providers with wider family members to ensure access to mainstream health and social services for both children and adults. By ensuring parents and the wider extended family understand and address the impact of the current caring situation on the young person, this particular strategy engages the entire extended family to help change (versus support) the young person’s caregiving role.

Owing much to the success of these interventions is the ‘Whole Family Approach’ taken to the assessment of all individuals with an illness or disability in the UK, a model designed to better identify potential young carers at the first point of contact with a care or service provider. Indeed, much of the push towards such an approach has been credited to the powerful scholarly critique from disability scholars, who argued against the development of dedicated young carer services and supports in the early years of the movement (Keith & Morris, 1995; Newman, 2002; Olsen, 1996; Olsen & Parker, 1997; Wates, 2003). Researchers taking this position argued that if formal services offered to
those with care needs were appropriate or sufficient, there would be no need for family members to provide inappropriate levels of care, with the call for services to be improved for the person requiring the care. Responding to this critique, early young carer advocates (Aldridge & Becker, 2003; Becker, Aldridge, & Dearden, 1998; Frank, 2002; Frank & McLarnon, 2007) maintained the need to provide dedicated services to young carers, in addition to providing more comprehensive needs assessments of vulnerable families as a whole, so that both sets of needs (those of the young carers and the care receivers) may be properly accounted for.

Incorporating a whole family approach into federal policy has also meant an attendant expansion of multi-sectoral partnerships and collaborations with professionals across health, social care and educational networks. Consequently, registered charities (most notably The Children’s Society, The Princess Royal Trust for Carers and Carers Trust) have taken a lead role in partnering with policy makers, nurses, school officials and public health staff to identify and assist young carers across the various health and social services. Successful collaborative efforts under these partnerships include: (1) the development of Young Carer ID cards that operate in some local authorities. These cards alert adults, particularly teachers and social workers, about young carers’ added responsibilities so they may avoid continually explaining their personal situations in public and/or have to request deadline extensions or flexibility surrounding school absences, etc., (2) the naming of a young carer ‘School Lead’ responsible for supporting young carers within their continuing professional development and (3) the creation and dissemination of a wide range of educational and assessment toolkits, including Joseph, Joseph et al. (2009) ‘Manual for Measures of Caring Activities and Outcomes for Children and Young People’ to the development of ‘young carer channels’ on the existing Makewaves2 social media learning platform that operates in schools. Here, professionals with The Children’s Society have worked with Makewaves to provide a safe networking page for schools to use with young carers.

Undoubtedly the third, and arguably strongest, predictor of an advanced young carer movement is support from the national legislative body. In the case of the UK, legal rights were officially granted to young carers under the age of 18 with the 1995 ‘Carers (Recognition and Services) Act’ that have since been strengthened with the amended and forthcoming (April 2015) ‘Care Act’. Now, more stringent protocols operate to better identify young carers, with the act stipulating that: (1) local authorities have the responsibility to assess a carer’s needs for support based on the appearance of need (new), and (2) refer young carers to available support services in their area or provide the option of ‘Direct payments’ in lieu of services should the carer prefer to directly manage how their support is provided (NHS, 2015). What is noteworthy about this forthcoming legislation is its incorporation of research demonstrating a weakness in its earlier form that put the onus on the young carer to request a needs assessment or be shown to undertake a ‘regular and substantial’ amount of care. By expanding the scope of the legislation to provide an assessment based on just the appearance of need, a more preventative approach is enabled that additionally targets the many missed young carers and their families who may not have been aware of their rights or know how to ask for support.

The study

Given the paucity of related Canadian research in the area, the purpose of this study was to provide an exploratory review of the range of services offered to young carers while documenting those barriers to improving their respective scope and reach.
Method
In-depth, semi-structured interviews were conducted with select frontline staff at each of the three existing young carer programmes across Canada. A range of questions were asked, varying from the rationale and process behind the programmes’ development, the types of services offered, the staffing availability and daily operational procedures, to those struggles encountered with expanding and improving upon available programming. Interviews were audiotaped and transcribed from which subsequent contextual (looking at the data as a whole) and categorical analysis (organising the data into coded data by ideas or themes) took place. Reflective of the iterative nature of exploratory qualitative research, the series of question-and-answer cycles were also slightly modified with each subsequent interview to factor in emerging themes discovered throughout the interview process.

As a methodological note, a qualitative interview approach was chosen over a quantitative approach (e.g., surveys) for two reasons. First, qualitative techniques tend to be ideal for exploratory analyses and given the young carer movement is in a period of development, there is limited information available on the current programming available, let alone its strengths or limitations. To date, only one such related study exists, with Chalmers (2011) providing a single-site quality assurance of the Powerhouse Project’s YCI with use of feedback from parents of young carers in the programme. Second, qualitative interviews are better suited to discovering the first-hand experiences of those working in the field by enabling informants to ‘describe their actions, experiences, beliefs, and values as they view them, without being limited to the investigators’ predetermined concepts, theories, and questions, as with a survey’ (Parker et al., 2009, p. 232). Subsequently, careful effort was made to derive as many detailed descriptions as possible while retaining the personal narratives of those interviewed so not to distort the lived experiences of those staffers.

Participants
Participants were recruited using purposive ‘stakeholder’ sampling (Palys, 2008) of frontline staff who either launched or currently managed one of the three Canadian young carer programmes. Choosing these staffers was an ideal starting point to reviewing both the current range of young carer service available while gaining in-house expertise as to what is needed for their respective improvement and/or growth. Interviews lasted between 60 and 90 minutes and were conducted by telephone from 12 to 23 January 2015, with a total of five current and previous frontline staffers included in the sample (representing 45% of the total staff employed by all three programmes). No funding was received to carry out this research and ethics approval was sought and approved by the Canadian Tri-Council Panel on Research Ethics.

Limitations
While close to half of the current combined programme staff was interviewed, the final sample pool of five participants alongside the range of participants selected (i.e., directors and managers) posed a limitation of the study. Thus, while the goal of this research was to provide an exploratory review of young carer services in Canada, future research could provide a more formal evaluation of programming by adding additional perspectives from a wider range of participants including programme users (i.e., young carers), volunteers and other relevant stakeholders.
Findings

Recently, Purcal, Hamilton, Thomson, and Cass (2012) provided a framework for categorising young carer support services according to three overarching goals: (1) assisting young people who provide care (assistance); mitigating the caregiving responsibility (mitigation); and preventing the entrenchment of a young person’s caring role (prevention). While the framework was applied to existing support services for young carers in Australia, it may also be used to categorise supports in other countries while also clarifying service objectives and identifying gaps in service provision (Purcal et al., 2012, p. 792).

Assistance-based (or assistive) services aim to support young carers in their caregiving role, by helping them cope with their added responsibilities and/or encouraging them to seek additional help, either for themselves or the person they care for. These services are usually provided on a short-term basis and include interventions, such as, counselling for the young carer, information on other services or the provision of self-help strategies and access to peer support groups (Purcal et al., 2012, p. 796). Mitigation-based services work to reduce care responsibilities by either lowering the intensity of caring or by cutting down the time spent on caring, for example through respite services for young carers or tools to reduce the long-term negative educational or social impacts of caring on the young person. Interventions in this domain include education assistance, training and employment assistance and/or financial support (Purcal et al., p. 796). Preventative strategies aim to avoid the entrenchment of a young person’s caring role and associated negative outcomes across a range of domains, including school, employment, health and well-being. These approaches provide support to the family when a disability or chronic illness first manifests itself and in the case of youths who have already taken on a caring role, work to create an optimum combination of formal and informal supports that are tailored to each individual family. As such, they are personalised, encompass a whole-of-family approach, and involve an integration of social, health and disability services (Cass, Smyth, Hill, Blaxland, & Hamilton, 2009).

While the framework demarcates three distinct categories of young carer supports, there is operational overlap in practice since many services provide cumulative benefit. As Purcal et al. (2012) pointed out, many services aim to achieve more than one of the above goals with young carer camps designed to provide assistance to young carers in the form of access to peer support and information while simultaneously mitigating the strain of caregiving by providing respite.

The range of young carer services in Canada

Currently, the range of dedicated young carer services in Canada remain either assistance or mitigation-based, with none operating at a preventative level.

The Young Carers Initiative (YCI): Powerhouse Project provides the largest range of weekly services to young carers in the Niagara, Haldimand and Norfolk regions, offering a mix of individualised and, albeit limited, whole-family programming. Assistance-based services range from home-visits or one-to-one counselling sessions (or referrals to other counselling services) to peer support group access for both teens and young adults. Life skills programming is another integral component of programming, with workshops aimed at developing a range of self-help tools among young carers, from ‘Calmcare’ where youth learn to use bubbles as a fun way to practice deep breathing techniques to ‘Fit for Youth’ where physical activity is used as a form of decompression therapy. Other workshops have taken form overtime when an unmet need arises, with one such example being the
development of youth-based cooking classes due to a situation where a young carer’s parent was taken away in an ambulance in the middle of the night, with the young carer left at home unable to accompany their parent to the hospital. In the morning, the young carer called the YCI staff in a panic alerting them there was no food in the house for them to eat, prompting an immediate home-visit by the programme director. Upon assessing the situation, the realisation was made that there were a variety of (frozen) food options available, with the child understandably failing to possess the requisite knowledge required to prepare it.

A dual assistance and mitigation-based intervention exists with the development of a ‘Youth Advisory Group’ that enables interested young carers the opportunity to contribute ideas to the types of programming offered while participating in awareness workshops and conferences organised by the staff. As a case in point, the group was recently involved in a conference funded by the YCI and attended by an audience of researchers, local community agencies, educators and young carer families. Here, they put on a dramaturgical performance of ‘what it means to be a young carer’ which not only provided them access to a peer support group (assistance) but also aimed to reduce some of the long-term negative educational and social impacts of young caring by developing their organisational and public speaking skills (mitigation).

‘Hospice Toronto’s YCP’ provides a similar, though smaller scale, model of assistance and mitigation-based programming for young carers across the GTA. As expressed by the programme manager, the overriding goal of the programme is to ‘connect young carers with other young carers so they know they are not alone in their experience … and that alone creates a sense of normalcy since they feel disconnected from other peers’. Providing access to a peer support group, therefore, is of paramount importance and is further supplemented by the provision of information and/or referrals for services not provided by the programme.

Dual assistive and mitigative-based services include workshops geared at developing self-help strategies to be used outside of the programme ranging from weekly and monthly programming for both ‘YCP Teens’ (designed for teenagers) and ‘YCP Kids’ (for kids of age 12 years and below) which include monthly outings (e.g., sports events and movie nights) and ‘All About’ workshops that provide additional information for youth about their family member’s condition through age-appropriate, non-threatening activities and medical play.

Providing advocacy for young carers within the school system is another important (mitigation-based) service that involves staff reaching out to school personnel when young carers require added accommodation, for example with frequent absences and/or deadline extensions. As the programme manager recounted, one pair of siblings were continually getting in trouble for having their cell phones on during class time, with teachers failing to understand that the parent was at home on survival equipment that, if malfunctioned, would require the youth to rush home and/or call 911. Finally, a lunchtime programme was also piloted in one Toronto school but a siphoning of interest from both school staff and administration led to the programme having just over a 3-month run, with staff reporting difficulties on two fronts: (1) in gauging the level of need from teachers who were asked to complete and return information sheets probing the level of classroom need, and (2) receiving back parental consent forms needed for those youth under the age of 18 years to participate in the programme.

Finally, the Cowichan Young Carers Program has taken a slightly different approach than the Ontario-based programmes, with a dual assistance and mitigation-based goal geared at involving young people in a leadership capacity to build awareness on the issue,
particularly within schools. With the development of a ‘Youth Resource Team’ (YRT) comprised of the programme director, local youth (both young carers and non-carers) and a handful of adult volunteers, bi-weekly meetings have resulted in: (1) the creation of a documentary film (*Ending the Silence*) and a curriculum guide for educators, both of which are available for purchase by schools and community organisations; (2) more than 80 presentations made to various local schools, community organisations and public officials; (3) the design and execution of an annual youth-based conference (with young caring being the underlying theme) drawing in an average of 100 students from 10 neighbouring schools; and (4) a consultative role in the Action Canada Task Force (2013)³ dedicated solely to raising awareness for this ‘invisible population’.

One very important and distinct mitigation-based gain made by the Cowichan programme has been the collaboration with the local school board (District 79) to allow for a volunteer course credit allowance for those YRT members dedicating 100 hours or more to the programme. Not only is this a factor declared vital by staff for enabling some young carers to graduate but it also provides the programme with a steady stream of both non-caregiving and caregiving youth volunteers. Pursuant to this, a commitment of even 30 hours by any YRT member would satisfy their provincial-based volunteer-work graduation quota (applicable to both Ontarian and British Columbian high school youth), with many YRT members completing both their volunteer work quota and receiving a full course credit with their involvement in the programme.

On the whole, despite each of the three programmes offering a variety of services geared at both helping the young person cope with their caring role through services including counselling and the provision of self-help tools (i.e., assistance-based services) and providing limited respite and/or educational assistance (i.e., mitigation-based services), none have the operational capacity to function at a preventative level. Doing so would require a whole-family approach catered to each individual family that would invariably require a collaborative effort among a variety of social, health and disability service providers. Given the current Canadian healthcare mandate involves concentrating on the needs of the care-receiver alone, facilitating such a holistic approach to service delivery that accounts for the needs of care-giver as well becomes effectively eliminated from the outset.

**Barriers to programme expansion and/or improvement**

The largest issue facing all three programmes involved their inability to move past an assistance-mitigation-based level of programming. To recap, *preventative* strategies focus on avoiding the entrenchment of a young person’s caring role by providing support to the family when a disability or chronic illness first manifests itself or, alternatively by creating an optimum combination of formal and informal support tailored individually to each family where a young carer exists (Purcal et al., 2012). At present, a preventative model is blocked due to two key issues surrounding: (1) a lack of stable and sufficient funding and (2) the difficulty in creating collaborative partnerships with local school boards.

**Funding**

All three programme staff raised similar concerns surrounding the lack of stable and sufficient funding and how that impacted the scope and reach of their programming. As it relates directly to the delivery of programming from a non-profit sector perspective, this can be seen as resulting from policy changes targeting funding protocols for community
care and social service agencies, particularly relating to the transition towards ‘project-funding’ regimes (Gibson, O’Donnell, & Rideout, 2007). Previously, governments provided long-term public or ‘core-funding’ commitments to many non-profit organisations that allowed them to cover their basic administration and organisational costs in addition to those required in running the programmes. Towards the late 1990s and into the first half of the 2000s, however, a ‘funding crisis’ occurred that resulted in funders moving away from core funding towards project and outcome-based funding (Struthers, 2013, p. 11). These shorter duration grants produced a unique financial vulnerability among organisations who are now put in a process of perpetual application and re-application for time-sensitive, project-specific funding. Additionally, those organisations in receipt of funds are under increasingly strict accountability protocols, with staff urged to collect quantitative-based (data-driven) measures to assess outcomes, the collection of which was noted by all staff as taking up a sizeable amount of time that could otherwise be devoted to delivering services.

For Hospice Toronto’s YCP, an initial multi-year grant enabled the programme to launch based around dedicated service ‘deliverables’ including the youth-specific programming described earlier in addition to the development of a ‘young carer toolkit’ that could be replicated nationwide. When asked what the largest barrier to expanding the programme was, the staff unanimously agreed it was the lack of permanent funding and the ripple effect it had on staffing, space issues and the range and scope of available programming. For one, funding has only been able to accommodate an average of 2.5 paid staff to run a host of programmes and workshops for well more than 500 youth over in its 5-year run. While staff expressed gratefulness to the volunteer commitment that helped them execute workshops, especially the respite-based outings and camps, staff noted feeling ‘pretty stretched’ to maintain the existing level of programming. Funding shortages have also led to multiple office moves in order to accommodate rental costs with a siphoning of funds, which had a ripple effect on the amount of staff time left available for the delivery of programming. Staffers were acutely aware that a lack of a permanent home-base translated to less time available for programming. Funding shortages have also led to multiple office moves in order to accommodate rental costs with a siphoning of funds, which had a ripple effect on the amount of staff time left available for the delivery of programming. Staffers were acutely aware that a lack of a permanent home-base translated to less time available for programming.

The Cowichan programme similarly expressed funding challenges, principally related to the lack of necessary resources needed to hire additional staff with which to deliver more assistance-based services. Unlike the other two programmes, this programme focused its resources on raising awareness and creating a dialogue within local schools and the wider community. What was not a focus was the delivery of more self-help and respite-based programming, with staff lamenting the reason for this being funding-based staff shortages – a revelation particularly hard felt among staff given the large contingency of ‘first nations kids who really need the support but could not get it’ (previous programme director). In light of research revealing it was those areas across Canada with the highest proportions of indigenous populations (i.e., Northern Canada), which had the greatest proportion of young carers (Stamatopoulos, 2015), the finding that a large number of first nations youth were in need of these services was not an unexpected one. Important to note, however, is that despite staff trying to connect young carers with neighbouring services that could provide some of the services they were unable to budget for, issues arose to prevent many from taking advantage. In particular, the previous programme director recounted trying to arrange temporary respite services with the local island health...
authority, that is, a personal support worker to come to the house so the young carer could attend a school event, but significant paperwork combined with the fear of having a stranger come into the home prevented the youth from accessing the service. Indeed, the fear of an official welfare authority response, in that telling might lead to separation of family members, has been found to contribute to many vulnerable families keeping their family situations hidden (Cass et al., 2009; Moore & McArthur, 2007).

Comparing the three organisations, the Young Carers Initiative: Powerhouse Project has had the most stable funding since start-up resulting from multiple multi-year project grants in addition to assistance from the local integration health network and the ASNR. The difference between the YCI and the Toronto and Cowichan programmes, financially, is evident in the scope and reach of their programming.

For one, they have been able to keep a core staff of six employees on hand and provide additional perks that the other groups have not been able to budget for, including the provision of meals for young carers during programming and the payment of cab fares and/or staff vehicle gas costs to bring those young carers without transportation to and from programme nights. The ability to do so not only increases their participant reach but allows those in some of the most precarious financial situations to attend programming. With research revealing young carers are more likely to live in households with higher rates of income poverty than young people who are not carers (Becker, 2007; Cass et al., 2009; Saunders, 2005), these added benefits certainly maximise their ability to help a greater number of Canadian young carers. While staff acknowledged this feature as integral to assisting some of those most vulnerable young carers, it was nevertheless mentioned as one of the greatest barriers to expanding the programme given its hefty annual expenditure approximating CAD$25,000.

Second, they have been able to retain two permanent home-base offices large enough to accommodate drop-in visits and weekly workshops (one in Niagara, one in Haldimand–Norfolk), which serve as a hub for young carers and their families to connect.

Finally, having three times the amount of staff relative to the other programmes also increases their capability to apply for additional funding, the process of which all frontline staff noted as being highly time-intensive. Effectively, the result is more staff on hand to focus on project-funding applications, which makes all the difference to increasing the scope (i.e., being able to service more youth, more frequently) and range (i.e., having both individualised and whole-family) programming options available.

Integration with schoolboards

Given that young carers tend to spend the majority of their time either at school or at home, the value of establishing awareness and programming within schools was a factor repeatedly deemed necessary by all staff. In line with global research revealing young carers are reluctant to take breaks or socialise, because they feel they should stay home and help around the house (Barry, 2011; Cass et al., 2009), frontline staff were similarly aware that their evening and weekend programming meant additional time away from the household, which at times was stressful for the young carer, irrespective of the added respite-value. Taking programming to the schools, therefore, was viewed as a win–win for frontline staff and young carers alike but access was always an issue with the exception of the Cowichan programme. Specifically, the main issues experienced by the Ontarian programmes were twofold, with difficulties first connecting with administrative staff to gain entry and second, in connecting with individual teachers to gauge potential student need/eligibility.
The issue of ‘red tape’ was a recurring complaint, with staff noting instances whereby entry to the school was granted to provide information events (e.g., advocacy assemblies) but development of in-house programmes was halted due to the lack of turnaround for required parental consent forms. Contributing to this educational blockade, of course, is the lack of wider public awareness of young carers and the benefits of such programming, both of which posed a source of frustration for frontline staff and educators, who despite identifying interested young carers, could do nothing to help without parental consent for those students under the age of 18 years.

The Cowichan programme, on the other hand, was able to rather successfully gain entry to a wide range of schools due primarily to a particularly supportive superintendent who acted as a gatekeeper into the local schoolboard. With his help, the programme director (alongside young carers in the programme) were able to provide dozens of awareness raising public presentations across a wide range of local schools. Additionally, the development of a course credit allowance for eligible members of the YRT worked to not only facilitate a steady stream of caregiving and non-caregiving youth volunteers into the program but also eased potential parental concerns related to their child’s involvement. Taken together, this added educational support facilitated a greater turnaround in the necessary parental consent forms required for student’s participation in the programme but also added legitimacy to the programme and its mission.

Discussion: moving from assistance to prevention

Using qualitative interview data with frontline staff at each of the three Canadian young carer programmes, this research aimed to review the range of services offered to young carers while documenting those barriers to improving their scope and reach. Findings revealed that available support services for young carers in Canada can be characterised as both assistance and mitigation-based in nature, with programming aimed at both assisting youth in their caregiving roles (via counselling, information on other services or self-help techniques and access to peer support groups) or mitigating some of the negative consequences incurred (via respite-based services, educational assistance and training and employment assistance).

While the three programmes have worked diligently to incorporate many of the best practices operating in the UK, they are still constrained from moving to a model of prevention that works against the entrenchment of a young person’s caring role and the documented negative outcomes corresponding with it. Specifically, a preventative model to young carer programming would include a personalised, whole-family approach that is currently impeded by two factors: (1) the lack of stable and sufficient funding resulting from an increasingly neoliberal approach to health and social services delivery within Canada and, (2) the inability to gain adequate entry into local schoolboards with which to provide in-house (lunchtime and/or after-school) young carer programming.

Given that many young carers feel a sense of guilt and social exclusion due to their commitment to their families (which restricts their mobility outside of their households and/or schools), a natural and efficient next step for service providers would be to promote and operate services from within schools. Knowing this, staff at all three programmes worked to gain entry and institute programming during lunch and after-school time-slots but issues related to administrative pull-back and difficulty obtaining parental consent restricted their success. Only one of the three programmes was able to successfully gain entry into the local schoolboard and that was due primarily to a particularly supportive superintendent.
Additionally, the scope and reach of young carer programming was directly proportional to the amount of funding procured by each organisation, with additional funds leading to both a wider range of services offered and a larger number of young carers able to access them. Regardless of inter-agency funding differences, programme staff unanimously noted the difficulty in securing resources, leaving their organisations in a constant struggle to secure insufficient and increasingly short-term funding. As other researchers in the community sector have noted, the consequence of shifting to project-funding regimes has been to create a ‘stressed-out social service environment, where organisations continue to attempt to provide adequate services while being underfunded’ (Gibson et al., 2007, p. 32). Barring a return of core-funding to the community care sector, young carer service providers will need to find alternative ways of securing the necessary funding needed to support an ever-growing contingent of Canadian young carers.

Finally, while the limited public and professional awareness on the issue of youth-based caregiving is surely a factor behind the lack of traction made within local schoolboards, the Canadian state holds greater power in its incidence via macro-level policy changes geared towards more individualised approaches to healthcare and social service delivery. When looking to the whole family approach that operates in the UK, for example, it becomes clear that a more holistic method to the needs assessment of vulnerable families (which seeks to provide adequate supports to both the caregiver and care receiver) not only circumvents the entrenchment of a young person’s caring role but reduces the negative outcomes associated with it.

We know from existing research that not only do many young carers come from hidden and marginalised groups, including children caring for family members with mental illness or a substance dependency, but they consistently miss out on a wide range of opportunities (e.g., educational, leisure and professional) that prevents them from thriving and enjoying their childhoods (Children’s Society, 2013). We also know that decisions to rely on informal care are often tied directly to constraints at the intra-familial and policy-level, with the state holding significant power to reducing youth-based caregiving by funding, providing and regulating formal care services. As the programme director of Hospice Toronto’s YCP accurately articulated in our interview:

*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.*

It is crucial, therefore, that efforts at promoting recognition for these youth continue and that better methods at identifying, supporting and ultimately preventing their entrenchment in substantial caring roles are implemented.

**Acknowledgements**

The author wishes to thank the frontline staff at the three Canadian young carer programmes for their participation in this research. Their dedication and support of young carers should not go unnoticed.

**Disclosure statement**

No potential conflict of interest was reported by the author.

**Notes**

1. As defined by Broszormenyi-Nagy and Spark (1973), parentification implies the subjective distortion of a relationship as if one’s partner or even children were his or her parent.
2. Makewaves is a safe social learning platform that offers schools a safe environment in which to publish blogs, videos, pictures and audio online, where they can be shared with a like-minded network of schools around the world. Makewaves is free to join and every member school is given its own space within the community, where work can be safely published and shared (https://www.makewaves/).

3. Action Canada a registered charity funded in part by the Government of Canada with a mandate to build leadership for Canada’s future. Each yearly task force brings together experts with a vested interest in promoting a special topic, with the 2013 topic based on young carers.

Notes on contributors
Vivian Stamatopoulos is a Ph.D. Candidate at York University (Toronto, Canada) in the Department of Sociology. Her dissertation research concentrates on young carers in Canada, examining such areas as the prevalence, policy and practice of youth-based caregiving.

References
Action Canada Task Force. (2013). Who cares about young carers? Raising awareness for an invisible population. Action Canada. Retrieved from http://www.actioncanada.ca/en/fellows/projects/20122013-who-cares-about-young-carers-raising-awareness-for-an-invisible-population/

Aldridge, J., & Becker, S. (1993). Children who care: Inside the world of young carers. Loughborough: Young Carers Research Group.

Aldridge, J., & Becker, S. (2003). Children caring for parents with mental illness: Perspectives of young carers, parents and professionals. Bristol: Policy Press.

Armstrong, P. (2003). Wasting away: The undermining of Canadian health care. Toronto: Oxford University Press.

Association of Directors of Adult Social Services. (2014). Census 2011 briefing-age statistics. Retrieved from http://www.adass.org.uk/AdassMedia/stories/Carers/Census%202011%20briefing%20Age%20statistics%202011%20.pdf

Baago, S. (2004, Winter). The unrecognized caregiver: Children of dementia. Perspectives, 27, 3–4.

Baago, S. (2005). Inside the developmental ‘Black Box’ of young carers, a literature review prepared for the Young Carers Initiative Niagara. Ontario: Ontario Trillium Foundation.

Barry, M. (2011). ‘I realised that I wasn’t alone’: The views and experiences of young carers from a social capital perspective. Journal of Youth Studies, 14, 523–539. doi:10.1080/13676261.2010.551112

Becker, S. (2007). Global perspectives on children’s unpaid caregiving in the family: research and policy on ‘young carers’ in the UK, Australia, the USA and sub-Saharan Africa. Global social policy, 7, 23–50. doi:10.1177/1468018107073892

Becker, S., Aldridge, J., & Dearden, C. (1998). Young carers and their families. Oxford: Blackwell Science.

Bilsborrow, S. (1992). You Grow up fast as Well … Young carers on Merseyside. Liverpool: Carers National Association, Personal Services Society and Barnardos.

Broszormenyi-Nagy, I., & Spark, G. M. (1973). Invisible loyalties: Reciprocity in intergenerational family therapy. Hagerstown, MD: Harper & Row.

Brown, E. M. (1989). My parent’s keeper: Adult children of the emotionally disturbed. Oakland, CA: Harbinger Press.

Cass, B., Smyth, C., Hill, T., Blaxland, M., & Hamilton, H. (2009). Young carers in Australia: Understanding the advantages and disadvantages of their care-giving. Social Policy Research Paper No. 38. Canberra: Australian Government Department of Families, Housing, Community Services and Indigenous Affairs.

Chalmers, H. (2011, June). Powerhouse program evaluation report: 2010–2011 Programming year. Retrieved from http://powerhouseproject.ca/wp-content/uploads/2013/07/2010-2011-quality-assurance-summary1.pdf

Chalmers, H., & Lucyk, L. (2012). The impact of caregiving: Is it who I am or what I do? Relational Child & Youth Care Practice, 25, 37–46.

Charles, G. (2011). Bringing young carers out of the shadows. Reclaiming Children and Youth, 20, 26–30.
Charles, G., Marshall, S., & Stainton, T. (2010). Demographics profiles and initial results from the British Columbia Young Carers Study. *Relational Child and Youth Care Practice*, 23, 64–67.

Charles, G., Stainton, T., & Marshall, S. (2008). Young carers in Canada: An invisible population. *Relational Child and Youth Care Practice*, 21, 5–12.

Charles, G., Stainton, T., & Marshall, S. (2009). Young carers: Mature before their time. *Reclaiming Children and Youth*, 18, 38–41.

Charles, G., Stainton, T., & Marshall, S. (2012). *Young carers in Canada: The hidden costs and benefits of young caregiving*. Ottawa: Vanier Institute of the Family.

Children’s Society. (2013). *Hidden from view: The experiences of young carers in England*. Retrieved from [http://www.childrenssociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-carers_final.pdf](http://www.childrenssociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-carers_final.pdf)

Cranswick, K., & Dosman, D. (2008). *Eldercare: What we know today*. *Canadian Social Trends*. Statistics Canada Catalogue no. 11-008-X. No. 86.

Frank, J. (2002). *Making it work: Good practice with young carers and their families*. London: The Children’s Society and The Princess Royal Trust for Carers.

Frank, J., & McLarnon, J. (2007). *Key principles of practice for young carers, parents and their families*. London: The Children’s Society.

Gibson, K., O’Donnell, S., & Rideout, V. (2007). The project-funding regime: Complications for community organizations and their staff. *Canadian Public Administration*, 50, 411–436. doi:10.1111/j.1754-7121.2007.tb02135.x

Gindin, S., Armstrong, H., Armstrong, P., Leys, C., Lister, J., Lexchin, J., & Mehra, N. (2005). *Whose health care? Challenging the corporate struggle to rule our system*. Socialist Interventions Pamphlet Series.

Hospice Toronto. (2015, February 6). *Mission and goals*. Retrieved from [http://www.ycptoronto.com/index.html](http://www.ycptoronto.com/index.html)

Imagine Canada. (2006). *National survey of nonprofit and voluntary organizations: Financial challenges of nonprofit and voluntary organizations*. Retrieved from [http://www.imagene canada.ca/sites/default/files/ww/en/nsnvo/n_financial_challenges_factsheet.pdf](http://www.imagene canada.ca/sites/default/files/ww/en/nsnvo/n_financial_challenges_factsheet.pdf)

Joseph, S., Becker, F., & Becker, S. (2009). *Manual for measures of caring activities and outcome for children and young people*. Essex: Princess Royal Trust for Carers.

Keith, L., & Morris, J. (1995). Easy targets: A disability rights perspective on the ‘children as carers’ debate. *Critical Social Policy*, 15, 36–57.

Meredith, H. (1991). Young carers. *Contact*. Summer.

Meredith, H. (1992). Supporting the young carer. *Community Outlook*, May.

Moore, T., & McArthur, M. (2007). We’re all in it together: Supporting young carers and their families in Australia. *Health & Social Care in the Community*, 15, 561–568. doi:10.1111/j.1365-2524.2007.00719.x

National Health Service. (2015). *Carers’ rights and the care act*. Retrieved from [http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/carers-rights-care-act-2014.aspx](http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/carers-rights-care-act-2014.aspx)

Newman, T. (2002). Young carers and disabled parents: Time for a change of direction? *Disability & Society*, 17, 613–625. doi:10.1080/0968759022000010407

Ofsted. (2013). *Reducing Young caring through family group conferencing – Bolton Council and Barnardo’s*. Retrieved from UK Government: Research and Analysis [https://www.gov.uk/government/publications/reducing-young-caring-through-family-group-conferencing](https://www.gov.uk/government/publications/reducing-young-caring-through-family-group-conferencing)

Olsen, R. (1996). Young carers: Challenging the facts and politics of research into children and caring. *Disability & Society*, 11, 41–54. doi:10.1080/09687599650023317

Olsen, R., & Parker, G. (1997). A response to Aldridge and Becker–‘disability rights and the denial of young carers: the dangers of zero-sum arguments’. *Critical Social Policy*, 17, 125–133. doi:10.1177/026101839701705007

Palys, T. (2008). Purposive sampling. In L. Given (Ed.), *The sage encyclopedia of qualitative research methods* (pp. 57–59). Thousand Oaks, CA: Sage.

Parker, L. E., Kirchner, J. E., Bonner, L. M., Fickel, J. J., Ritchie, M. J., Simons, C. E., & Yano, E. M. (2009). Creating a quality-improvement dialogue: utilizing knowledge from frontline staff, managers, and experts to foster health care quality improvement. *Qualitative Health Research*, 19, 229–242.

Pupo, N., & Duffy, A. (2012). Unpaid work, capital and coercion. *Work, Organisation, Labour & Globalisation*, 6, 27–47.
Purcal, C., Hamilton, M., Thomson, C., & Cass, B. (2012). From assistance to prevention: categorizing young carer support services in Australia, and international implications. *Social Policy & Administration, 46*, 788–806. doi:10.1111/j.1467-9515.2011.00816.x

Saunders, P. (2005). *The impact of disability on poverty and living standards*. Australian Social Policy Conference. University of New South Wales, Sydney.

Scott, K. (2003). *Funding matters: The impact of Canada’s new funding regime on nonprofit and voluntary organizations*. Ottawa: Canadian Council on Social Development.

Service Canada. (2014). *Being a caregiver – Service Canada*. Retrieved from http://www.servicecanada.gc.ca/eng/lifeevents/caregiver.shtml

Stamatopoulos, V. (2015). One million and counting: The hidden army of young carers in Canada. *Journal of Youth Studies, 18*, 809–822. doi:10.1080/13676261.2014.992329

Statistics Canada. (2011). Fifty years of families in Canada: 1961–2011. *Census in Brief*. Catalogue no. 98-312-X2011003.

Struthers, M. (June 2013). *Fair exchange: Public funding for social impact through non-profit sector*. Toronto: Metcalf Foundation. Retrieved from http://metcalffoundation.com/publications-resources/view/fair-exchange/.

Toporas, C. (May, 2003). *Growing up strong: Supporting the children of parents with multiple sclerosis*. Toronto: MS Society of Canada.

Wates, M. (2003). *It shouldn’t be down to luck: Results of a consultation with disabled parents*. London: Disabled Parents Network.