WHO CARES ABOUT Young Carers?

RAISING AWARENESS FOR AN INVISIBLE POPULATION

AN ACTION CANADA TASK FORCE REPORT
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The Action Canada Task Force responsible for this report is made up of:

Vasiliki Bednar, MPP (Toronto), Manager of Engagement and Executive Assistant to the Director at the University of Toronto's School of Public Policy and Governance, is a seasoned research associate and fellow, avid blogger, and aspiring comic who wants to make public policy more fun.

Nicholas Chadi, MD (McGill), Pediatric Resident Physician at Sainte-Justine University Hospital, musician, athlete, bilingual writer, and humanitarian who strives to reduce inequalities in child and adolescent health care.

Matt DeCourcey, MPR (MSVU), Community outreach and engagement specialist, proud New Brunswicker who works with the provincial Child and Youth Advocate, has international development experience, former Aide on Parliament Hill, and sport enthusiast.

Alexandra Kuperman, MPA/MA (NYU), Director of Operations at Macro Properties and founding Director of Genesis: UJA Federation's Centre for Jewish Innovation, is passionate about nonprofit startups and the environment.

Andrew Pilliar, LLM (UBC), Lawyer, former Massey College Junior Fellow and current PhD student, is working to improve access to civil justice, and is community board chair at Gordon Neighbourhood House, a social services agency in Vancouver.

Benjamin Scott, BA (UofC), Associate Director of Official Languages in the NWT, current EMBA student in Aboriginal Business and Leadership (SFU), works to foster multistakeholder partnerships and identifies as a proud Tlicho Dene.

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Any errors or omissions are the responsibility of the Task Force.

This report is dedicated to Young Carers across Canada.

Executive Summary

Young Carers are young people who provide significant care to family members because of illness, disability, or other challenges. While Young Carers are found in every classroom in Canada, they are too often invisible to their teachers and others who could provide support when needed. Because of this, Young Carers may not receive the care *they* need. When properly supported, young caregiving can be a positive life experience. But without proper support, Young Carers can run into educational, health and social barriers that can last a lifetime. These barriers translate into costs and lost opportunities for Young Carers and for society.

This report introduces Young Carers to Canadians, and calls for three first steps to improve conditions for Young Carers across the country: increased awareness, improved data collection and research, and a multi-sector effort to support Young Carers in their communities. Drawing on international examples, the report suggests tangible actions on each of these fronts.

Contents

Meet Kai and Katiana

Kai Bighorn and Katiana Moussa each know what it means to be a Young Carer.

Kai grew up in a Sioux family in the town of Cowichan, BC. When Kai was 16 years old, his father suffered a heart attack, brought on from the stress of congestive heart failure. Kai became responsible for his father's care.

Katiana is 16 years old and lives in Toronto. She has an older brother and an older sister, each of whom has autism, epilepsy, cerebral palsy, scoliosis, and is non-verbal. Katiana's siblings have had these conditions since before she was born.

After his father's heart attack, Kai took on progressively more duties to care for him, sharing these duties with his mother, Deloria. This work varied. Sometimes, Kai helped with house-cleaning and outdoor work – work his father had done before the heart attack. Later, Kai learned how to administer dialysis after his father's kidneys failed. Kai and his mother lived forty-five minutes away from the nearest hospital that specialized in dialysis.

Katiana grew up learning about her siblings' conditions and how to help care for them. She became very attached to her siblings, but was often worried about them. As a seven-year old, she called 911 when her brother had a seizure.

Through his caregiving responsibilities, Kai developed a close bond with his father before his father died in 2008. He also developed a close bond with his mother as they worked to support each other. Kai developed time management and priority-setting skills uncommon for someone his age. But caring for his father weighed on Kai. He stopped caring for his own health because of the strain of caring for his father. He also had to give up part-time jobs because of the time commitment.[1]

Katiana spends much of her spare time with her brother and sister, who live at home, and helps her parents look after them. She talks and plays with her siblings, helps them to bed, and helps her parents with chores around the house.[2]

Kai and Katiana are two of the many Young Carers in Canada. Their stories, like the stories of other Young Carers found throughout this report, are different in many aspects. The goal of this report is to introduce the idea of Young Carers, explain why this issue is of growing importance to Canada, and suggest how communities across Canada can better support these young people when they need it.

WHAT'S IN A NAME?

This report highlights the term "Young Carer". This term is in common use in the UK, Australia, and New Zealand, and has been used in Canada. In the US, "young caregiver" is the most common term. Other terms in Canada include youth caregiver, teen caregiver, or family caregiver. Some Young Carers choose not to identify with a term, or choose their own. The lack of consistent terminology in Canada emphasizes the need for more awareness and research.

Who Are Young Carers?

Young Carers are young people who provide significant care for another person within their family.[*,3]

Many young people participate in work around the home. But as the examples of Kai and Katiana make clear, Young Carers do more than just that. What sets Young Carers apart is that they play “substantial, regular or significant roles” in caring for family members.[4]

Young Carers often have different experiences than youth who are not significant caregivers.[5] Young Carers’ responsibilities can include practical, personal, and emotional caregiving tasks. They can perform a wider range of domestic tasks than their non-caregiving peers, such as shopping, doing laundry, and making dinner.[6] They can also perform more emotional care and general nursing-type care.[7]

Research on Young Carers from other countries suggests that boys and girls become Young Carers at similar rates.[8]

It is important to note that the degrees and types of care provided by Young Carers vary significantly. More important than what Young Carers do is how being a Young Carer *affects* them. And as explained in the next section of this report, being a Young Carer can bring challenges as well as benefits.

Young Carers are found in every classroom in Canada. Too often, they are invisible to their teachers, their peers, and people in their communities who could offer support when they need it. Young Carers themselves may think of what they do as simply a family responsibility. As a result, they may be reluctant or may not know where to look for assistance if they need it. Also, Young Carers may not ask for help out of fear that something bad might happen to their families. This can lead to more serious challenges for Young Carers, and can reduce some of the possible benefits of being a Young Carer.

Research suggests that without appropriate support, Young Carers may face increased social and physical isolation, and may experience lifelong barriers to education and employment.[9] Preventing these barriers is therefore crucial.

Figure 1

WHAT SITUATIONS LEAD TO YOUNG CARING?

- **Addiction** →
- **Mental Illness** →
- **Terminal Illness** →
- **Chronic Physical Illness** →
- **Chronic Physical Condition** →
- **Absence of a Parent Due to Divorce** →
- **Absence of a Parent Due to Economic Reasons** →
e.g. distant work, military service, etc.

Note: These conditions may overlap.

YOUNG CARER STORY: CASSY

“I have been helping to look after my brother for about four years. He uses a wheelchair because he has a disease called muscular dystrophy which makes his muscles waste away. I help him out with everyday things - I get his drinks and cut up his food. I also help out with lifting and picking him up. He’s getting older so it’s getting harder. I’m 12 and he’s 15 so he’s bigger than me.”

Young Carers NZ. (n.d.). *Cassy’s story.* Retrieved from http://www.carers.net.nz/carer_community/young_carers_nz/young_carers_stories/cassys_story.

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[*] Researchers have used the following, more precise, definition: “Young carers can be defined as children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision.”

A recent Canadian high school study found that 12% of youth between the ages of 12 and 17 self-identify as Young Carers.[10] As shown in Table 1, studies from other countries that have researched young caregiving more extensively suggest that there are likely tens of thousands of Young Carers across Canada.

TABLE 1: NUMBERS OF YOUNG CARERS[11]

Country	Population	Number of Young Carers
United States	314 million	1.3–1.4 million
United Kingdom	63 million	175,000
Australia	22 million	170,000
New Zealand	4 million	10,500
Canada	**34 million**	**?**

As a signatory to the United Nations *Convention on the Rights of the Child*, Canada has committed to do everything it can to uphold and safeguard the rights and best interests of all children and youth.[12] Specifically, the *Convention* sets out the right to be protected from all forms of violence, injury, abuse, neglect or maltreatment (Art. 19), the right to a good quality education (Art. 28), and the right to play and rest (Art. 31).[13] This commitment must extend to Young Carers, who provide valued and valuable care for family members. Young Carers may be deprived of their rights, which are vital to their social and psychological development.

CANADA'S COMMITMENTS

Canada has ratified the UN *Convention on the Rights of the Child* and the UN *Convention on the Rights of Persons with Disabilities*. Also, the Canadian *Charter of Rights and Freedoms* protects the right to "life, liberty and security of the person". These commitments support a "whole of family" approach to young caregiving, which is respectful of both child rights and disability rights perspectives.

Young Carers come from a wide variety of backgrounds, geographies, family circumstances, and experiences. This means that any efforts to support or assist Young Carers should be flexible enough to deal with the diversity of Young Carers.

Aspects of Young Caregiving

Being a Young Carer can have its ups and downs. Research from around the world illustrates that being a Young Carer may be linked with both positive and negative effects for the Young Carer.

School can be a place where Young Carers face significant challenges and opportunities. Research from Australia, for example, has highlighted the importance of school for Young Carers.[14]

If Young Carers do not receive support, school can be a challenge. Young Carers can miss school or have educational problems because of caring obligations.[15] Young Carers also experience school absences, lateness, tiredness (affecting attention and concentration), difficulty completing coursework and homework, poor attainment, restricted peer networks at school, difficulty joining extracurricular activities, bullying, and behavioural problems.[16] These can lead to adverse effects in a variety of areas, including: school retention, entry into post-secondary education and training, employment, social connections, and health and wellbeing. For example, an Australian study found that only four percent of Young Carers between the ages of 15 and 25 were in education, compared to 23 percent of the non-carer population in the same age range.[17]

But school can also be a place of stability for Young Carers, and can provide a much-needed social environment and a break from caregiving activities.[18] School can provide an opportunity for Young Carers to connect with other Young Carers, or access community support services relevant to their needs.[19]

In addition to challenges at school, Young Carers may also experience the following difficulties:

- Increased levels of stress and anxiety from worrying about a care recipient or because of the responsibilities of caregiving;[20]
- Resentment of their position as a caregiver;[21]
- Being bullied because they are perceived as different;[22]
- Poor sleep habits because of needing to stay up to care during the night;[23]
- Back problems from lifting people;[24] and
- Constrained opportunities for social, sporting, and other recreational activities and friendship networks, leading to isolation and social exclusion.[25]

YOUNG CARER STORY: KATE

“My name’s Kate, and I’m 18. I care for my younger brother Toby who has severe autism, and my dad who has depression ...

I only found out that my dad had depression when I was 12, but apparently he’s had it since before I was born. Even though I don’t do much in the practical sense of caring, I do worry about him a lot and have had to give my mum a lot of emotional support. When she’s away, I make sure that he takes his medication and I cook for him, since he often forgets to eat. I still love him though, even though it’s not always easy.”

Young Carers NZ. (n.d.). *Kate’s story.* Retrieved from http://www.carers.net.nz/carer_community/young_carers_nz/young_carers_stories/kates_story.

Some Young Carers may experience inappropriate caring situations, or even abuse. Such situations may require intervention to protect those young people. According to language used in the UK, “a Young Carer becomes vulnerable when the level of caregiving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her emotional or physical well-being or educational achievements and life chances.”[26]

YOUNG CARER STORY: HALIME

“I’m Halime. I care for my parents who don’t speak English. I never took my role of being a Young Carer as a burden, because you could not help somebody without helping yourself. Every time I cared for my parents, I knew it was a learning experience and I was growing as a person.”

Youth champions. (2012, June 1). *Hospice Toronto Young Carers Program newsletter*, 2(1), 7. Retrieved from http://hospicetoronto.ca/PDF/HT_YCP_NewsletterVol2Issue_1.pdf.

But again, being a Young Carer can also lead to positive developments, such as practical skill development, independence, maturity, and understanding of illness and disability.[27] In addition, families and care recipients often see benefits such as reduced costs of external care, and the benefit of family integrity and resilience.[28]

Unfortunately, youth who provide care often do not initially identify as Young Carers, and may have difficulty reaching out to make use of support that is available.[29] Caregiving in the family can be a very private affair, and there may be concern on the part of the family or the Young Carer that involving people outside of the family could disrupt the family itself.

Some research has suggested that it is important to understand how ideas about family responsibilities may differ across cultures in order to provide meaningful support for Young Carers. Studies in both

Australia and New Zealand have identified indigenous status as a relevant research dimension, particularly since indigenous conceptions of family and family responsibilities may affect perceptions of caregiving and the role of Young Carers.[30] Studies in the UK have also noted that views about caregiving duties may be affected by family conceptions, particularly in minority ethnic or immigrant families.[31]

It is important not to *assume* that all Young Carers are in inappropriate situations. As Canadian researchers have noted, the perception of Young Carers and their families as "broken" can lead to a much different response than viewing Young Carers as members of "normal" families that find themselves in abnormal circumstances.[32]

This report recommends awareness of Young Carers in a way that does not negatively stigmatize them. It is, however, important to recognize that there may be types and degrees of care that are inappropriate for young people.

Providing support for Young Carers when needed can be crucial in maximizing the beneficial outcomes of being a Young Carer, while minimizing the negative outcomes. As Canadian researchers recently noted, "the higher the level of support [a Young Carer] 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."[33]

Responses in Other Countries

Several countries have taken significant steps to understand and respond to the reality of Young Carers, notably the UK, Australia, and New Zealand. The US has also recently begun to address young caregiving.

In the UK, the government has enacted legislation providing for assessment of Young Carers (and caregivers generally) to understand specific challenges and opportunities in particular situations.[34] Young Carers in the UK are individuals under 18 years old.[35] The number of Young Carers in the UK is assessed through questions on the national census, though researchers have noted that these figures are likely underestimates.[36]

In Australia, Young Carer recognition has been driven by non-governmental caregiving support and advocacy organizations. These organizations subsequently partnered with government policy makers and university researchers to better understand the dimensions of Young Carers in Australia and tailor

YOUNG CARER STORY: GRANT

Grant is a 13 year old caring for his younger brother Macauley who was born with pneumonia and has developed several problems since then.

Sometimes it all gets too much for Grant. When he's sitting in school trying to concentrate but can't stop worrying about what's going on at home.

"What I like about being a carer is knowing I am different. It makes me feel good because I am helping someone. I don't resent the time I give to looking after him because he is special to me and it's not his fault that he is ill."

Swain, G., & Carers Trust (UK) (2007, June). *Grant's story*. Retrieved from http://www.carers.org/grants-story.

responses to those dimensions. Young Carers in Australia are individuals under 25 years old.[37]

In New Zealand, awareness about Young Carers has grown over the past decade. Some caregiver support is provided through national and regional governments, as well as through the Accident Compensation Corporation. Young Carers have recently been recognized under the New Zealand Carers' Strategy.[38]

In the US, research in recent years has begun to identify the incidence and dimensions of young caregiving. Young Carers in the US are individuals under 19 years old. This research is beginning to form the basis for broader awareness and more responsive projects to assist Young Carers.[39]

Responses in Canada

Research has just begun to unearth the issue of young caregiving in Canada. Several researchers have undertaken work to raise the profile of Young Carers in recent years. Most recently, the Vanier Institute of the Family published a report on Young Carers in 2012.[40] This report highlights and summarizes much of the Canadian and international research on Young Carers.

In addition to research efforts, three programs currently exist in Canada to deal specifically with the needs of Young Carers: two in Ontario, and one in British Columbia.

The Powerhouse Project is an inter-agency project in the Niagara region of Ontario. The project grew out of the Young Carers Initiative, which was founded by the Alzheimer Society of the Niagara Region in 2003. The Powerhouse Project provides workshops, events, drop-in opportunities, respite services, and a library for Young Carers and individuals who support Young Carers.[41]

Since 2011, a similar support project has been set up in Toronto by Hospice Toronto. Operating in a much more urban setting, the project also circulates a regular newsletter about Young Carers. Hospice Toronto is in the process of developing a resource guide for organizations looking to set up Young Carer projects across Canada.[42]

In British Columbia, the Youth Caregivers Project has been operated by the Cowichan Family Caregivers Support Society on Vancouver Island since 2010. The project has developed a documentary film (*Ending the Silence*, www.youthcaregivers.org) and an accompanying curriculum guide to raise awareness about Young Carers. In addition to giving presentations to local and national audiences, the project also holds regular drop-in sessions for Young Carers to socialize and find support for their caregiving activities.[43]

YOUNG CARER STORY: SAM

Sam is 14 years old and dreams of becoming a doctor. He lives with his eight-year old sister Susannah, and his mum. His mum has diabetes and has trouble walking...

Sometimes, because of all the things he had to do in the morning, he would be late for school and his form teacher always asked why he was late. He wanted to tell the teacher, but he didn't want to do it in front of his classmates, so he usually made excuses...

After school, he couldn't join in football training or hang out with his mates because he had to rush to pick up his sister and then get home to make sure his mum was OK.

NHS (UK). (2011, May 31). *Being a young carer – Sam's story*. Retrieved from http://www.nhs.uk/CarersDirect/young/young/Pages/Youngcarers stories.aspx.

A Call for Action

Young Carers exist in Canada. However, they are often not identified or supported. This lack of recognition and support does a disservice to Young Carers, who play important roles in their families. If we do not take steps to improve how we support Young Carers, we fail to live up to our international obligations to promote and protect the rights and well-being of young people. We also fall behind other nations that are taking steps to support Young Carers.

The UK, New Zealand, and Australia each boast a coherent national policy response that benefits from national data on the number of Young Carers.

In fact, research from Australia has suggested that the labour of Young Carers saves the health care and social care systems in that country approximately $18 billion per year.[44]

Researchers in Australia have also noted that Young Carers have likely increased in recent years as government support for residential care has decreased and home-based and community-based care has increased.[45] This is a trend that has also been noted in Canada.[46]

There are three reasons why Young Carers should be a concern for Canadians. First, Young Carers are common but often invisible. Second, appropriate young caregiving can have widespread potential benefits for Young Carers, their families, and society. Third, if not properly supported, young caregiving may lead to serious, long-lasting ill effects, including educational challenges, increased unemployment and social exclusion. These effects are felt not just by individual Young Carers, but also ripple throughout society in the form of increased social assistance burdens.

Recommendations

The 2012 Vanier Institute of the Family report on Young Carers in Canada described the call from researchers and activists in many countries to "acknowledge, understand and better support Young Carers and their families".[47] This report echoes those three recommendations, and adds detail about how to do so in Canada. These recommendations aim to build on existing resources and to network existing capacity, where possible.

Recommendation 1: Raise Awareness

To provide better support for Young Carers, it is necessary to first introduce the name and the concept to youth and to individuals who work with youth. To this end, we recommend the initiation of a national campaign to improve public awareness and recognition of Young Carers in Canada. Our goal is to have Canadians recognize the term "Young Carer" and understand both the positive and negative consequences that can be associated with young caregiving. We also hope this will help make it easier for Young Carers to self-identify.

An awareness-raising campaign should engage the following:

- Youth-serving organizations, including:
  - Legislative offices with oversight mandates for children and youth (provincial child and youth advocates);
  - The education sector (e.g. schools, teachers, principals, school nurses, counsellors, and specialized educators);
  - The healthcare sector (e.g. doctors, nurses, social workers, and psychologists);
  - Non-governmental organizations; and
  - Government ministries and departments (e.g. ministries of child and family services, social development departments).
- Organizations that support and advocate on behalf of care recipients;
- Young Carers and their peer support networks;
- Canadian families from all socio-economic backgrounds, ethnicities, and those living anywhere in Canada, in urban, rural or remote settings.

Recommendation 2: Improve Data Collection and Research

It is critical to improve national data collection and research in order to better understand the dynamics of young caregiving across Canada.

To improve data collection, national surveys should include questions about young caregiving. Statistics Canada should enhance existing national surveys such as the Census and the National Household Survey to include questions that would allow researchers to identify and describe Young Carers.

The following existing surveys also provide opportunities to achieve this national snapshot:

- The Participation and Activity Limitation Study (PALS);
- The Canadian Community Health Survey (CCHS); and
- The Canadian Survey on Disability (CSD).

Other federal organizations, such as Health Canada, could also play an important role in improving data collection.

In addition, provincial and territorial data collection and research bodies should engage in data gathering about Young Carers. This could include student opinion surveys, school entry and exit surveys, school registration forms, and medical intake forms for children and adults.

It is also important to support academic research that can explore dimensions of young caregiving that are particularly relevant in Canada. These dimensions might include the effect of geography on conditions for Young Carers, the role of Young Carers in indigenous communities, and the role of Young Carers in immigrant communities.

Recommendation 3: Multi-sector Approach

It is clear that Young Carers may need support in different areas of their lives, from school to health and social services. Addressing the needs of Young Carers requires a multi-sector approach.

It is important for teachers, health professionals, needs assessors and others to understand that youth may act as Young Carers, and to recognize the diversity of Young Carers. For example, sometimes Young Carers play a role even if another adult in the family also acts as a caregiver. Multi-sector collaboration should involve government, non-governmental organizations, the private sector, families and youth. This approach should encourage cooperation at the community, provincial, and national level including at least the following key sectors:

a. Education;
b. Health (including mental health and addictions) and disability;
c. Child and family services (including child protection) and newcomer families;
d. Social development; and
e. Public safety.

In order to build on existing capacity in communities, we recommend that one organization in a community take on the role of Champion for Young Carers. This Champion organization would then act to convene a discussion with other community organizations on the issue of Young Carers, or bring the issue of Young Carers to the table if a network of community agencies already exists.

Conclusion

The recommendations in this report are only first steps.

Improving support for Young Carers requires many friends. Private and corporate philanthropists may see an opportunity to help their communities in concrete ways. Media may see Young Carers as a topical and pressing story that needs a more public profile. Schools may see an opportunity to address the needs of students who may be falling behind for previously unexplained reasons.

But more than anything, this is an opportunity for Young Carers like Kai and Katiana to understand that they are not alone; that society values them and the valuable role they play in their families, and is willing to support them when they need it.

Opportunities for Action

There are many opportunities for action to support Young Carers. Here are some that we came across that raise awareness and use a multi-sector approach:

Awareness:

- A national Young Carers Day to celebrate and connect Young Carers and their families
- Assemblies, special activities, or special days in schools to explain Young Carers to students and to allow Young Carers to self-identify and be recognized
- Training workshops and educational packages about Young Carers for education and healthcare professionals and any professional working with children, youth, or adults
- An online platform where Young Carers can share their stories and access information about their rights, the nature of their work, and resources and support services that are available to them
- A community “scavenger hunt” to build local resource maps for Young Carers
- Activities that explain young caregiving integrated into elementary and/or secondary school health curricula
- Creation of a national Young Carers Bill of Rights or Charter of Rights, which may first be established as a national Carers Bill of Rights
- A video game to make the concept of young caregiving more accessible to children and teenagers

Multi-Sectoral:

- Open a discussion about extending adult caregiving allowances to include Young Carers
- Recreational programs and activities either at school or in the community that allow Young Carers to connect and interact with one another
- A designated resource person (existing staff) for Young Carers in every Canadian school to serve as a local champion and ally
- Support programs to help teenage carers transition from high school into higher education and into the labour market
- Short term respite services for Young Carers who are overwhelmed by their caring duties. They could consist of planned visits in the home, adult day-centre programs, and short term stays in residential centres for relatives with increasing healthcare needs.
- Youth advisory council to help guide policy

Appendix

Young Carers Around the World: Policy Matrix

Category	Canada	England (UK)	Australia	New Zealand	United States	Scotland (UK)
National Carers Strategy	No	Yes – National Carers Strategy: Caring about carers (1999)	Yes – National Carer Strategy Action Plan (2011)	Yes – New Zealand Carers' Strategy & Five-Year Action Plan (2008)	No – National Family Caregivers Association = proxy	Yes – Caring Together: The Carers Strategy for Scotland (2010-2015)
National Young Carers Strategy	No	Some – Kent, Surrey	No	No	No	Yes (2010)
National Young Carers Organization	Young Carers Canada	National Young Carers Coalition	Young Carers (part of Carers Australia)	Young Carers NZ (part of carers.net.nz)	None	YCNET
Website	www.youngcarers.ca	www.youngcarers.net	www.youngcarers.net.au	*Website in development*	http://www.aacy.org/	www.youngcarers.net
Tax Transfer/ Allowance	No	Carer's Allowance (16+)	Not for young carers but for carers	No, government is currently consulting on this. There has been little research about young carers in New Zealand to date	No	Carer's Allowance (16+)
Respite option(s)	Limited	Yes	Yes	Not for young carers but for carers	No	Limited, some options available
National Survey of Young Carers	None	Yes, conducted by the Carers Trust	Yes, conducted by government	Yes, conducted by government	None	Yes, conducted by government

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Design by Michelle Hopgood
michelle.hopgood@gmail.com