

Exploring Services Available for Young Carers in Waterloo Region

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Table of Contents

| | |
|---|-----------|
| Introduction..... | 3 |
| Literature Review | 3 |
| Purpose of Research | 6 |
| Research Paradigm..... | 7 |
| Method | 8 |
| Findings..... | 11 |
| Discussion..... | 18 |
| Opportunities for Further Research | 22 |
| Conclusion | 22 |
| References | 24 |
| Appendix A: Email Scripts for Participant Recruitment | 26 |
| Appendix B: Survey Information/Consent Form | 29 |
| Appendix C: Interview Information Letter/ Consent Form | 35 |
| Appendix E: Survey Questions | 47 |
| Appendix F: Interview Questions..... | 48 |
| Appendix G: Focus Group Questions | 49 |

Introduction

This report presents the findings of a project that explored social service agencies' awareness, knowledge, and capacity for supporting young carers in Waterloo Region. This project was completed by a multidisciplinary team of five undergraduate students who participated in a research internship with the Centre for Community Research Learning and Action (CCRLA) at Wilfrid Laurier University. CCRLA is an interdisciplinary research centre that focuses on community well-being and social justice. All studies facilitated by CCRLA are guided by community-based research values, which emphasize community-situated, collaborative, and action-oriented approaches. Throughout the course of the eight-month internship, the student researchers worked in collaboration with a community partner called the Young Carers Project (YCP). YCP is an organization based out of Waterloo Region in Ontario, and operates in a collaborative setting to improve knowledge, awareness, and services involving young carers (Townsend, Areguy, desRoches & Amatulli, 2013). It is hoped that the findings will benefit the YCP, researchers doing work in this area, and other organizations in the community, by providing an increased knowledge about the community's awareness of and response to the needs of young carers, as well as directions for future research and development.

Literature Review

Defining young carers. A review of the literature provided a variety of definitions of the term "young carer", and three main definitions emerged. One definition of a young carer is "all children under the age of 18 who engage in in caregiving responsibilities" (Moore & McArthur, 2007, p.561). A second definition is "those youth under the age of 25 years who provide substantial unpaid support to a family member due to factors including, but not limited to, familial or parental absence, disability, mental health issue(s) or problems with alcohol and/or

other drugs” (Stamatopoulos, 2015, p.801). A third definition, and the definition that our study uses, is the one YCP has adopted: “a child, youth, or young adult who cares about a family member with an exceptional need” (Townsend et al., 2013, n.p.). YCP members prefer this definition as it states that a young carer is someone who ‘cares about’ a family member as opposed to narrowing it down to a young carer ‘cares for’ a family member.

Identifying young carers. Regardless of the definition, previous studies have indicated that many policy makers and service providers lack the ability to identify and support young carers (Cass, Smyth, Hill, Blaxland, Hamilton, 2009). It is important that service providers are able to identify and support young carers due to the fact that the population of young carers is expected to dramatically increase in Canada (Stamatopoulos, 2015). This increase in the population of young carers is expected due to Canada’s aging population, shrinking of the pool of potential family carers due to women’s increased employment, adults waiting to have children until later in life, and the increase in grandparents living with their adult children and their families (Stamatopoulos, 2015).

With the population of young carers increasing, the need for service providers to be able to identify young carers becomes more important, as many young carers do not identify themselves as young carers and may not know that there is support available. Many young carers do not identify themselves as such because they view caring for another family member as just part of fulfilling a familial role or duty (Cass et al., 2009). This is particularly the case among immigrant families who are more likely to think of caregiving as a filial duty (Charles, Stainton & Marshall, 2010).

As young carers often do not self-identify, it places greater importance on those professionals in the varying service fields, such as education and health, to be able to help

identify a young carer and provide them with the supports that they need. These professionals do not always identify young carers though due to a lack of knowledge and understanding of the issues surrounding young carers, and also because many young carers go to extreme lengths to hide their home and caring situations from their peers and teachers (Dearden & Becker, 2002). Clearly, young carers would benefit from knowledgeable trained professionals that are able to accurately identify a young carer (Dearden & Becker, 1997).

Importance of social and instrumental support. The degree of social support that a young carer receives is a strong predictor of the level of adjustment outcomes for young carers (Pakenham, Chiu, Burnsall & Cannon, 2007). Past studies have shown that receiving one-to-one support from a service provider or doing group work with other young carers makes a positive influence in a young carers life. These supports provide young carers with a sense of control, opportunities to enjoy themselves, and a break from their caregiving responsibilities (Grant, Repper & Nolan, 2008). In addition to social supports, there is a high need for instrumental supports for young carers. Instrumental supports are defined not only as physical assistance, but also emotional support, advice, and information on caregiving (Kavanaugh, Noh & Studer, 2015). All young carers have unique family situations, for example, a teenage girl who cares for her mother with a physical illness, or a teenage boy caring for a number of siblings (Fives et al., 2010). Thus, young carers may have various kinds of support they need to cope with caregiving responsibilities (Dolan, 2008).

Barriers to supports for young carers. There are both systematic and personal barriers that prevent young carers from accessing social supports. Barriers also limit the implementation of social supports in the first place. As previously stated, many young carers do not identify themselves as such and so do not seek out instrumental supports. Further, when they do identify

themselves, those in the service fields may be unaware of their unique needs and thus may be unable to help them. There is also a lack of variety in the services offered for young carers. Services that do exist that might be beneficial for a young carer and their family are sometimes unaffordable, inaccessible, or simply lack visibility (Moore & McArthur, 2007).

Lack of research available. Research on young carers is not as prevalent in Canada as in other parts of the world, such as the United Kingdom, Ireland, countries in sub-Saharan Africa, and Australia. The UK began producing research on young carers in the early 1990s, when it was identified as an emerging social issue that young carers are hidden and do not have support services available to them (Dearden & Becker, 2002).

One study suggests that children's informal caring roles in both developed and developing countries can be located along the "caregiving continuum" and that young carers globally have much in common irrespective of where they live, or how developed their nation's welfare systems are (Becker, 2007). This study emphasizes the identification of young carers regardless of their nationality or culture. There is a need in all countries for young carers to be recognized, identified, analyzed, and supported as a distinct group of "vulnerable children" (Foster, Levine, & Williamson, 2005). While young carers are a distinct group whose members have various factors in common regardless of where they live, it is important to verify that these common factors are true among young carers from different countries. In order to do that, research on young carers must be done in a variety of countries, including Canada.

Purpose of Research

It is clear from the above that there is a gap in our knowledge about young carers and the support systems they need in order to cope with the reality of caregiving. In Canada in particular, research on young carers remains in the beginning stages with very few studies having been

completed (Stamatopoulos, 2015). YCP completed a study in 2014 to begin assessing the level of awareness that service providers in Waterloo Region have about young carers, which was the first study of its kind in this community. The present study aims to address research gaps – locally and nationally – regarding young carers, as well as to continue the previous research completed by YCP. The goal of this research is to build usable knowledge to support the YCP in enhancing the work of the collaborative. To these ends, the following research questions guided our research:

- 1) What is the current capacity of social service organizations in Waterloo Region to support young carers?
 - a) What do organizations know about young carers?
 - b) What services and programs do community organizations in Waterloo Region have in place to support young carers?
 - c) What resources have been helpful in assisting organizations to better address the needs of young carers?
- 2) What information and resources do social service organizations in Waterloo need to better support young carers?

Research Paradigm

The research paradigm that has guided our study is a pragmatic approach. Pragmatism is defined as a new paradigm that emphasizes action and experiencing the outcomes, and focuses on beliefs that connect to action (Morgan, 2014). The pragmatic approach and constructivist approach were chosen in order to enhance knowledge and to produce practical application in assisting community organizations to better support young carers. Moreover, this approach has allowed the researchers to fully understand and analyze the different experiences of social

service organizations in the Waterloo Region. This is beneficial to our study as we are researching various social service organizations in Waterloo Region in respect to their awareness and capacity of young carers.

Method

This study employed a qualitative approach. Qualitative methods were selected because they are best able to elicit responses about participant's needs, desires, and personal experiences, which is what our research study requires. Additionally, qualitative methods are ideal for exploratory research on complex issues. The researchers first conducted online surveys to obtain a general understanding of what community organizations know about young carers and how they are responding to their needs. Then the researchers conducted semi-structured interviews with survey participants in order to explore their responses in-depth. Lastly, the researchers co-facilitated a focus group to gain insight from the individuals who are involved in the YCP collaborative.

Participants. The online survey participants were staff members of community organizations across Waterloo Region. In all, 14 people completed the online survey. The interview participants were staff members from community organizations, who are also members of the YCP collaborative. Four (4) people participated in interviews, while 14 participated in the focus group. Table 1 displays the sectors that survey participants' organizations represented. The sector most commonly represented was the health sector.

Participants were asked a series of questions about the types of clients their organizations serve, to assess whether they are likely to be providing programs and services to young carers. The size of the client population served ranged from 12 to 20000, with one quarter of participants' organizations serving fewer than 100 clients (n=14). The number of clients who are

Table 1: Sectors Represented by Participants' Organizations

| Sector | Number of Participants |
|-----------------------------|------------------------|
| Health | 4 |
| Mental Health and Addiction | 3 |
| Developmental Services | 3 |
| Social Services | 3 |
| Education | 1 |

children or youth ranged from 0 to 2300, with nearly three-quarters of participants' organizations serving fewer than 50 clients who are children or youth (n=11). The percentage of clients that have children or youth living in the home ranged from 0-100%, with two-fifths of participants' organizations serving 100% clients who live with children or youth (n=10). The percentage of clients who have another family member requiring assistance (due to illness, disability, or language barrier) living in the home also ranged from 0-100%, with half of participants' organizations serving primarily clients who live with a family member that requires assistance (n=9). Some participants responded that they were unable to provide the above information, as they did not know the answer, or their organization does not collect that information. When asked directly, 38% of participants said that their agency currently provides support to a client's child or to a child who has caretaking responsibilities.

Recruitment. This study used a purposive sampling approach. The prospective participants for both the survey and the interview were identified by the community partner, who provided the researchers with a list of members of the YCP mailing list. This included approximately 300 organizations that provide services to youth and/or their families who might identify as a young carer. The researchers added to this list by reviewing the Community

Information Centre of Waterloo Region database (<https://waterlooregion.cioc.ca>) in order to identify other organizations that might also serve young carers but were not on the mailing list.

The community partner sent the list of potential survey participants an invitation by email to participate, which included an information letter and a link to the survey. The community partner then emailed an invitation to potential interview participants. When participation numbers were low, the community partner sent an email to the members of the collective to invite them to participate in the focus group. A copy of these recruitment emails can be found in Appendix A, while copies of the information/consent letters can be found in Appendices B, C, and D.

Procedure. An online anonymous survey with 13 questions was administered to participants to determine their organization's knowledge and practices with regards to identifying and serving young carers (see Appendix E). The survey consisted of yes or no questions followed with comment boxes to allow participants to provide further explanation for their answer. The survey also included short answer questions. The rationale behind choosing surveys as a research method is due to its convenience, flexibility, and high response rates (Fricker, 2002). It is important to note that this survey is based on one previously administered by YCP to community organizations in 2014, with a few extra questions added by our research team.

Interview participants were asked a series of 11 questions, which included topics such as: how their organization identifies young carers, what services and programs they offer that support young carers, what resources have supported them in becoming more responsive to the needs of young carers, what they perceive as emerging best practices locally, and what else their organization needs to improve their support of young carers (see Appendix F). Semi-structured

interviews were chosen for this study as they are an effective approach that allows participants to go in depth and provide detail of their lived experiences. The interviews ranged from 15-60 minutes in length.

Focus group participants answered a series of 9 questions, which included topics such as: current understanding of young carers, barriers and assistances with implementing supports for young carers, resources and training that have been used, what has changed the community, and the YCP collaborative's direction for the future (see Appendix G). The focus group was 90 minutes in length.

Analysis. Quantitative survey data was analyzed using Excel and SPSS. Qualitative survey data was analyzed thematically. The interview and focus group data was transcribed and coded manually. For the interviews, each researcher coded the transcript of the interview they conducted, after which all researchers met to debrief and identify common themes across all interviews.

Findings

Defining young carers. No common definition of young carers emerged, as different organizations had different definitions. Some organizations did not include an age range in the definition. As one participant explained, "That would be a bit exclusionary. I think when you define an age then anyone that falls out of that range doesn't get the definition which is not as inclusive as we'd like it to be". Others did include an age range. As one participant stated:

"An age range [...] has a service shape, service delivery shape, function. Because it's easier to secure funding, and it's easier to create programs, programming, and to link with other organizations to potentially find young carers within the age range. So the advantage of using the inclusive definition also comes with disadvantages where it's hard

to find people if you can't very easily say this is who we are looking for cause it's a very broad, we see it as a very broad thing.”

One participant even said their organization did not have a definition, but that each staff person had their own understanding of the term: “I don't think there's an organizational definition per say, I think individuals have different definition that they work with and some of my networks haven't heard of [the term] before”.

Besides age, participants also pointed out other contradictions in how young carers are defined. One person differentiated definitions that include a focus on the caring activities a young carer does, and more inclusive definitions such as the one adopted by YCP: “I think that the other definitions sometimes focus on what the young carer does, whereas we kind of changed the definition so it's not like you care for someone, but you care about that person so it doesn't matter what you do for them but you're still impacted”. Relatedly, one participant explained that, “a lot of the research that is coming out is more of a medical model and saying that these people are providing physical support, but nowhere do they mention emotional support [that young carers provide]”.

Unsurprisingly then, many participants felt that current definitions of young carers are ambiguous and limited. Not only was the definition of young carers debated by participants, but so was the actual term ‘young carer’. As one person stated: “Young carers isn't really a great name [...] we need something that actually tells you what it is”.

Understanding of young carers. Participants were aware that young carers have extra responsibilities that cause them to miss out on other aspects of their lives. Participants see young carers as facing issues such as “anxiety”, “stress”, “falling behind in school work”, and “missing out on social activities”. It was recognized that this requires a particular level of understanding;

as one participant stated, “I think the role of being a young carer, also with the pressures of going to school, can really impact that youth’s life. So I think it is important to take into consideration what some of the burden is on young carers.”

Identifying young carers. All participants (100%) said that their agency assesses the needs of children living in the home (n=8). However, only 20% of participants said that their agency routinely asks what responsibility the child has within the home (n=14). These questions convey to us what, if any, steps are taken to identify young carers that the organization may come into contact with.

Participants commonly stated that organizations would meet the individual who required assistance, but did not always come in contact with the individual that would be taking care of them. For example, one participant said, “sometimes I wouldn’t even meet siblings”. Another common statement was that our society does not view young people as possibly taking on the caregiver role. One participant stated, “We see adults as caregivers but we neglect the rest of the family”. Participants frequently told us that young carers are still an invisible population.

Related to this point, it was acknowledged that there is currently a significant lack of awareness about young carers within the Kitchener Waterloo community as well as Canada as a whole. One participant stated that, “Canada is really lagging behind,” noting that research on young carers comes mainly from Europe.

Current programming and services. Participants spoke of different supports that their organizations currently have in place to support young carers. These supports included, “in-home volunteer support”, “counselling services”, “therapy”, and “group discussions”. Others mentioned that they did not provide specific services or programming for young carers, but that they provided training about young carers to volunteers and staff. One participant said, “So we

have staff that work one on one or two on one with those individuals [...] siblings are in the program as well so it would help them understand the dynamic”. There were also some participants who felt that serving young carers was not part of their mandate.

Members of the YCP collaborative provided an overview of the work that they are doing as a group, such as providing training and information-sharing opportunities. It was emphasized that the collaborative is focused primarily on raising awareness of these issues across Waterloo Region. As one participant explained,

“I think the largest part of this collaborative is bringing awareness in our region to it, as opposed to really making systematic changes at this point. It’s more of having people getting an understanding for it and to identify and think about ‘oh actually yeah maybe I am, or maybe I know someone who is a young carer that could benefit from any supports that this group could provide, or I could collaborate together with the organizations that are sitting around the table.”

Finally, participants mentioned that while a peer support program is not currently in place to support young carers, the YCP is in the process of developing such as program. One participant informed us that the YCP is, “looking at starting up here a support group with our peer support programs, which hasn’t officially started yet”.

Supports to implementation. Nearly half (46%) of participants said that over the coming year their organization planned to create new programs and services that address the needs young carers, while over a third (38%) said their organization planned to enhance existing programs and services.

Participants identified a few supports that assisted their organizations in building their capacity to support young carers, namely training and partnerships with other organizations. The

YCP training was identified as something that assisted with increasing awareness and understanding of young carers. As one participant said,

“I think that the [YCP] training was helpful, especially the scenarios that were shared. It just gave us a better understanding of the pressures on young carers but also the impact, and I think that’s what really stuck with me is looking at the long term impact on young people who have to care for their parents or siblings.”

Several participants spoke of the changes that their organization made after their staff attended the YCP training, which often involved sharing the content more broadly with their organization’s coworkers, volunteers, and clients. As one person stated,

“As part of our volunteer training, we’ve put in the video link to and the website link to the young carers project. So we also talk about that when train our volunteers so that they have some awareness around how to support young carers.”

Another participant said, “we have a monthly newsletter and share the information that way, we share the documentary online, and also through social media. We just put it out there so that hopefully parents will begin to recognize that in their children”.

Barriers to implementation. Participants also shared barriers they faced in regards to implementing programs and services for young carers. Participants frequently mentioned that awareness about young carers is extremely important, and that the lack thereof presents a significant barrier. One participant stated that,

“It’s still getting people to recognize who they are [...] without the awareness you can’t get the people. I think there’s a lot that needs to be done before we can almost even get to that point of supporting young carers because it’s not recognized.”

Similarly, another participant explained that,

“Young carers are everywhere and often times people don’t know what’s going on in their family home so it’s really hard to even do things like get the research and start a program and really do much of anything because there’s not the awareness”.

Even if organizations are aware of young carers, some participants felt that many service providers find it difficult to prioritize this population. As one person explained:

“It’s at the bottom of the list of all the other things they feel like they need to address, and so I think it’s like the work that young carers do – it’s not valued in our community and in our society, and it’s just like many things that young people do... I think because there is not value placed on it we don’t do much about it.”

A related theme that emerged was the lack of staffing or capacity to focus on young carers. For example, one participant explained that, “some frontline staff are very limited in what they can do [...] I question is it not so much the interest or awareness or understanding of it, but they just don’t have the capacity in their roles to do it.”

Participants also frequently said that identifying young carers is a challenge, as many families want their personal business kept private and many young carers do not self identify as such. As one participant explained,

“They’ve been kind of placed within that family structure of doing it and not really identifying with it. They just believe that that’s kind of what life is, that’s what you gotta do, kind of do your part within the family. I feel if the label gets out there [...] as soon as people identify with it than I think the community can definitely support and help them out much more than what it is now.”

Because young carers do not recognize themselves as doing caregiving work, they may not know what services are available specifically for them. As one participant stated, “I think one of our

challenges is: do young carers know that our services are offered for them? So I think that's a big barrier."

Finally, one participant explained that funding structures are a barrier, "the way health care funding works models of service delivery work, you're supporting the sibling who has special needs or learning needs but you're not supporting the family".

Opportunities for development. Participants also spoke about what opportunities for development exist to address some of the barriers mentioned above. Further training was identified as something that is needed for organizations in Waterloo Region, in particular, making existing training more accessible. One participant stated that, "I would like to see something online that is readily accessible and can be shared with more people [...] online tutorials that would be great". Participants also frequently mentioned that ongoing access to resources beyond the training is also necessary. As one person stated,

"It's not just doing that afternoon training, but also having sort of some ongoing information. I think as workers you go to lots of different workshops and you get lots of different training, so it's having something that keeps that continued contact helps".

Some mentioned that without having young carers included in their organization's mandate it is hard to have programs directed at young carers. Conversely, as one participant explained, "it's really easy to mobilize service providers when something is part of their mandate".

Participants also identified that organizations in Waterloo Region need more funding to be able to support young carers. As one participant stated, "How great would it be to spin off with a young carers peer-support program? That's where certain money would come in handy". Another participant suggested that funding to provide young carers with practical resources like

transportation would be helpful. Related to this point, one participant said that they “don’t know that young carers are on the radar of our government in terms of health and wellness”. A lack of awareness of the existence of young carers, and their unique needs, may present a barrier to accessing additional funding.

Lastly, participants pointed to the need for societal change to support young carers. As one participant commented, “it’s the perception that it’s burdensome because it limits participation in other things that maybe aren’t an obligation”. If negative stigma around young carers is reduced then some young carers may be more comfortable with self-identifying and their families may become more comfortable as well. This may facilitate their uptake of services.

Discussion

Overall, the findings suggest that the capacity of social service organizations in Waterloo Region to support young carers may be somewhat limited. Most capacity building described by participants was at the individual level, related primarily to raising the awareness of staff and volunteers, who would then independently integrate this knowledge into their programming. However, findings also point to opportunities to enhance capacity development and utilization at organizational levels, so as to institutionalize best practices in meeting the needs of young carers.

Knowledge of young carers. As in the literature, participants provided varying descriptions of young carers. Regardless, all knew what a young carer is and most also identified challenges in using the term, demonstrating a high level of knowledge of the concept. In particular, some participants felt the term ‘young carers’ sometimes carries negative connotations, thus resulting in further stigmatizing children and young individuals. Others simply felt the name is confusing, and that common definitions of the term are too restrictive to be useful. It is clear that the terminology and concept of young carers in the local context

warrants further examination, refinement, and even redefinition. Unsurprisingly then, members of YCP are currently in the process of redefining the term young carers for the purposes of their collaborative work.

Aside from knowing what a young carer is, participants were also largely well-informed as to the needs of young carers and able to identify the challenges they experience. However, they also commented on how a broader lack of knowledge about young carers in Waterloo Region is a significant barrier to service access and delivery. This echoes the literature, which points to a significant research gap and widespread lack of awareness of young carers in North America.

While participants can be said to have an individual level of awareness, comments suggested that their organizations have not yet widely adopted best practices in identifying young carers. Specifically, few participants said their staff members routinely ask about what responsibilities children and youth have in the home, and others said they never meet the family caregivers. As a result, young carers are likely to continue to remain invisible to some service organizations. Yet the literature highlights the critical importance of young carers being identified by professionals in fields like health and education, as this supports their access to needed services.

Supports for young carers. The programs and services offered by participants' organizations to address the needs of young carers were mostly described as universal programs, rather than programs or supports specifically for young carers. It is unclear to what extent young carers in Waterloo Region are accessing those universal programs, or how these are promoted in order to attract young carers. Additionally, without targeted promotion, young carers may not know that these services and programs are available for them.

The literature suggests that young carers benefit from instrumental supports designed specifically for them, or with them in mind. Yet no such supports were described by participants, except for a peer-support program that is currently being developed. It is worthwhile to mention that during the focus group, there was a genuine concern among participants about the lack of supports that directly address the needs of young carers. Like other research studies, the comments from participants suggest that the relative lack of support services for young carers can be associated with the lack of awareness of young carers in Waterloo Region.

Participants were aware of the lack of supports for young carers in Waterloo Region, and they identified some barriers that are hindering local agencies' ability to adopt best practices. These included: a lack of general awareness, challenges in identifying young carers (or young carers identifying themselves as such), competing priorities, and a lack of resources. Again, similar themes can be found within the research and practice literature.

Helpful resources. Participants also commented on resources that facilitated the implementation of new supports for young carers. The YCP training in particular helped organizations to develop their own resources to support staff and volunteers in building their capacity to work with young carers. These resources, mobilized through various channels across different organizations, have the potential to raise broader awareness of young carers among parents and other community members. Our findings suggest that this awareness raising, information sharing, and knowledge mobilization is critical to building individual and eventually organizational capacity to support young carers. This is supported in the literature, which suggests that proper training and education enables organizations to properly address the needs of young carers.

Recommendations

Our findings suggest that there are several opportunities to build the capacity of organizations in Waterloo Region to better meet the needs of young carers. There is a need to continue raising awareness of young carers, their needs, and the concept itself – locally provincially, and nationally. YCP should continue to offer its training program, and look at developing additional training materials and resources that can be distributed electronically. This would help to reach a broader audience in two ways: 1) by making information more widely accessible online that can be reviewed at a future date outside of in-person training, and 2) by providing organizations with materials that they can distribute to their staff and volunteers, as well as parents who may be accessing their services and have a young carer at home.

In addition to awareness-raising materials, resources are needed to support organizations in identifying young carers, as the findings suggest that service agencies might be routinely missing opportunities to do so. A tool to screen for young carers that could be widely distributed and adapted by agencies into their intake processes would be a useful resource, and make it more likely that young carers become visible to service agencies and access needed supports.

The lack of funding is a barrier to creating new programs and services. However, an emphasis on providing training and developing resources that agencies can then integrate into their every day operations may be a practical solution. Participants indicated that they have already been taking this approach, and it has been effective in building their organizations' capacity. Another option is to continue seeking opportunities to leverage partnerships in order to create new supports, such as is being done for the new peer-support program.

Finally, given the research gap on young carers, it is also recommended that YCP consider exploring opportunities to conduct a comprehensive needs assessment for young carers

in Waterloo Region. This research would provide an empirically sound evidence base to inform program and service development, and support future grant applications. This research might also support ongoing awareness-raising efforts, as well as encourage organizations to see this issue as part of their mandate.

Opportunities for Further Research

The researchers experienced several challenges in attracting participants to the study and in gathering the desired in-depth responses. It may be beneficial for future researchers to try and establish a more personal relationship with potential participants. For example, conducting a series of phone calls or attending events where they are likely to attend, rather than relying on emails. Additionally, extending the recruitment process over a longer period of time might be helpful in recruiting participants.

Additionally, it is possible that potential participants who do not already know what a young carer is might have self-selected out of the research. It could therefore be helpful to highlight the working definition of a young carer throughout the recruitment process and encourage participants who are unfamiliar with the term to participate. Finally, offering survey participants additional open-ended questions, instead of relying on follow-up interviews, might be more effective in gathering data from staff from non-profit organizations who are already overworked and have limited time to participate.

In terms of directions for future research, it may be fruitful to focus on how “young carer” is conceptualized, to support organizations in coming to a more universally understood definition. Another potential consideration is to expand this research to a broader geographical scope, beyond Waterloo Region. Finally, it should be noted that most of the participants in the current study were highly informed about the experiences of young carers, as many were

members of the YCP. Given the comments about a general lack of awareness in Waterloo Region about young carers, it would be useful to aim to recruit participants from organizations that are not already engaged in building their capacity in this area.

Conclusion

Although there are various barriers to increasing the community's capacity to support young carers, the awareness building activities of the past four years appear to have had some impact. There are currently various activities underway that are enhancing individual-level capacities, and new programs and services to address young carers' needs are being developed. By continuing these efforts and taking up opportunities to expand and build on the existing foundation of knowledge, YCP can further support the capacity of organizations to understand and identify young carers, as well as to take up best practices in providing instrumental supports that increase their wellbeing.

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Appendix A: Email Scripts for Participant Recruitment

Email for Survey Participants

Hello,

We are a team of undergraduate student research interns with the Centre for Community Research, Learning and Action (CCRLA) at Wilfrid Laurier University. In partnership with the Young Carers Project (YCP), we are completing an environmental scan regarding social service agencies' awareness, knowledge, and capacity for supporting young carers in Waterloo Region.

As part of this study, we are inviting approximately 100 staff members from community organizations in Waterloo Region to answer an anonymous online survey. The survey will only take 10-15 minutes to complete, and all participants have the option to be entered into a draw for a chance to win one of five \$10 Tim Horton's gift cards. Your chances of winning are estimated to be 1 in 19.

Please read the attached letter for more information about our study. If you would like to participate, the link below will take you directly to the consent form. We would like to emphasize that participation is voluntary.

[Insert link to consent form]

If you have any questions, please contact us at YCPresearch@wlu.ca, or one of the project supervisors, Dr. Manuel Riemer at mriemer@wlu.ca or Sue Weare at sweare@wlu.ca.

This project has been reviewed and approved by the Wilfrid Laurier University Psychology Department Research Ethics Committee (#5172P).

Thank you,

Deeqa Mussa, Holly Armour, Olivia Courneya, Sulaika Mazhar, and Tristan Simonetta (student researchers)

Email for Interview Participants

Hello [NAME],

We are a team of undergraduate student research interns with the Centre for Community Research, Learning and Action (CCRLA) at Wilfrid Laurier University. In partnership with the Young Carers Project (YCP), we are completing an environmental scan regarding social service agencies' awareness, knowledge, and capacity for supporting young carers in Waterloo Region.

As part of this study, we are inviting six members of the YCP collaborative who have completed the YCP training workshop to participate in a 60-minute interview. All participants will receive a \$25 gift certificate to Chapters/Indigo in thanks for their time.

Please read the attached letter for more information about our study and the interview. If you would like to participate, please contact us at YCPresearch@wlu.ca to arrange a date and time. We would like to emphasize that participation is voluntary.

If you have any questions, please contact us at YCPresearch@wlu.ca, or one of the project supervisors, Dr. Manuel Riemer at mriemer@wlu.ca or Sue Weare at sweare@wlu.ca.

This project has been reviewed and approved by the Wilfrid Laurier University Psychology Department Research Ethics Committee (#5172P).

Thank you,

Deeqa Mussa, Holly Armour, Olivia Courneya, Sulaika Mazhar, and Tristan Simonetta (student researchers)

Email for Focus Group Participants

Hello,

We are a team of undergraduate student research interns with the Centre for Community Research, Learning and Action (CCRLA) at Wilfrid Laurier University. In partnership with the Young Carers Project (YCP), we are completing an environmental scan regarding social service agencies' awareness, knowledge, and capacity for supporting young carers in Waterloo Region.

As part of this study, we are inviting all 15 members of the YCP collaborative who have completed the YCP training workshop to participate in a 60-minute focus group. All participants will receive complementary coffee, tea, and baked goods in thanks for their participation.

If you have already participated in an interview with one of our research team members, you are not expected to attend the focus group, as we will be asking very similar questions. Please let us take this opportunity to thank you for your time!

If you did not have the chance to participate in an interview, and would like to attend the upcoming focus group, please read the attached letter for more information. If you decide you would like to participate, please join us 1 hour prior to the next YCP collective meeting. A reminder will be sent to all members ahead of time.

If you have any questions, please contact us at YCPresearch@wlu.ca, or one of the project supervisors, Dr. Manuel Riemer at mriemer@wlu.ca or Sue Weare at sweare@wlu.ca.

This project has been reviewed and approved by the Wilfrid Laurier University Psychology Department Research Ethics Committee (#5172P).

Thank you,
Deeqa Mussa, Holly Armour, Olivia Courneya, Sulaika Mazhar, and Tristan Simonetta (student researchers)

Follow Up Email for Interview and Focus Group Participants

Hello,
This is a friendly reminder of the scheduled interview / focus group taking place [DATE] from [TIME] at [LOCATION]β. Please see the previous email and the attached information letter for details.

If you have any questions, please contact us at YCPresearch@wlu.ca, or one of the project supervisors, Dr. Manuel Riemer at mriemer@wlu.ca or Sue Weare at sweare@wlu.ca. This project has been reviewed and approved by the Wilfrid Laurier University Psychology Department Research Ethics Committee (#5172P).

Thank you,
Deeqa Mussa, Holly Armour, Olivia Courneya, Sulaika Mazhar, and Tristan Simonetta (student researchers)

Appendix B: Survey Information/Consent Form

WILFRID LAURIER UNIVERSITY

INFORMED CONSENT STATEMENT

Exploring Services Available for Young Carers in the Waterloo Region

Student Researchers:

Tristan Simonetta, Holly Armour, Deeqa Mussa, Olivia Courneya, Sulaika Mazhar

Research Supervisors:

Sue Weare, Associate Director, Laurier Centre for Community Research, Learning and Action

Dr. Manuel Riemer, Associate Professor, Department of Psychology, Wilfrid Laurier University

Information

You are invited to participate in a research study. In this study, we are completing an environmental scan regarding social service agencies' awareness, knowledge, and capacity for supporting young carers in Waterloo Region. As part of this study, we are inviting approximately 100 staff members from community organizations in Waterloo Region to answer an anonymous online survey. Participants will be asked a series of questions about their organization's knowledge and practices with regards to identifying and serving young carers. The survey should take no longer than 15-20 minutes to complete. The researchers conducting the study are five undergraduate students that are working in partnership with the Young Carers Project, an organization in Waterloo Region that strives to improve the knowledge, awareness, and services surrounding young carers. Tristan Simonetta, Deeqa Mussa, Olivia Courneya, and Holly Armour are completing the research study as part of an internship with the Centre for Community

Research, Learning and Action (CCRLA) at Wilfrid Laurier University, under the supervision of Sue Weare, CCRLA Associate Director, and Dr. Manuel Riemer, Associate Professor.

Risks

Participants could feel discomfort or anxiety in regards to the completion of the survey. The questions asked might lead you to recall a stressful event from the past, and answering the questions might cause feelings of discomfort. Moreover, the time commitment to fill out the survey could create feelings of stress and anxiety as participants have many other commitments. These feelings are normal and should be temporary. Please know that you may skip any question or procedure and/or withdraw from the study at any time. If you experience any persistent negative feelings as a result of participating in this study, please contact the researchers and/or a local mental health care resource (Visit the Canadian Mental Health Association – Waterloo Wellington to find local resources: <https://cmhaww.ca/mental-health/find-help/>).

Benefits

The proposed research will help identify emerging best practices locally and enhance research knowledge about what helps organizations improve the lives of young carers. In addition, community organizations and researchers alike will benefit from using the results of this study to better design services and programs catered to young carers. Our community partner and the community at large will also benefit from having a new baseline upon which to measure local progress in meeting the needs of young carers.

Confidentiality

As a participant, your confidentiality is our utmost priority. Only the researchers listed at the top of this form will have access to the data. Please note, however, that while in transmission on the internet, confidentiality of data cannot be guaranteed. No names, emails, or other

potentially identifying information will be collected in association with the survey data. The researchers acknowledge that the host of the online survey (Qualtrics) may automatically collect participant data without their knowledge (i.e., IP addresses); however, the researchers will not use or save this information. Once the survey closes, the data will be transferred to the secured Wilfrid Laurier University network drive, which is accessible only to the researchers. No one from YCP will be involved in the collection of data whatsoever, nor will they have access to any information regarding the identity of participants. Finally, participants will remain anonymous in any publication, presentation, or release of study findings. Survey findings will be reported in the aggregate, and any quotes that are used in reporting will have identifying information removed. In this way, no one person could be directly associated with any one response. The anonymous electronic data will be securely stored and retained for a period of seven years (until April 30, 2024) on a password-protected network drive. After this period, the data will be destroyed by Sue Weare. You will be asked to provide your name and contact information to be entered into a draw (see the Compensation section below) and/or to receive a copy of the results; however, this information will be collected and stored separate from your data and will be destroyed at the end of the study (i.e., by April 30, 2017).

Participation

Your participation in this study is voluntary; you may decline to participate without penalty. If you choose to participate, you may skip any question or procedure, or completely withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study, your data will be destroyed. Your data cannot be withdrawn once data collection is complete because data are stored without identifiers.

Compensation

Survey participants will have the option to enter their name into a draw for a chance to win 1 of 5 \$10 gift cards to Tim Horton's. The odds of winning depend on the number of participants. We estimate that the odds of winning are 1 in 19. If you withdraw from the study, you will still qualify for the draw. The draw will take place no later than April 30, 2017 and the winners will be notified by email.

Feedback and Publication

The results of our research will be presented in a final report to the Young Carers Project and our supervisors. This report will be made available on the Young Carers Project's website by April 30, 2017. We will also present our findings at a mini-conference on April 25, 2017 in Kitchener, which is open to the public. Lastly, we aim to have our findings published in an academic journal. If you would like to receive an electronic copy of the results, please provide your email address below.

Contact

If you have questions at any time about the study or the procedures, or you experience any adverse effects as a result of participating in this study, you may contact the student researchers at YCPresearch@wlu.ca or the project supervisors Dr. Manuel Riemer at mriemer@wlu.ca or Sue Weare at sweare@wlu.ca or 519-884-0710 ext. 3494. This project has been reviewed and approved by the Wilfrid Laurier University Psychology Department Research Ethics Committee (#5172P). If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Doreen Weise, Human Research Ethics Coordinator, Psychology Department, Wilfrid Laurier University, 519-884-0710 ext. 2991, dweise@wlu.ca.

CONSENT

I have read and understand the information in this form. (Note: The researchers recommend that you print or save a copy of this form for your records).

Please check the appropriate box:

- I agree to participate** in this study [clicking here will lead to survey]
- I do not want to participate** in this study [clicking here will close the survey]

QUOTATIONS

The researchers may want to include quotations of your responses to the open-ended survey items in future presentations and/or publications that result from this research.

Please check the appropriate box:

I allow the researchers to use my anonymous quotations. I understand that I will not have the opportunity to review my quotations, but I trust that the researchers will remove any identifying information before they are used.

- I do not allow** the researchers to use my quotations.
-

DRAW

All survey participants can choose to be entered into a draw for the chance to win 1 of 5 \$10 Tim Horton's gift cards. The likelihood of winning depends on the number of participants. We

estimate that your chances are 1 in 19. The draw will take place no later than April 30, 2017 and the winners will be notified by email.

Would you like to be entered into this draw?

- Yes**, I would like to be entered into the draw. Please enter your email:

- No**, I do not want to be entered into the draw

FEEDBACK

The findings of this study will be available by April 30, 2017.

Would you like to receive an electronic copy of the study findings?

- Yes**, I would like to be sent an electronic copy of the study findings. Please enter your email: _____

- No**, I do not want to be sent an electronic copy of the study findings

Appendix C: Interview Information Letter/ Consent Form

WILFRID LAURIER UNIVERSITY

INFORMED CONSENT STATEMENT

Exploring Services Available for Young Carers in the Waterloo Region

Student Researchers:

Tristan Simonetta, Holly Armour, Deeqa Mussa, Olivia Courneya, Sulaika Mazhar

Research Supervisors:

Sue Weare, Associate Director, Laurier Centre for Community Research, Learning and Action

Dr. Manuel Riemer, Associate Professor, Department of Psychology, Wilfrid Laurier University

Information

You are invited to participate in a research study. In this study, we are completing an environmental scan regarding social service agencies' awareness, knowledge, and capacity for supporting young carers in Waterloo Region. As part of this study, we are inviting six members of the Young Carers Project (YCP) collaborative who have completed the YCP training workshop to participate in a one-on-one, face-to-face 60-minute interview. The interview will take place at a mutually agreed upon location, and will be audio-recorded. Participants will answer a series of questions about how their organization identifies young carers, what services and programs they offer that support young carers, what resources have supported them in becoming more responsive to the needs of young carers, what they perceive as emerging best practices locally, and what else their organization needs to improve their support of young carers. As you may already know, the researchers conducting the study are five undergraduate students that are working in partnership with the Young Carers Project, an organization in Waterloo

Region that strives to improve the knowledge, awareness, and services surrounding young carers.

Tristan Simonetta, Deeqa Mussa, Olivia Courneya, and Holly Armour are completing the research study as part of an internship with the Centre for Community Research, Learning and Action (CCRLA) at Wilfrid Laurier University, under the supervision of Sue Weare, CCRLA Associate Director, and Dr. Manuel Riemer, Associate Professor.

Risks

Participants could feel discomfort or anxiety in regards to the interview. The questions asked might lead you to recall a stressful event from the past, and answering the questions might cause feelings of discomfort. Moreover, the time commitment to complete the interview could create feelings of stress and anxiety as participants have many other commitments. These feelings are normal and should be temporary. Please know that you may skip any question or procedure and/or end the interview at any time. If you experience any persistent negative feelings as a result of participating in this study, please contact the researchers and/or a local mental health care resource (Visit the Canadian Mental Health Association – Waterloo Wellington to find local resources: <https://cmhaww.ca/mental-health/find-help/>).

Benefits

The proposed research will help identify emerging best practices locally, and enhance research knowledge about what helps organizations improve the lives of young carers. In addition, community organizations and researchers alike will benefit from using the results of this study to better design services and programs catered to young carers. Our community partner and the community at large will also benefit from having a new baseline upon which to measure local progress in meeting the needs of young carers.

Confidentiality

Data will be confidential. Only the researchers listed at the top of this form will have access to the data. Interviews will be recorded using an MP3 audio recorder. The recordings will be transferred to a secure Wilfrid Laurier University network drive, which is only accessible by the researchers. Once transferred, the recordings will be deleted from the audio recorder. The recordings will be transcribed for the purpose of data analysis. Once transcribed, the recordings will be deleted from the network drive and only the transcribed data will be maintained. The consent forms will be securely stored in a locked cabinet at Wilfrid Laurier University (CCRLA office). All identifiable data will be destroyed by April 30, 2017. The de-identified data will be retained for a period of seven years (until April 30, 2024), after which they will be destroyed by Sue Weare.

At no time will anyone other than the researchers have access to the data. Although our community partner is supporting the recruitment of participants, they are merely promoting the study on our behalf. No one from YCP will be involved in the collection of data whatsoever, nor will they have access to any information regarding the identity of participants. They will also not know who participated in an interview.

Participants will remain anonymous in any publication, presentation, or release of study findings. Any quotes that are used in reporting will have identifying information removed, such that no one person could be associated with any one response.

Participation

Your participation in this study is voluntary; you may decline to participate without penalty. If you choose to participate, you may skip any question or procedure, or completely withdraw from the study at any time without penalty and without loss of benefits to which you

are otherwise entitled. If you withdraw from the study, your data will be destroyed. Your data cannot be withdrawn once data collection is complete because data are stored without identifiers.

Compensation

Interview participants will receive a \$25 gift card to Chapters/Indigo in thanks for their time. If you choose to withdraw from the study, you will still receive the gift card.

Feedback and Publication

The results of our research will be presented in a final report to the Young Carers Project and our supervisors. This report will be made available on the Young Carers Project's website by April 30, 2017. We will also present our findings at a mini-conference on April 25, 2017 in Kitchener, which is open to the public. Lastly, we aim to have our findings published in an academic journal. If you would like to receive an electronic copy of the results, please provide your email address below.

Contact

If you have questions at any time about the study or the procedures, or you experience any adverse effects as a result of participating in this study, you may contact the student researchers at YCPresearch@wlu.ca or the project supervisors Dr. Manuel Riemer at mriemer@wlu.ca or Sue Weare at sweare@wlu.ca or 519-884-0710 ext. 3494. This project has been reviewed and approved by the Wilfrid Laurier University Psychology Department Research Ethics Committee (#5172P). If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Doreen Weise, Human Research Ethics Coordinator, Psychology Department, Wilfrid Laurier University, 519-884-0710 ext. 2991, dweise@wlu.ca.

CONSENT

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature _____ Date _____

Investigator's signature _____ Date _____

QUOTATIONS

The researchers may want to include quotations of your responses in future presentations and/or publications that result from this research.

Please check the appropriate box:

I allow the researchers to use my anonymous quotations. I understand that I will not have the opportunity to review my quotations, but I trust that the researchers will remove any identifying information before they are used.

I do not allow the researchers to use my quotations.

FEEDBACK

The findings of this study will be available by April 30, 2017. If you choose to provide your email address below, it will be detached from this form and destroyed after the results have been sent to you (i.e., by April 30, 2017).

Would you like to receive an electronic copy of the study findings?

- Yes**, I would like to be sent an electronic copy of the study findings. Please enter your email: _____.
- No**, I do not want to be sent an electronic copy of the study findings

Appendix D: Focus Group Information Letter / Consent Form

WILFRID LAURIER UNIVERSITY

INFORMED CONSENT STATEMENT

Exploring Services Available for Young Carers in the Waterloo Region**Student Researchers:**

Tristan Simonetta, Holly Armour, Deeqa Mussa, Olivia Courneya, Sulaika Mazhar

Research Supervisors:

Sue Weare, Associate Director, Laurier Centre for Community Research, Learning and Action

Dr. Manuel Riemer, Associate Professor, Department of Psychology, Wilfrid Laurier University

Information

You are invited to participate in a research study. In this study, we are completing an environmental scan regarding social service agencies' awareness, knowledge, and capacity for supporting young carers in Waterloo Region. As part of this study, we are inviting all members of the Young Carers Project (YCP) collaborative who have completed the YCP training workshop to participate in a 1 hour focus group. A maximum of 14 people will participate in the focus group. The focus group will take place at Kitchener City Hall prior to a scheduled meeting of the collaborative, and will be audio-recorded. Participants will answer a series of questions about how their organization identifies young carers, what services and programs they offer that support young carers, what resources have supported them in becoming more responsive to the needs of young carers, what they perceive as emerging best practices locally, and what else their

organization – and our community – needs to improve supports for young carers. As you may already know, the researchers conducting the study are five undergraduate students that are working in partnership with the Young Carers Project, an organization in Waterloo Region that strives to improve the knowledge, awareness, and services surrounding young carers. Tristan Simonetta, Deeqa Mussa, Olivia Courneya, and Holly Armour are completing the research study as part of an internship with the Centre for Community Research, Learning and Action (CCRLA) at Wilfrid Laurier University, under the supervision of Sue Weare, CCRLA Associate Director, and Dr. Manuel Riemer, Associate Professor.

Risks

Participants could feel discomfort or anxiety in regards to the focus group. The questions asked might lead you to recall a stressful event from the past, and answering the questions might cause feelings of discomfort. Also, sharing opinions openly can create feelings of anxiety, or create conflict if there are disagreements in the group. Additionally, attending a focus group is not anonymous as other participants will know that you participated, and so the comments you make could be shared outside of the group. Finally, the time commitment to complete the focus group could create feelings of stress and anxiety as participants have many other commitments. These feelings are all normal and should be temporary. Please know that you will not be personally called upon during the focus group to respond to a question. Also, you may skip any question and/or leave the focus group at any time, for any reason. If you experience any persistent negative feelings as a result of participating in this study, please contact the researchers and/or a local mental health care resource (Visit the Canadian Mental Health Association – Waterloo Wellington to find local resources: <https://cmhaww.ca/mental-health/find-help/>).

Benefits

The proposed research will help identify emerging best practices locally, and enhance research knowledge about what helps organizations improve the lives of young carers. In addition, community organizations and researchers alike will benefit from using the results of this study to better design services and programs catered to young carers. Our community partner and the community at large will also benefit from having a new baseline upon which to measure local progress in meeting the needs of young carers.

Confidentiality

The focus group will be recorded using an MP3 audio recorder. The recording will be transferred to a secure Wilfrid Laurier University network drive, which is only accessible by the researchers. Once transferred, the recording will be deleted from the audio recorder. The recording will be transcribed for the purpose of data analysis. Once transcribed, the recording will be deleted from the network drive and only the transcribed data will be maintained. Only the researchers listed at the top of this form will have access to the transcript of the focus group. The consent forms will be securely stored in a locked cabinet at Wilfrid Laurier University (CCRLA office). All identifiable data will be destroyed by April 30, 2017. The de-identified data will be retained for a period of seven years (until April 30, 2024), after which they will be destroyed by Sue Weare.

At no time will anyone other than the researchers have access to the transcript. Although our community partner is supporting the recruitment of participants, they are merely promoting the study on our behalf. The researchers will not share with YCP the names of people who participated in the focus group, nor share the focus group transcript with members of YCP. However, potential participants are reminded that other members of the YCP collective who

attend the focus group will know who else participated and what comments they made. The researchers will ask all participants not to share the identity of focus group participants and their comments outside of the focus group.

Although your participation in the focus group is not anonymous, all efforts will be taken to ensure that in the reporting of findings your identity is protected and kept confidential. Participants will remain anonymous in any publication, presentation, or release of study findings.

Use of Quotations

By participating in the focus group, participants consent to the use of their quotations in reporting on findings. Any quotations that are used in reporting will have identifying information removed, such that no one person could be associated with any one response. Participants will not have the opportunity to review their quotations prior to inclusion in reporting.

Participation

Your participation in this study is voluntary; you may decline to participate without penalty. If you choose to participate, you may skip any question or procedure, or completely withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study, all best efforts will be made to erase your data from the transcript. However, given the nature of a focus group and that the data is being stored without identifiers, this may not be possible.

Compensation

Focus group participants will receive complementary coffee, tea, and baked goods in thanks for their time. If you choose to withdraw from the study, you will still receive these as they will be provided during the focus group.

Feedback and Publication

The results of our research will be presented in a final report to the Young Carers Project and our supervisors. This report will be made available on the Young Carers Project's website by April 30, 2017. We will also present our findings at a mini-conference on April 25, 2017 in Kitchener, which is open to the public. Lastly, we aim to have our findings published in an academic journal. If you would like to receive an electronic copy of the results, please provide your email address below.

Contact

If you have questions at any time about the study or the procedures, or you experience any adverse effects as a result of participating in this study, you may contact the student researchers at YCPresearch@wlu.ca or the project supervisors Dr. Manuel Riemer at mriemer@wlu.ca or Sue Weare at sweare@wlu.ca or 519-884-0710 ext. 3494. This project has been reviewed and approved by the Wilfrid Laurier University Psychology Department Research Ethics Committee (#5172P). If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Doreen Weise, Human Research Ethics Coordinator, Psychology Department, Wilfrid Laurier University, 519-884-0710 ext. 2991, dweise@wlu.ca.

CONFIDENTIALITY AGREEMENT

As described above, your identity will be known to the other focus group participants and the researchers cannot guarantee that other participants will respect the confidentiality of the group members or what was discussed. When providing your consent to participate, you will be asked to agree to keep all comments made during the focus group confidential.

CONSENT

By signing below, you agree to the following statements:

- I have read and understand the above information.
- I have received a copy of this form.
- I agree to maintain confidentiality of information shared in this focus group.
- I agree to participate in this study.

Participant's signature _____ Date _____

Investigator's signature _____ Date _____

FEEDBACK

The findings of this study will be available by April 30, 2017. If you choose to provide your email address below, it will be detached from this form and destroyed after the results have been sent to you (i.e., by April 30, 2017).

Would you like to receive an electronic copy of the study findings?

- Yes**, I would like to be sent an electronic copy of the study findings. Please enter your email: _____.
- No**, I do not want to be sent an electronic copy of the study findings

Appendix E: Survey Questions

- 1) What is the nature of the service that your agency provides?
- 2) How many clients does your agency have?
- 3) How many children make use of the services provided?
- 4) What percentage of your client's has children living in the home?
- 5) What percentage of your clients who have another family member requiring assistance (due to illness, disability, or language barrier) living in the home?
- 6) Does staff within your agency routinely ask what responsibility the child has within the home?
- 7) Does your agency provide support to a client's child or a child who has caretaking responsibilities?
- 8) Does your agency assess the needs of children living within the home?
- 9) Does your organization plan to establish services that address the needs of young carers over the next year?
- 10) Does your organization plan to enhance existing services that address the needs of young carers over the next year?
- 11) What has supported your organization in building capacity to address the needs of young carers (e.g., training, new partnerships), if anything?
- 12) What additional resources would your or your organization find helpful in supporting young carers, if anything?
- 13) Please use the space provided below to offer any additional comments on your organization's capacity to support young carers.

Appendix F: Interview Questions

Do you have any questions before we begin? I am going to start the audio recorder now.

1. Tell me about your organization and your role within it.

PROBE: organization mandate and sector

2. How would you describe your current understanding of young carers?

PROBE: What would you say young carers need?

PROBE: What issues would you say are young carers facing?

3. How does your organization go about identifying young carers?

PROBE: do they self identify

4. Do you have specific programming for young carers?

PROBE: physical supports, advice supports, mental health supports, or any other instrumental supports

5. What kinds of changes has your organization made to better address the needs of young carers?

PROBE: created more programming, participated in training, partnered with organizations

6. What are some of the things that made it possible for your organization to implement supports for young carers?

PROBE: supportive leadership, funding, training

7. What are some of the barriers your organization has experienced in implementing supports for young carers?

PROBE: unsure of the needs of young carers, barriers you personally face

8. What has changed as a result of your organization having implemented some of these programs / services / approaches?

PROBE: have more young carers self-identified?

9. What resources or training have you accessed to support your organization in becoming more responsive to the needs of young carers?

PROBE: Did you take the training workshop with Young Carers?

10. Do you feel this training and these resources have adequately prepared you for work with young carers?

PROBE: Was the YCP training helpful? If yes, how so? If no, what would you change?

11. What additional resources does your organization need to better support young carers?

PROBE: what training supports, what financial supports, etc.

I will now turn off the audio recorder. Is there anything you would like to ask me off-the-record?

Appendix G: Focus Group Questions

Do you have any questions before we begin? I am going to start the audio recorder now.

1. How would you describe **your current understanding** of young carers?
 - How does YCP define who is a young carer?
 - Is that different from your organization? If yes, how so?
 - What would you say young carers need? What issues would you say are young carers facing in WR?
2. **What kinds of changes**, if any, has your organization made to better address the needs of young carers?
 - Created more programing, participated in training, partnered with other organizations
3. What are some of the **things that made it possible** for your organization to implement supports for young carers?
 - Supportive leadership, funding, training.
4. What are some of the **barriers** your organization has experienced in implementing supports for young carers? (e.g., unsure of the needs of young carers, barriers you personally face)
5. What **resources or training have you accessed** to support your organization in becoming more responsive to the needs of young carers?
 - Did you take the training workshop with Young Carers?
 - If yes, what do you remember most about that training?
 - What did you find most useful about the training?
 - Did you or your organizations make any changes based on what you learned? If yes, please give an example.
 - What would you change about the training? How would that help?
6. What **additional resources** does your organization need moving forward to better support young carers? (What training supports, what financial supports, etc.)
7. **What has changed in the community** since the establishment of the YCP, if anything?
 - Can you give an example? What made that change possible?
 - What barriers do you think exist for community organizations that impede efforts to support young carers?
 - What gaps still exist, if any, in terms of how our community responds to the needs of young carers?
 - What might help to address those gaps? What resources do you think are needed to increase support for young carers in the broader community?
8. **What can the YCP Collaborative do in the future** to build capacity within the community for supporting young carers?

I will now turn off the audio recorder. Is there anything you would like to ask me off-the-record?