STUDENTS WHO ARE CAREGIVERS

What Postsecondary Institutions Need to Know
Suggested Citation:
Boule, J.D. Students who are caregivers: what postsecondary institutions need to know. The University of Guelph: Ontario, 2017.
Acknowledgements

This report has been created by Jessica Boulé (BASc.) with the purpose of fulfilling a graduate course requirement in Knowledge Translation and Evidence Based Practice, at the University of Guelph.

Led by Dr. Andrea Breen, Assistant Professor in the Department of Family Relations & Applied Nutrition, this course has been designed in order to provide MSc. and PhD students with an opportunity to build skills in Knowledge Translation by developing and implementing Knowledge Translation tools. This course has been developed in collaboration with the Community Engaged Scholarship Institute (CESI).

I, Jessica Boulé, wish to acknowledge and thank the University of Guelph, CESI, Dr. Andrea Breen, Dr. Kim Wilson, Caroline Duvieuxart-Déry, as well as the guest speakers from the community and other institutions that assisted in the production of this report by sharing their experiences and insights in Evidence Based Practice and Knowledge Translation.

I also wish to acknowledge and thank the University of Waterloo, the University of Guelph, the Young Carers Project, Dr. Steven Mock, Dr. Andrea Breen and Fitsum Areguy for sharing research results regarding the personal anecdotes of Young Carers from Ontario Universities.

Lastly, I wish to thank Dr. Andrea Breen, Dr. Kim Wilson, Dr. Steven Mock and Fitsum Areguy for reviewing the contents of this report.
Who are Young Carers?
Young carers are people between the age of 15-29 providing unpaid care to a relative or friend living with an illness, disability, addiction, injury. ¹ ²

Some Caring Tasks Include:
- Household tasks: cleaning, cooking, shopping
- Physical tasks: lifting and moving a person
- Personal tasks: dressing and hygiene
- Scheduling tasks: appointments and transportation
- Financial tasks: budgeting, paying bills
- Health care tasks: managing medications
- Offering emotional support and helping with communication ³ ⁴

Who do Young Carers Care For?
While the majority of young carers provide support to only one person, 47% were supporting multiple friends or family members.

Grandmothers received the most care.

Research on Young Carers
Canada lags behind other countries such as the United Kingdom, United States of America, Australia and Sub-Saharan Africa in research, policy and practice to support young carers.

New research is shedding light on the experiences of young carers who are postsecondary students, the impacts of caregiving on their social and academic development, and their needs for support and accommodations.
Every School Has Young Carers

In general, young adulthood represents a period of time with endless possibilities and future opportunities. Responsibilities like marriage, parenthood and careers are often postponed in order to seek out a higher education. During this stage, young adults develop new relationships and connections, travel, and experience an overall exploration of self.

For young carers though, they may not have the supports in place to help them maneuver these many new life choices and changes while also meeting the demands of caregiving. Many young carers do not have the time to build new relationships or even participate in activities outside of school, work, and their caregiving role. While others, may feel as though they do not 'fit in' and that the University or College does not understand the distress and isolation they experience.

As such, many young carers keep their identity hidden and their caregiving role private from faculty, staff, peers, and other campus supports. Many young carers keep their identity hidden and their caregiving role private from faculty, staff, peers, and other campus supports.
"My grandmother had cancer and was fighting severe anxiety. I was up with her late at night [...] and then staying with her until she fell asleep. It prevented me from being fully and properly rested for school or completing my work to the best of my ability. There were negative effects of me having to care for her but it brought me closer to her."

- Young Carer from an Ontario University
The Possible Negative Impacts of Being a Young Carer and a Student

Students providing care are 4x more likely to drop out of University than their peers.17

Physical Effects
- Chronic (lasting) stress 17
- Limited sleep and physical exhaustion from fulfilling caring tasks throughout the day and possibly throughout the night as well 18,19
- Injuries from lifting a person or helping them move 20
- Illness as a result of neglecting their own health needs 21
- Eating problems, substance abuse and self-harm 22

Mental and Emotional Effects
- Limited ability to cope with stress and difficulties in finding resilience 23
- Increased anxiety, depression, isolation, feelings of sadness or anger- 45% reported a mental health problem 24,25
- Constrained to one identity and pressure to fulfill other roles and life events 26
- Emotional exhaustion from witnessing another person’s pain, distress, or discomfort 27

Educational Effects
- Issues in attendance (missing classes and showing up late)
- Increased drop-out rates and unenrollment
- Incomplete or poor completion of assignments and tasks
- Limited participation in academic and social activities
- Lack of understanding from faculty and staff 28,29

Financial Effects
- Unlike older caregivers (45-64), there are no financial resources or benefits available to student carers 30
- Most bursaries require academic excellence and do not support the full academic year 31
- Student carers may work while attending school, in order to provide for their education and the person(s) receiving their support

Social Effects
- Difficulty maintaining and creating friendships or relationships
- Limited time to keep up with activities or participate in new hobbies
- Conflict with family members or individuals receiving care
- Difficulty finding time for partners 32,33
One in five young carers felt that their education had been impacted in a negative way:

- Missed Classes
- Limited Time to Study
- Felt Distracted
- Incomplete Assignments

Adverse impacts typically occurred when young carers spent greater than 10 hours/week on caregiving activities.

7% of young carers could not attend school because of their caregiving activities, postponing education to a later date or indefinitely.  

Data source: 2012 General Social Survey on Caregiving and Care Receiving
How Can Faculty and Staff Support Young Carers?

Being a caregiver is a stressful task, one that may become more difficult when there are additional pressures such as school, paid work, volunteer work, friends, clubs, or any other extra-curricular activities.

A young carer may use their education as a positive distraction. However, a lack of time, finances, energy, interest, sleep or inability to focus may interfere with their ability to attend classes, study, and complete assignments in time.

With limited services, group programs, and policies on campus that target young carers, these students must overcome many challenges on their own. As faculty and support staff, you have the ability to help these individuals buffer the negative impacts of caring.
1. Be Approachable
Create a space where young carers feel comfortable sharing their identity. Offer these students the appropriate support and encouragement they may need to continue their education.

2. Raise Awareness
Share the term "young carer" with other staff, faculty and students. Describe the experiences of young carers on campus and describe the impacts of this role. Help create a group identity.

3. Find Resources
Locate services, resources, and other supports on and off campus that may be inclusive to student carers in your area. Offer these resources to young carers that you meet and explain how they might be accessed.

4. Keep an Open-Mind
Young carers come from a variety of backgrounds. A carer may need to feel heard and know that they are in a safe space to share their thoughts and experiences without judgment or pity. Do your best to provide positive feedback.

5. Be Flexible
Be understanding when a student carer shows up late or is unable to attend a class or appointment. Provide extensions on deadlines when a young carer is experiencing an emergency.

6. Advocate!
Collaborate with other postsecondary institutions, services and community organizations to raise awareness of young carers. Advocate to integrate a new framework on campus that supports young carers.
Carers Trust's Framework for Supporting Young Carers on Campus

Carers Trust is a not-for-profit organization, located in the United Kingdom, that supports caregivers of all ages. Through their research on student young carers, Carers Trust developed two frameworks that could be implemented at the postsecondary level. The frameworks have been summarized as the following phases:

Mission and Vision
The institution will acknowledge and support the inclusion of young carers, which will reflect this commitment by amending relevant policies, literature, website, etc.

Include Staff and Faculty
A committee will provide evidence-based research on young carers experiences and needs. Current student carers will be invited to serve as mentors, representatives and advisers.

Introduce a Lead
The institution assign an individual or team to connect resources and supports across departments, faculty, services and students and local young carer organizations.

Support Systems
The institute will provide support systems that will accommodate young carer needs. This will include: information, supports from student services and unions (e.g., Student Accessibility Services; Financial Counselling).

Raise Awareness
The institution, or lead, will train faculty, staff, and relevant on campus service providers of young carers. This will include more inclusive support systems on campus and initiatives at events (e.g., Frosh Week, Campus Tours).

Identify
The institution will raise awareness of young carers through information provided in the application, enrolment, and self-identification methods. The database will be shared across campus services.
"The first word that comes to mind is sacrifice. You sacrifice your time, friends, and things that make you happy. It's exhausting, hard on your mind and body, and it can be depressing. However, the people I care for are my loved ones. I would not change anything about having to help them."

- Young Carer from an Ontario University
Ontario has shown a higher number of young carers than the national average (27%).

Three young carer programs exist within Ontario: the Young Carers Project of Waterloo (youngcareresproject.ca), the Powerhouse Project of Niagara Region (powerhouseproject.ca) and the Young Carers Program: Hospice Toronto (ycptoronto.com).


Notes

1. A. Breen (2016)
2. Bleakney (2014)
5. A. Breen (2016)
32. Day (2015)
34. Bleakney (2014)
36. Young Carers Project (2015)
38. Young Carers Project (2015)
41. Bleakney (2014)
For more information concerning the information presented in this report please contact:

The University of Guelph
50 Stone Rd. E
Guelph, ON
N1G 2W1

Andrea Breen, B.Ed., Ed.M, Ph.D.
Associate Professor, Department of Family Relations and Applied Nutrition
Telephone: 519-824-4120, Ext.: 53967
Email: abreen@uoguelph.ca