



# Young Carers in Canada

*The Hidden Costs and Benefits of Young Caregiving*

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***Les jeunes aidants au Canada : Les avantages et les coûts cachés des soins prodigués par les jeunes***

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# Executive Summary

There are times when adults in Canadian families are unable to care for themselves or provide care for others due to illness, injury or disability. As a result, they need help with daily activities, ranging from the basics such as eating, dressing or taking medications to the more complex tasks of financial planning and navigating the health care system. Typically, another adult in the family will step in to help fulfill the responsibilities of parenting, caregiving and household management. In cases where adults are unavailable, young family members may be required to take on the role as primary caregiver well before it would normally be expected.

Research conducted with high school students in Vancouver has found that 12% of youth aged 12 to 17 identify as young carers. These young Canadians play an increasingly essential role in the maintenance of family and community well-being. They fill in caregiving gaps and help meet the needs of family members recovering from illness or injury, managing a chronic, episodic or progressive health condition or mental illness, or at the end of life.

Until very recently, young caring has been an invisible feature of the family caregiving landscape. The voice of young carers, their needs and those of their families have been largely missing from the national dialogue on family well-being. Researchers, advocates, practitioners and young carers are breaking this silence. A more accurate portrait of young caring is emerging that tells the story of opportunity gained and lost at the individual, family, community and societal levels.

Early caregiving is not always easy or desirable, but it can be an incredible opportunity to build closeness and connection across generations. It can lead to feelings of pride and competence as youth develop new skills and awareness, and it can foster empathy and compassion during difficult times.

The costs and consequences of young caring can also be heavy. Some young carers undertake high levels of care. Often learning as they go, young carers are vulnerable to stress, anxiety and social isolation. The demands of young caring typically come at a time when youth are facing the challenges of adolescence, completing school, entering the labour market and making important decisions about their own futures. Many young carers trade time with friends, at school or on their own for the responsibilities of early caregiving. These youth risk failing to acquire the skills and education necessary for future success and well-being.

A strategic approach to supporting young carers and their families begins with an increased understanding of the unique place and status young carers hold within a system of family and adult care. Building awareness and developing supports and resources at the family and community levels, in schools and universities and colleges and in the workplace will help mitigate the potentially adverse consequences of caring on young carers and their families.

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## Introduction

Caring is at the heart of family life. Taking care of family members and maintaining a home are among the most important roles undertaken by families. Most of us will experience being a family caregiver at some point in our lives, caring for a relative or friend who is ill, disabled or aged. Families and communities rely heavily on the care that members provide to those whose needs have surpassed their ability to live independently. Carers make a big difference to the lives of the people they care for. Whether in response to a short-term crisis or in support of someone over a long period of time, family caregiving is essential to individual and family well-being.

In some families, the need and demand for family caregiving places tremendous strain on the family unit. Among those most vulnerable to the stresses of caregiving are families wherein the “natural” caregiver (usually a parent) is ill, incapacitated or absent. Typically, care within families – for children, elders or those with an illness or disability – is provided by adults with younger family members progressively contributing what they can, according to their age and developmental stage.

Most parents expect their children to contribute to the daily functioning of the family. Exactly what that contribution looks like may vary with culture, age, gender or ability. In cases where adults are unable to assume their caregiving role, young family members may be required to take on a range and depth of care-related responsibilities well before they might otherwise be expected or prepared to on a regular basis. These young people are **young carers**<sup>1</sup>.

Young carers fill a vitally important role in their families and communities and yet, until quite recently, have been largely absent from the discussion of family caregiving in Canada (Charles, Stainton and Marshall, 2008). This paper traces the emergence of “young carers” as a legitimate group of caregivers in Canada over the last 10 years, highlighting the varied and complex pathways into early caregiving and the many challenges, opportunities and outcomes associated with assuming exceptional care responsibilities at a young age. The authors will demonstrate that families, in general, and young carers, in particular, benefit from the support of a comprehensive system of formal and informal, community-based health care and social services that meet the needs of ill, incapacitated and disabled persons of all ages (see Aldridge and Becker, 1996).

Without adequate support, young carers risk trading “normal” childhood and adolescent experiences and development for the demands of caregiving. And whereas it is clear that young caring can be positive and beneficial for the young care provider, it is equally clear that young caring places young carers at risk of not finishing school or acquiring the skills, knowledge and social maturity necessary to thrive in both the short and long term.

*Without adequate support, young carers risk trading “normal” childhood and adolescent experiences and development for the demands of caregiving.*

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<sup>1</sup>“Young carers” is the term generally used in Western countries to refer to anyone “under the age of 18 years who is the primary care giver in the family due to parental illness, disability or addiction” (Aldridge and Becker, 1993). This definition has been expanded to include the phrase “beyond what would be normally culturally expected” in order to reflect variations in the expectations of child contributions to family well-being that families may have across different cultures (Charles, Stainton and Marshall, 2009, 2011).

## Young Carers Provide Primary Care

As both a concept and a recognized practice, young caring entered the public discourse in Canada in the early 2000s, echoing the increasingly articulate voice of young carers being heard in the United Kingdom, Australia and, to a lesser extent, in other Western countries. Led by researchers and activists, the call to acknowledge, understand and better support young carers and their families in Canada found traction among academics, practitioners and advocates concerned with healthy child and family development, with the provision of caregiving supports and services, and with the well-being of Canadians living with illness and/or disability and their families.

As might be expected with any emergent concept, the definition of what it means to be a young carer and to practise young caring continues to be refined and expanded. The feature that ultimately differentiates young carers from other young people who contribute to the well-being of their families is that young carers take on a **primary** caregiving role. For some, this may translate into the provision of high levels of care; for others, it may be frequent low levels of care. The care recipient may be a parent, grandparent, aunt, uncle, sibling or any other family member.

## Young Caring is Not Uncommon

Despite the central importance of young carers to family and community well-being, the largely private and often hidden nature of their contributions makes it hard to identify the exact number of young carers in Canada. Just who these young people are and how they experience their caregiving responsibilities is only beginning to be publicly understood. What we do know is that being a young carer is not uncommon. Indeed, it appears to be a “normal” experience for a small but significant percentage of young people.

A recent survey of high school students in Vancouver conducted by the authors found that 12% of youth are in a caregiving role (Charles, Marshall and Stainton, 2010). Assuming an average classroom size of 30 students, this translates into at least three young people per class providing substantial care, assistance or support to another family member.

*12% of youth are in a caregiving role.*

The high school population surveyed was made up of 1,179 ethnically diverse students from grades 8 through 12. Only students who wanted to participate, and had parental permission to do so, filled out the survey. The final sample size was 483, with marginally more female (270) than male (213) respondents, representing 40.97% of the overall school population.

Those identified as young carers answered yes to the question “Do you spend any time taking care of an adult in your family because they cannot care for themselves?” They ranged in age from 12 to 17 years old, with a mean age of 14 years. The findings showed no significant relationship between identifying as a young carer and the ethnicity or country of origin of the respondent, nor was a distinction drawn between young carers and non-carers with respect to perceived familial socio-economic status. From a family dynamics perspective, fewer young carers than non-carers reported living with both parents (58.6% vs. 70.8%), whereas more young carers reported living with their mothers most of the time (18.9% vs. 13.9%). In 39.7% of cases, parents were the recipients of primary care; another 36.2% of young carers were caring for a grandparent, 6.9% were caring for an aunt or uncle and 15.5% for another family member (Charles, Marshall and Stainton, 2010).

Although preliminary, these findings take us an important step closer to understanding the experiences of young carers in Canada and shed light on a population that has been largely invisible on the family caregiving landscape.

## Young Carers Do Exceptional Work in Exceptional Circumstances

*Once stigmatized, few young people come forward and identify themselves as a young carer.*

Efforts to address the unique needs of young carers and their families can be complicated by the apparent stigma associated with being a young carer and with being part of a family that needs young people to take on caregiving roles. Once stigmatized, few young people come forward and identify themselves as a young carer (Charles, Marshall and Stainton, 2010). Parents are typically even less likely to admit that they have to rely on their children to help support them and the family.

Part of the stigma is borne by a blurring of the lines between what it means to be a young carer and/or a "parentified" child. Child parentification is a process whereby parents abdicate their roles in the family, forcing a young person to take on adult responsibilities, regardless of their developmental level (Boszormenyi-Nagy and Spark, 1973; Chase, 1999). While it is true that all parentified children are young carers of a sort, not all young carers are parentified. Parentification insinuates that none of the parent-to-child support, mutuality or reciprocity that would be expected in a healthy parent-child relationship is present.

In the case of a young carer, there is typically mutuality and reciprocity in at least some of the parent-child relationship. In many families where there are young carers, the circumstances may dictate that the adult abdicate some of his or her parental responsibilities, although not necessarily willingly, permanently or fully. A young carer may, in fact, be responding both necessarily and willingly to temporary, abnormal circumstances by taking on a primary caregiving role.

This distinction is important because the nature of family relationships and dynamics – both perceived and real – influences how we respond as a society. The perception of young carers and their families as dysfunctional or "broken" (as is typical of a parentified child) begs quite a different support response or intervention than does the perception of a "normal" family that finds itself in abnormal circumstances. The former may elicit a child protection or punitive response, while the latter may benefit most from individual and family support interventions.

Academics and activists largely from the disability community have raised concerns about the potential for the label "young carer" to further marginalize a group of families already struggling to meet their own needs (Keith and Morris, 1995; Newman, 2002; Olsen and Parker, 1997). Objections have been made to the characterization of "young carers" as "caring for their dependent parent" or, in its stronger form, "parenting their parents." It is argued that doing so characterizes the adult receiving care as a helpless dependent being "parented" by their child. Such a characterization can undermine the already tenuous position many parents with disabilities find themselves in with regard to how other people perceive their parenting role and legitimacy. And, whereas it is acknowledged that the caregiving contributions of young carers are, indeed, unique and potentially problematic, it is also argued that children normally contribute to household duties and that providing care of one sort or another does not necessarily constitute "parenting."

The response to this critique from the research and service communities has been to emphasize the caring duties of young carers as exceptional, rather than as within the norm of household contributions. References to "parenting their parents" are generally avoided (see Aldridge and Becker, 1996).

## Young Caring Doesn't Stop at 18

As our understanding of young caring has grown, questions have been raised about the appropriateness of limiting the definition of “young carer” to those 18 years of age or younger. The contributions that young carers make to their families typically don't stop once they reach the age of majority. Rather, most go from being a young carer to being a young adult carer overnight, without any change to their roles or responsibilities. Many continue to fulfill their care obligations while also navigating entrance into the paid labour market or into post-secondary education.

Research and experience would have us understand that the needs of young people for ongoing support do not dissolve on the eve of their 18th birthday. Australia has acknowledged this dissonance and bridged the potential gap in support by defining a young carer as anyone in a family caregiving role up to the age of 25 years (Smyth, Blaxland and Cass, 2011).

## The Circumstances of Young Caring Are Varied and Complex

When a crisis occurs or when a parent or adult is ill or incapacitated, families typically move quickly to shore up resources and support to enable ongoing functioning. When the responsibilities of primary care are quickly transferred to a young person, the luxury of gradually growing into the new caregiving role is denied. Young carers rarely have a choice or the time to develop caregiving skills. They do what they can to keep their families intact and functioning regardless of the costs to themselves (Charles, Stainton and Marshall, 2008, 2009, 2011).

While we do not have baseline measures of “normal” responsibilities for children in families, we do know that young carers exceed what would be expected of young people in most families and what the young people themselves would expect (Smyth, Blaxland and Cass, 2011). In this sense, young carers “prematurely” assume adult roles and responsibilities.

Young people take on caregiving roles in their families for a variety of reasons, all having to do with the illness, disability or incapacity of a family member or members and/or parental absence. This might include circumstances where a family member has either a terminal or chronic physical illness or a condition, mental illness or addiction (Charles, Marshall and Stainton, 2010). Young carers are also found in families where there is parental absence either because of divorce or desertion or because of economic reasons that compel one or both parents to be away from home for extended periods of time to provide for the financial needs of the family (Charles, Stainton and Marshall, 2011). In many cases, the reasons a young person takes on caregiving responsibilities are overlapping, such as having a parent with a chronic physical condition and a mental illness (Charles, Stainton and Marshall, 2008, 2011).

Given the diversity and changeable nature of family context, the young carer role typically varies in both duration and range of responsibilities. Being a young carer can encompass an entire childhood and adolescence in the case of a family member with a chronic condition or it may be an intermittent or episodic experience that does or does not recur. Whatever the context, young caring is typically unpredictable and can be highly demanding.

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The types of responsibilities that young carers take on reflect the circumstances in which the family finds itself. The range of duties falls into six broad categories: domestic tasks, household management, personal care, emotional care, sibling care and financial/practical care (Joseph, Becker, Becker and Regel, 2009). Domestic care includes activities such as washing dishes or cleaning the house. Household management may involve shopping or doing repairs around the family home. Personal care can include physically caring for the family member by helping them use the washroom, administering medications or changing dressings. Emotional care might mean supervising the family member or providing him or her with emotional support. Sibling care involves taking care of brothers and sisters. Financial/practical care can involve paying the bills, working to support the family or taking on the role of interpreter. In some cases, the young carer is the sole provider of the care, while, in other situations, there are shared responsibilities with other family members (Charles, Stainton and Marshall, 2011).

## Early Caregiving Can Disrupt “Normal” Development

Understanding the dynamics and impacts of young caregiving on young carers, their families and their communities lends itself to an exploration of the unique importance of the parent-child relationship to healthy child development. At its simplest, the purpose of parenting is to raise children into adults. The role of the parent, in this sense, is to impart the necessary knowledge and to create the opportunities for growth and learning to occur. In practice, parenting is neither a linear nor a unidirectional process (Kuczynski, Marshall and Schell, 1997). Rather, the parent-child relationship is one of reciprocal exchange and influence with parent and child affecting each other's attitudes and behaviour (Bell, 1968; Bell and Harper, 1977; Ambert, 2001).

In a healthy context, this reciprocity is mutually beneficial and supports positive development and growth for the entire family unit. Research has long demonstrated that the bi-directionality of the parent-child relationship is foundational to a child's physical, emotional, cognitive and social development (Kuczynski, Marshall and Schell, 1997). Children are most likely to develop age- and ability-appropriate skills and characteristics when given the opportunities to do so within an emotionally secure and physically safe context. From here, they learn how to modulate emotions associated with stress, such as fear, and how to find comfort or reassurance from others and from within (Bugental, Olster and Martorell, 2003).

A positive parent-child relationship also sets the stage for the acquisition of ability-appropriate skills across a range of domains (Maccoby and Martin, 1983). This process is typified by the incremental taking on of roles and responsibilities in preparation for adulthood, ranging from self-care to simple chores to more complex cooperation and household tasks.

Some of the “pushes and pulls” associated with the uptake of responsibilities may result in conflict as expectations are tested and new roles are defined (Collins and Luebker, 1994). All of this is considered “normal” within the context of the transition to adulthood. Indeed, it is expected of most young people in most families. For many young carers, the “normal” life course is disrupted by their early caregiving responsibilities.

*For many young carers, the “normal” life course is disrupted by their early caregiving responsibilities.*

## Context Matters... So Does Choice and Control

The myriad ways in which a young carer may be impacted by the caregiving relationship are largely influenced by the circumstances of care (Thomas et al., 2003). For example, a young carer growing up in the often chaotic environment of a family with an adult member who has a serious mental illness is more likely to experience adversity in the role than a child who provides care for a parent with a physical illness or disability (Anderson and Hammen, 1993; Barkmann, Romer, Watson and Schulte-Markwort, 2007; Hirsch, Moos and Reischl, 1985). Positive consequences seem to be more likely to occur if there is a healthy degree of mutuality in the parent-child relationship (Armstrong, 2002). Adverse consequences appear more likely if the caregiving is of a longer duration and if the responsibilities are disproportionate to the developmental ability of the young person (Aldridge, 2006). It appears that the younger the person is when he or she is placed in the young carer role, the higher the likelihood of negative consequences. This may simply be a reflection of a greater chronic degree of stress in the family or may be due to more troubling dynamics.

Positive outcomes also appear more likely to happen if the young person believes that he or she has the ability to meet the demands of the caregiving role as well as some degree of control over decisions regarding the care activities (Tatum and Tucker, 1998). The more control the young person has over the experience and the higher the level of support he or she receives both from the care recipient and other people, the more likely there will be positive outcomes. The less the young person's experiences are validated and the less support he or she receives, the higher the likelihood of adverse consequences.

It is important to note that most young people are placed in these roles due to circumstances beyond the control of their parents. Family circumstances can change quickly and dramatically in the event of an illness or accident. Families do what they can when met with adversity. At times, this means that extraordinary burdens can be placed upon young people regardless of what is in their best interests or even within control of the adults in the family.

## The Costs and Consequences of Young Caring

Among the greatest challenges facing a young carer is the social and physical isolation that can result from being burdened with age-inappropriate responsibilities. For some, the cost comes in the form of a childhood lost to the demands of providing family care (Jurkovic, 1997; Noble-Carr, 2002). Young carers typically lack time for themselves and their peers. Missing out on age-appropriate activities coincides with growing up too fast in order to meet the needs of a family (Noble-Carr, 2002). For some young people, although not all, the consequences of this loss can be devastating.

### **Stress and anxiety**

Stress is one of the most debilitating of the common consequences of being a young carer (Butler and Astbury, 2005). In addition to a heavy caregiving load, these youth can be equally burdened by the weight of worry, ranging from concerns about not having the necessary skills required to complete their tasks to being concerned about their parent's health and being fearful that their parent(s) will experience a crisis - medical or otherwise - while the young person is, for example, in school (Aldridge and Becker, 1993; Armstrong, 2002; Noble-Carr, 2002).

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*Some young carers are deeply conflicted between a longing for a “normal” life and the tug of responsibility they feel for the health of their family.*

*The home-based demands of caregiving often limit the time young carers have to develop friendships or engage in social activities.*

*The demands of caring can lead to significant time away from school.*

Many young carers seem to have high levels of anxiety due to the unpredictability of their lives and the potentially unstable nature of the condition of the person in their care (Armstrong, 2002). This instability may be particularly acute in families where parents are struggling with addiction and/or mental illness. That said, the stress and distress of having to run a household, even in a relatively stable family environment, can be entirely overwhelming (Butler and Astbury, 2005).

### **Isolation and resentment**

Given the personal costs, it is not surprising that some young carers report deep resentment of the position they find themselves in as caregivers (Banks et al., 2002; Noble-Carr, 2002). Some are deeply conflicted between a longing for a “normal” life and the tug of responsibility they feel for the health of their family (Barnett and Parker, 1998; Cline, Crafter, de Abreu and O’Dell, 2009). Associated feelings of anger, guilt and loss are common (Noble-Carr, 2002; Robson and Ansell, 2000).

Without the same opportunity to have what might be seen as an age-appropriate life (Dearden, 2000), young carers may report feeling “different” from their non-caregiving peers (Charles, Marshall and Stainton, 2010). This sense of difference stems from the unique nature of their caring role and responsibilities, and the accompanying social isolation. The home-based demands of caregiving often limit the time young carers have to develop friendships or engage in social activities (Armstrong, 2002; Butler and Astbury, 2005; Noble-Carr, 2002).

Feelings of social isolation may also be triggered by any stigma associated with their parents’ conditions (Richardson, Jinks and Roberts, 2009). Some young carers have reported being bullied because of their differences (Richardson, Jinks and Roberts, 2009). Given the very real possibility of ridicule and rejection, young carers may keep their concerns and circumstances hidden from their peers, cutting themselves off from possible support and camaraderie (Armstrong, 2002). This fear of being stigmatized is a powerful force (Barnett and Parker, 1998; Tisdall, Kay, Cree and Wallace, 2004): even if the young carer is not a loner by nature, circumstances may render him or her so (Aldridge and Becker, 1993; Becker 1995; Becker and Dearden, 2004).

Adolescence is a time when youth are connecting to peers, developing new ways of interacting in relationships and building a sense of mastery, independence and confidence in their ability to transition into adulthood. Young carers often bypass this important training ground, compelled by circumstances to remain focused inward and on their family (Charles, Marshall and Stainton, 2010; Chase, 1999). Future relationships with friends and intimate partners may suffer as a result of these lost opportunities to learn how to navigate in the “social” world outside of the family context (Charles, Marshall and Stainton, 2010). The anger, depression and aggression that can accompany prolonged isolation may also serve as a relationship impediment, both in the present and the future (Barnett and Parker, 1998).

In this context, many young carers find themselves caught in a circle of isolation and developmental delays that slow the acquisition of the type of social skills needed to overcome the isolation (Barnett and Parker, 1998; Tisdall, Kay, Cree and Wallace, 2004).

### **Time away from friends and school**

Choice – or lack of it – is a hallmark of the young carer’s experience (Aldridge and Becker, 1993; Becker, 1995). Bound by the needs of their families, young carers are often required to put caregiving ahead of almost everything else. This is particularly impactful when it comes to school and education. The demands of caring can lead to significant time away from school (Aldridge and Becker, 1996; Dearden and Becker, 1995; Moore, 2005). Young carers may need to miss school to

care for a parent in crisis or to take a family member to a medical appointment. Many report being exhausted when they do attend school, having been up all night caring for a family member. Sleep deprivation may result in poor concentration (Page, 1988) and/or aggression with peers (Aldridge and Becker, 1993; Keigher, Zabler, Robinson, Fernandez and Stevens, 2005). Generally, the more demanding the caring responsibilities, the more significant the influence it has on the formal education of the young person, often resulting in poor performance and lower than anticipated educational outcomes (Noble-Carr, 2002; Thomas et al., 2003). This lack of school achievement can have lifelong consequences for young carers by significantly limiting future career choices and opportunities (Davidson, 1996; Noble-Carr, 2002; Moore, 2005).

### **Sensitivity, empathy and compassion**

Despite the very real potential for negative outcomes, it is equally possible for young carers to derive something very positive from their caregiving experiences. When compared with their non-caregiving peers, many young carers report that they have a heightened sensitivity to the needs of others and a corresponding increased level of altruism and compassion (Grossman, 1972). Many young people also report that they enjoy a meaningful and heightened closeness with the person for whom they are providing care (Aldridge and Becker, 1993; Noble-Carr, 2002). Some report experiencing a great deal of satisfaction from what they perceive to be their sense of selflessness and ongoing commitment to the other person (Aldridge and Becker, 1993; Noble-Carr, 2002). Some young carers also appear to derive satisfaction from performing caregiving tasks, as it makes them feel more mature than their peers (Banks et al., 2002;). Many have reported that their sense of feeling needed and loved has led to an enhanced view of themselves as worthwhile, contributing individuals (Aldridge and Becker, 1993). Some indicate having a higher tolerance of others (Johnston, Martin, Martin and Gumaer, 1992) and deriving a great deal of satisfaction from knowing that they are keeping their family together (Banks et al., 2002; Charles, Marshall and Stainton, 2010).

## **Looking Back: Adults Reflect on Their Experiences as Young Carers**

Understanding the long-term consequences of early caregiving on the lives of young carers will require longitudinal research. To fill in some of the gaps, the authors recently conducted a retrospective study, asking 50 adults in British Columbia who were once young carers to look back on their lives (Charles, Marshall and Stainton, 2010). The ages and ethnicities of the respondents varied, as did their pathways into and out of young caring. Some have done well in their lives and others reported still struggling as a result of their earlier and subsequent life experiences.

Despite their diversity, a number of common themes linked the individual stories. Among the most often repeated was the feeling of “invisibility” experienced during their time as young carers when few people seemed to have known about their caregiving responsibilities. It also appeared to the few participants who said that people knew about what was going on that little or no support was offered. This “invisibility” seems to have been the result of a combination of outsiders not paying attention to the family circumstances as well as the inclination of the young carers (and their parents) to not want others to know of the “problems” within the family. Family privacy and preservation were universal concerns among the study participants when they were young.

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*Young carers and their parents often do not want others to know of the “problems” within the family. Family privacy and preservation are universal concerns.*

As adults, study participants were able to look back and identify in their younger selves a premature maturity. It was felt that their family circumstances demanded they grow up faster than would be expected or desired, serving to isolate them from their peers. Many of the participants believed that they did not fit in because they were “older” in spirit, not in age, than their peers.

Many also thought that the roles they took on as young people had a significant influence on them as adults. Many reported that they continued to engage in caregiving roles within their families of origin and in other relationships. They felt they had been “trained” in their childhood and adolescence to be caregivers. A number also reported that they struggled to a greater or lesser extent in later relationships.

Despite having taken on roles as young people that in some ways influenced them negatively later in life, many of the adult young carers also identified positive impacts, stating that they enjoyed the “special” relationship they had shared with the people for whom they were caring. Although the “loss of childhood” was among the consequences of their earlier caregiving roles, they also believed that growing up “faster” helped them later in life to be able to care for themselves. Some participants mentioned that they became more altruistic as a result of their time caregiving.

The extent to which the experience was negative or positive seems, according to the participants, to have been significantly influenced by how they were treated by other family members while being young carers. If they were in parentified relationships or if there were a lack of reciprocity in the interactions with the adults in their families, then the consequences to them were more likely to be negative. When, as young people, they were treated as “children” in the family rather than simply as carers, then they tended to do well later in life. Those who were expected to be the “adult” in the family or who were devalued in the process, tended to struggle later in life.

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## Supporting Young Carers and Their Families

The potentially adverse consequences of young caring can be at least partially mitigated through supports within a young carer’s family and community environment (Tatum and Tucker, 1998). What these supports look like, to some degree, is linked to how the practice of young caring is conceptualized. If young caring is seen purely as a function of the inadequacy of the broader care system, then energies will likely focus on addressing the causal factors associated with young caring rather than on the immediate and long-term needs of young carers more directly. If young caring is understood in a purely pathological sense – that is, young people in “inappropriate” or even abusive situations – then the inclination might be toward a child protection or psychotherapeutic response. If young carers are acknowledged simply as young people in an adult role – a role that may potentially leave them vulnerable for many of the reasons cited above – then the focus is more likely to be on building timely, responsive support for young carers and their families.

A strategic approach to supporting young carers acknowledges their needs as primary care providers without losing sight of the much larger questions of why this type of care is being provided in the first place. Some research cautions against confusing efforts to support and legitimize the role of young carers with tacit acceptance of the shortcomings in the range of resources available to the family member/families in need of care.

Young caring is seen as a function of an under-resourced system of family and adult care. From this perspective, building better supports specifically for young carers requires the development of a fully adequate system of support for ill and disabled persons and their families in general (see Aldridge and Becker, 1996). To wait to address the needs of young carers until such time as a comprehensive care system is fully realized, however, would ignore the rights and more immediate

needs of these children. This would put them at risk of becoming what could be construed as a convenient (and cheaper) band-aid solution to any shortcomings in the public support currently available in communities for ill, disabled and older persons (Moore, 2005).

## Canada's Public Policy Response: Learning From Others First

Canada's strategic public policy response to young carers and their families is in the early stages of development. Wisdom moving forward, however, can be drawn from the the United Kingdom, where a multi-faceted approach to policy and practice has been developed. Through a series of progressive legislative initiatives, young carers in the UK are legally recognized and entitled to regular assessments of their own ability and/or suitability to provide care as part of the overall care plan assessment of the person being cared for. The young carer assessment considers the impact of caring on the young person's life and on current and future development. In this context, young carers are seen as vital and potentially vulnerable members of the care system.

The UK experience speaks to the importance and impact of local young carer programs and direct support services to the well-being of young carers and their families. Evaluations of these initiatives indicate that young carers find the support positive and useful and affirming of their experiences and value as care providers (Butler and Astbury, 2005; Dearden, 2000; Frank, 1995; Frank, Tatum and Tucker, 1999; OFSTED, 2009). These supports can range from respite services to young carers festivals to online peer-to-peer or youth counselling to national helplines for young carers looking for confidential information or advice.

Getting young carers and their families the supports they need requires tackling questions of stigma, invisibility and under-reporting. (Charles, Stainton and Marshall, 2008; Eley, 2004). Young people and their parents are rarely asked by professionals who come in contact with them about who is expected to take on what caregiving responsibilities in the family (Charles, Stainton and Marshall, 2011). In a recent survey of mental health workers supporting families struggling with severe mental illness or addiction, it was found that many practitioners saw the adult with the mental health issue as their sole client and did little work with rest of the family. As such, the young carers in these families are often left out of the care plan. Working with health professionals and front-line service providers to better explore and support a family's caregiving plan/options would go a long way toward relieving some of the stigma associated with early caregiving while also serving to draw young carers out of the shadows (Charles, Marshall and Stainton, 2010; Charles, Lees, Brown and Chovil, 2009).

In 2009, the British Parliament addressed this problem of young carer invisibility by enacting legislation that both acknowledges the unique contributions of young carers to family well-being and safeguards their ongoing health and well-being. The result has been a series of directives from the Directors of Adult and Children Social Services requiring health care professionals undertaking adult and family care assessment to be aware of and to take into account the presence and needs of young carers as follows:

*Young carers are seen as vital and potentially vulnerable members of the care system.*

*A “whole family” approach to supporting young carers delivers the most promising positive results.*

Where a parent or another family member has care or welfare needs arising from physical or mental illness, substance misuse or disability, we will work together and with our partners in health and carers organizations to ensure that:

- There are no “wrong doors” and that young carers are identified, assessed and their families are supported in ways that prevent inappropriate caring and support parenting roles, regardless of which service is contacted first.
- Risks to independence, safety and welfare are responded to in line with “Think Family” concepts and guidance on “Working Together to Safeguard Children.”
- Earlier, better integrated and effective responses to young carers and their families are available using “whole family pathway” approaches.
- Children are protected from undertaking excessive or inappropriate caring roles; further inappropriate caring is prevented; and emotional support is available where needed.
- Parents feel supported in their parenting role.
- The transition to adulthood is supported.
- No care or support package for a parent or sibling relies on excessive or inappropriate caring being undertaken by a young carer to make it sustainable.
- Young carers are helped to achieve their potential and to have the same access to education, career choices and broader opportunities as their peers.
- There is better recognition and greater participation of young carers and their families in shaping what we do and in the development and delivery of responses that promote greater choice and control and prevent further inappropriate caring.

(Association of Directors of Adult Social Services and Association of Directors of Children’s Services, UK, 2009)

Programs built from this framework have been evaluated to show that a “whole family” approach to supporting young carers delivers the most promising positive results, including reduced level of care needs by the adult, reduced level of inappropriate care provided by the young carer, better awareness among schools and other professionals, improved school attendance, increased family resilience and a one-third reduction in children being identified as child protection risks between entry and exiting the program (HM Government, 2008, 2010).

## Young Carer Programs in Canada

It is difficult to compare policy and programming in Canada to that in the UK, where public recognition of, and commitment to, young carers and their families is more firmly entrenched. Three established young carer programs currently operate in Canada. The first one was developed in 2003 by the Alzheimer Society of the Niagara Region called the Young Carers Initiative Niagara (YCIN). YCIN has since evolved into a non-profit agency called the Young Carer Initiative (YCI) to promote the well-being of young carers and their families. In 2008, YCI set up the Powerhouse Project (PHP) as an interagency strategy established to work across sectors with young people and families. PHP offers a variety of supports, including workshops, special events, a drop-in centre, a resource library and respite services. This is the only program in Canada that receives ongoing base funding.

Hospice Toronto has recently developed a young carers program. Operating within a large urban area, this initiative offers similar services to PHP, such as drop-in nights for young people as well as practical skills training, expressive arts, sports, field trips and homework support.

The third initiative, the Youth Caregivers Project, is operated by the Cowichan Family Caregivers Support Society on Vancouver Island in British Columbia. The project has developed a resource team made up of young people and adults who provide support to young carers and their families. The team has also created a documentary film entitled *Ending the Silence* ([www.youthcaregivers.org](http://www.youthcaregivers.org)) and an accompanying curriculum guide that is used to raise community awareness of the existence and needs of young carers and their families. The team has been holding meetings with local school authorities and service providers to begin to embed young carer initiatives in ongoing programs.

## Moving Forward: Child-Centred and Family-Focused

There is still so much left to learn about young carers and their families. Our collective lack of knowledge of the long-term repercussions of being a young carer is significant, especially when coupled with our still developing understanding of the dynamics in families where young people take on considerable caregiving roles. Without this information, the development of responsive and timely supports and services for young carers and their families risks failing to meet their diverse needs.

Experience in other countries is pointing to the benefits of a strong, integrated approach that does not isolate the young person from the broader family context and that does not simply focus on giving young carers a break. Given the infancy of Canada's program and policy response, the opportunity is ripe to work toward the development of what Moore and McArthur (2007) have called a child-centred, family-focused approach wherein the rights of the child are considered within the context of the rights and dynamics of the family (Moore, McArthur and Noble-Carr, 2011).

*There is still so much left to learn about young carers and their families.*



*It is estimated in Australia, a country with a population two-thirds the size of ours, that the labour of young carers annually saves the health and social care systems more than \$18 billion.*

This approach acknowledges the contributions that young carers are making to Canada's social and health care systems through their unpaid labour. While we do not have figures for this in Canada, it is estimated in Australia, a country with a population two-thirds the size of ours, that the labour of young carers annually saves the health and social care systems more than \$18 billion (Moore, 2005). Add to this the emotional, educational and physical costs associated with being a young carer that could be eliminated or at least decreased with the provision of appropriate services, and the costs of not supporting young carers are inexorable.

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