



# THE CROSSROADS OF GRIEF

Reflecting on our work with  
Marginalized Grieving Youth

## Full Research Report Summary

Victoria Pileggi, PhD

Research & Evaluation Coordinator, Children and Youth Grief Network



Ontario  
Trillium  
Foundation



Fondation  
Trillium  
de l'Ontario

## Introduction to *Crossroads of Grief*

The Children & Youth Grief Network (CYGN) is a group of organizations located in Halton, Peel and Toronto that collaborate in an effort to increase awareness of the needs of grieving children and youth. Currently, the CYGN is comprised of 11 network partners, including (in alphabetical order): Acclaim Health, Andrea Warnick Consulting, Bethell Hospice, Carpenter Hospice, C. Elizabeth Dougherty Consulting, Dorothy Ley Hospice, Dr. Jay Children's Grief Centre, Emily's House Hospice, Family Education Centre, Heart House Hospice, and Lighthouse. The vision of the network is that every child has honest information and well-informed support when someone they care about is dying or has died, and our mission is to advocate for educational opportunities and support services that benefit grieving children and youth. To learn more about the CYGN and the resources and research it has produced, visit our [website](#).

In April 2015, the CYGN received funds from the Region of Peel to complete a Literature Review of evidence-based studies published in peer-reviewed journals to better understand the current state of research on children's grief and bereavement, and the primary principles that support our understanding of support provision. A supplemental document compiled a comprehensive list of resources available to grieving young people, including helplines, chats, social media feeds, websites, and other online supports. We also completed a needs assessment to identify barriers and gaps that prevent young people from accessing grief services. Following these projects, the CYGN used data from the 2016 Canadian Census to estimate the number of bereaved children in Canada.

Our literature review identified that 1 in 7 children living in Western countries will experience the death of a parent or sibling before they turn 20. In 2016 alone, it is estimated that over 39,000 Canadian children under the age of 18 experienced the death of a parent or sibling that lives in their home. This equates to over 15,000 children in Ontario, and three children in every Ontario school. If we broaden our analysis to include children who are bereaved by a death in their larger family and community circle, this number increases to over 200,000 in Canada, and 77,000 in Ontario. Over the course of the last decade, there has been a significant increase in the amount of research being conducted on the experiences and needs of grieving young people, however, there is still a scarcity of literature available. Moreover, the availability of well-informed and evidence-based supports and resources remains limited. One of the most considerable gaps can be found in the amount of literature pertaining to grief in vulnerable populations of children and youth. Although the population of grieving families we are serving in our communities is becoming increasingly diverse, we understand little about the complex interplay of grief (a barrier itself) with other sociological barriers, such as cultural, racial and linguistic diversity, histories of immigration, poverty, Indigeneity, sexual identity, disability, geographical region, and histories of criminal activity or contact with the child welfare system.

In early 2018, the CYGN successfully applied to the Ontario Trillium Foundation's Seed Program for funds to conduct and share research that would enhance the knowledge and skills of its network partners and community stakeholders in relation to working with marginalized grieving children. The project is titled, *The Crossroads of Grief: Understanding Grief & Diversity*. By engaging in this work, we intended to better inform our resources and services, ensuring that they are sensitive to the needs of marginalized communities. The activities encompassed within the project included:

- 1) Updating the previously-conducted literature review;
- 2) Undertaking a new, comprehensive review on marginalized communities and grief, with particular emphasis on Canadian populations; and,
- 3) Developing and delivering four information sessions for clinicians, healthcare providers, educators, and parents/community members to share findings, inform best practices and determine our next steps.

This report summarizes the last year of research work at the CYGN, and shares the most significant findings and recommendations.

## Methods

The *Crossroads* project was split into three phases: literature review and statistical estimation; original research with grief and community organizations; and, exchange events with four groups of stakeholders (clinicians, healthcare providers, educators and families). The phases occurred generally in a step-wise fashion, with previous phases nearing completion before the commencement of the next (see Figure 1). Within each of these larger phases however, were multiple, smaller chapters or stages that contributed to the overall success of the project. The methods involved in each phase are described below.



Figure 1: Crossroads of Grief project phases

### Phase I: Literature Review - October to December 2018

One of the key objectives of *Crossroads* was to update our 2015 literature review, with special focus on marginalized, vulnerable communities of children and youth. The CYGN engaged Barry Ashpole of MediaWatch, the consultant who completed our original review, to explore more recent literature (2015-2018) on children's grief and bereavement. In total, 150 articles were reviewed, and findings were categorized into one of nine research areas: children's understanding dying and death; pre- and post-death experiences; the intersection of grief, diversity and social barriers; the long-term impact of grief; programs and interventions; assessment tools, education and training initiatives; and valuable resources. The full literature review can be found on our [website](#).

Following the completion of the literature review, Andrea Warnick, one of our network partners and a renown psychotherapist, grief counsellor and educator, collaborated with Barry to summarize key findings and themes in the literature in an overview document available [here](#). The findings contained within this literature review are not referenced in depth through this report. However, the most significant theme highlighted in the literature is the lack of evidence-based, published studies exploring grief in the diverse communities we sought to learn more about, especially children and teens.

This children and youth-focused literature review was followed by another brief review of the literature on grief in marginalized communities in general. In total, an additional forty-two articles spanning a larger timeframe (2002-2018) were identified through database searches using key words (i.e. grief, bereavement, marginalization, diversity, poverty, low-income, racialized, Indigenous, LGBTQ+, immigration, refugee, disability). This literature review was not limited to peer-reviewed journals; rather, it included studies and articles from grey literature, including reports from government agencies and scholarly book chapters. As the number of papers relating solely to grief and bereavement was extremely limited in some communities, literature on related topics were incorporated into the search — including general mental health given it's relationship to grief and bereavement — to better understand individuals' experiences and the barriers faced when attempting to access supportive services and resources. Articles were read and key findings were analyzed to determine relevant themes within and across communities. A full list of referenced articles, grouped by topic area/community can be found in Appendix A.

Finally, we used the 2016 Canadian Census numbers to estimate the number of bereaved children living in marginalized communities (Statistics Canada, 2017a; 2018). Using the population estimates provided, the number of deaths that took place in Canada, and the number of census families living in the country, we first extrapolated the number of children 18 years and younger who were bereaved in 2016. We then examined the proportions of the population that identified as belonging to each of the marginalized communities listed above. These percentages were then applied to the

total number of newly bereaved children calculated to be residing in Ontario in 2016 to estimate how many were marginalized.

## **Phase II: Original Research - January to April 2019**

Once we come to a better understanding of the number of marginalized grieving young people in Ontario, as well as their needs, experiences and barriers, we conducted original qualitative research with our CYGN network partners to determine how these communities were being served within our organizations. To be clear, we elected to speak with our network partners as service providers, rather than with the groups we wanted to learn more about because we felt that we had not yet established strong enough ties to leaders and individuals living in these communities, and we did not want to be perceived as “using” any group merely for professional insight and economic advancement. We felt it may be important to first internally review our processes for supporting diverse grieving young people, reflect on our capacity to do meaningful work with these groups, and identify critical next steps to increase our accessibility and sensitivity to these groups before inquiring directly about their experiences and needs.

An interview protocol was developed with the CYGN executive committee that referred directly to these lines of inquiry. A full list of interview questions can be found in Appendix B. We focused the majority of the interview on the capacity of organizations to work with marginalized grieving young people, as opposed to having partners hypothesize what barriers existed for these clients. This was done intentionally to avoid further marginalizing communities of individuals by assuming their experiences and making recommendations that address them. Nine network partners from seven organizations were interviewed in the Winter and Spring of 2019. Each of these partners represented the grief and bereavement sector, working directly with children, youth and families impacted by death and dying. Two organization representatives were unable to be interviewed due to scheduling conflicts, and another felt it would be unable to speak directly to grief-related questions as it focused on general parent education. This organization did, however, take part in the survey stage of research collection (see below). At the time of the interviews, one organization had yet to enter a formal partnership with the CYGN. Interviews with network partners ranged from 36 minutes to 1 hour and 40 minutes. All interviews were audio-recorded, transcribed, and thematically analyzed to determine consistent practices, concerns, strengths and obstacles faced in their work with grieving families, especially those who identify as minorities in one or more ways.

Following these interviews, the CYGN executive committee created a short survey to explore the needs, experiences and capacities of other organizations. This survey was distributed to over 180 individuals and organizations working directly with marginalized children, youth and families, but not

specifically in the context of death and grief. The list included organizations such as: Reach Out Centre for Kids (ROCK), Peel Children's Centre, Ontario HIV Treatment Network, The Ontario Council of Agencies Serving Immigrants (OCASI), The Newcomer Centre of Peel, Elizabeth Fry Society of Peel Halton, The 519, Rainbow Health Ontario, Kids Help Phone, Children's Aid Societies of Toronto, Peel and Halton, Enahtig Healing Lodge, Home for Good Peel, Peel Aboriginal Network, Learning Disabilities Association of Ontario, and Big Brothers, Big Sisters. We inquired about the types of grief that organizations encountered in their work with clients (other than grief due to death), the percentage of clients they believe are grieving a death, and the way that grief impacts the work they do. The survey also asked respondents to share the barriers their clients face in accessing grief support, and ideas for resources and services they would like to receive to increase their capacity to work with grief. In total, 36 responses were submitted to this survey from a variety of organizations. The results were analyzed to determine themes within and across community partners and sectors. The data from these community organizations was also compared to the data collected from our network partners to determine similarities and differences in the priorities and perspectives of both groups.

### **Phase III: Knowledge Exchange Events - February to May 2019**

Finally, as part of our proposal to the Ontario Trillium Foundation, we aspired to share the findings of this project with community stakeholders, including educators, healthcare providers, clinicians and family members. We also hoped to share more about the CYGN, its mission and vision, as well as the variety of resources available to these community members. Over the course of Winter and Spring 2019, we held four Knowledge Exchange events.

The first was held on February 1, 2019 at the Halton District School Board (HDSB) in collaboration with our network partner, C. Elizabeth Dougherty Consulting. We had a total audience of approximately 80 school staff, including social workers, child and youth workers, speech language pathologists, and school psychologists. The CYGN presented about the collaborative and *Crossroads* project in the morning session (approximately 1 hour in length). We were joined by members of the network, who also shared information and eligibility criteria for their respective programs and services.

The second and third presentations were to an audience primarily composed of healthcare providers; we presented at the Hospice and Palliative Care Ontario (HPCO) Conference on April 30, 2019 in Toronto, and at the Trillium Health Partners' (THP) Hospice Palliative Care Week on May 1, 2019. In total, we presented to approximately 50 individuals at both of these venues combined, but the THP presentation was broadcast to a number of other health centres across the province. The audience included palliative care physicians, nurses, volunteers, as well as grief and bereavement clinicians

and hospice staff. Each presentation was approximately 1.5 hours in length and included breakout discussions and question and answer periods.

The fourth, and final, Knowledge Exchange was a webinar co-hosted with network partner, Andrea Warnick, on May 14, 2019. Andrea hosts monthly webinars on a variety of topics related to children's grief and bereavement. She and the CYGN collaborated to promote the new 1.5 hour webinar, focused on "building practitioners' toolboxes"; together, we highlighted the results of the research being conducted on marginalization, and explored a number of different resources available to grieving families, children and youth. A link to the webinar can be found on our YouTube channel [here](#). In total, we had 160 viewers online when the webinar went live, including healthcare professionals, clinicians, social workers, parents, and volunteers, however, over 400 individuals registered for the webinar and received a link to the recording once it was complete. We have since received over 170 additional views on our YouTube page.

An evaluation form was distributed at each of these exchange events, inquiring about the respondent's profession, the impact of the webinar, and possible next steps that the CYGN could pursue to support additional learning. The results of these evaluations are included in the Findings section below.

## Findings

### Phase I: Literature Review & Population Estimates

As was made clear in the overview completed by Ashpole and Warnick (Children & Youth Grief Network, 2018), literature on grief and bereavement is expanding, but there is still far less being published on young grievers. More specific details on their literature review can be found in their report and accompanying summary, however, one of the key themes of their review is that there is even less understood about grief in communities of marginalized, grieving young people. Upon searching various databases for additional literature on grief in marginalized communities, it is clear that scholarly inquiries are beginning to expand into this area, too, albeit in limited ways. While this review refrains from annotating individual studies, there were a number of key themes that arose from our closer purview of the literature.

Firstly, the literature on marginalized groups is often **one-dimensional**, focusing on only one aspect or element of a bereavement experience. For example, when surveying the literature on grief in racialized groups, specifically African Americans/Canadians, a large proportion of the studies explore the impact of homicide and other violent acts. Similarly, research with individuals living with disabilities (most commonly intellectual disabilities) is comprised mainly of assessments of their

understanding of death, and studies of Indigenous communities are primarily focused on the frequency and prevention of suicide. By focusing primarily on these themes, the literature tends to paint an extremely limited picture of these groups, one that is often dehumanizing and further stigmatizing. For example: the high proportion of studies on grief resulting from murder, gang-related activity and other violence suggests that minority groups, specifically Black Americans and Canadians are inherently brutal and cruel, and that the majority participate in criminal acts; the almost exclusive focus on suicidality in Indigenous communities may imply that these individuals are naturally mentally ill, depressed, unstable, or unable to deal with the pressures of day to day life; and, the preoccupation with individuals' narrow (or somehow disparate) understanding of death hints that those living with intellectual disabilities are biologically incapable of understanding simple principles and facts of life, unable to move through the world and grieve a death without professional support. It is, however, critical to note that much of this research is conducted without appropriate contextualization; there is little attention given to the way in which systemic barriers produce the conditions described in these studies, namely the way in which these groups have been historically excluded from a variety of institutions, the legacies of violence enacted on them in previous generations (including colonization, cultural genocide, slavery, sterilization and institutionalization), and the ongoing influence that racism and discriminatory economics and politics have on the lives, needs and treatment of these groups. When taken together, these themes signify that these marginalized groups are somehow mourning deaths unworthy of grief, or are undeserving of honesty and well-informed support.

This one-dimensionality similarly causes us to overlook the fact that these communities also grieve other types of deaths, including those caused by illnesses and accidents. Indirectly, this oversight can lead to the incorrect assumption that these deaths occur with less frequency in these populations. This in turn leads to grief scholars and educators having a limited understanding of the impact and experience of grief. If we are not exploring what all types of grief looks like in diverse populations, we remain unable to make accurate conclusions about what grief is, how it manifests, and how professionals can best provide support.

The literature is equally one-dimensional in that it rarely explores how multiple forms of marginalization intersect and influence one another in the grieving process. All humans occupy multiple identity categories at the same time (i.e. male/female, racialized/white, disability/ability, heteronormative/queer etc.). While these categories do not necessarily advantage or disadvantage people in additive or compounding ways, they do overlap in unpredictable manners, creating a wide variety of individual experiences (Erevelles & Minear, 2010; Garry, 2010; Hirshmann, 2013). Given the expression of grief is dependent upon one's age, gender, sexuality, race, culture, geography, class, religion, socioeconomic status and other facets of identity (Cowles, 1996; Stroebe & Schut, 1998), it



makes sense that very personal and unique experiences of grief will arise from the intersection of the categories they belong to. For example, a young, Black, Canadian-born woman living in rural Manitoba may have a very different grief experience than a middle age, South Asian man who immigrated to an urban city in Southwestern Ontario. Similarly, a white and cis-gender identifying, teenaged male living with a disability in a Muslim family will likely have completely distinct experiences from a non-disabled, trans-female living in a Jewish household. The diversity in people's perceptions of, and interactions with, the world undoubtedly have an impact on people's experiences of grief, their relationship to illness, death and dying, and the meaning made of both these processes and the traditions attached to them. However, this diversity tends not to be reflected in the literature on grief. Rarely do studies explore more than one of these identity categories at a time in their analyses. Instead, they focus on participants' sexuality, gender, race *or* religion without attending to how this one facet is tied to and/or mediated by others. As a result, our understanding of grief is flattened; we are made to falsely assume that everyone who identifies with a certain community or group has the same experiences of grief, needs the same level/type of intervention, or encounters the same barriers when attempting to access grief support.

This oversight bleeds into the second major theme identified within the literature: the finding that marginalized groups are **rarely represented** in studies that explore and develop assessment tools and program impacts. In our search of the literature, there were very few studies that emerged as focusing centrally on marginalized populations; searches that included grief/grieving/bereavement alongside other key terms such as "marginalization/marginalized, racialized/racialization, African American/Canadian, South Asian (and other cultural groups), poverty, low socioeconomic status, urban/inner city, LGBTQ\*, immigrant\*, refugee\*, Indigenous, disability and others were returned limited results. One study conducted by Granek and Peleg-Sagy (2015) investigated the representation of African Americans in the grief literature from 1998 to 2014. Excluding other literature reviews, case studies, and other grey literature (such as opinion pieces, book reviews, theses and dissertations), the authors' search using "bereavement" as a search term generated thousands of results — 2,428 using PsychNet, 3,505 using Medline, and 3,911 using CINAHL. However, the addition of "African American" to the search engine reduced the number of results to 40, 38 and 24 within each of these respective databases. They also determined that only 31 of the identified articles published in the selected timeframe used exclusively African American samples, while 28 other articles used African Americans as a comparative sample to whites. These numbers alone demonstrate the dearth of literature on grief in Black communities. While it is changing, this methodological oversight is also identified in some of the literature on individuals living with intellectual disabilities. A substantial proportion of the literature is being conducted from the perspectives of caregivers working with the individuals rather than with the individuals themselves.

To further complicate matters, 13 of the 59 studies identified involved tools and inventories that assess pathological grief outcomes such as traumatic and complicated grief. Unfortunately, these tools were developed primarily using samples of highly educated, middle-upper class, white, elderly widowed women (Granek & Peleg-Sagy, 2017). As such, these tools are being used to make clinical appraisals regarding the functionality and "normalcy" of grief in black communities, despite being validated in groups with extremely different social and political experiences. Consequently, the literature, though insufficient, is classifying the experiences of some marginalized groups as un/healthy and mal/adaptive depending on diagnostic criteria that likely does not apply to these groups, a phenomenon known as a "category fallacy" (Kleinman, 1987). Though similar meta-investigations into scholarly methods were not identified and appraised as part of this literature review, we can assume that similar patterns of exclusion and misclassification have occurred with poor, newcomer, Indigenous, and LGBT+ communities.

Finally, there are remarkable similarities in the **barriers experienced** by marginalized groups. We found that some of the literature specifically explored barriers to accessing grief support, however, by broadening our search slightly, we discovered that a number of scholars had explored the barriers that some communities experience as they navigate mental health services. We felt these articles were appropriate to include in our thematic analysis given the parallels that exist between these realms of clinical services. For example, in their exploration of the needs of immigrant, refugee, ethnocultural and diverse groups (IRER), McKenzie and colleagues (2016) determined that the most common barriers to service access include: service accessibility (i.e. wait times, cultural incompatibility, complicated procedures, and restricted hours of service); uncomfortable or insufficient interactions with healthcare providers (especially cultural divides between Anglo-Western providers and service users); circumstantial factors (i.e. transportation, financial concerns, location of services, insurance coverage, employment and family responsibilities); language; stigma; and, fear (especially fear of medicalization, children being taken into custody and status implications). In an analysis of South Asian youth living in Peel, Islam and colleagues (2017) discovered that youth feel challenged by: language barriers; the lack of "culturally safe" care (including a lack of South Asian professionals and youth-focused professionals in the field, as well as a lack of variety of models of care); transportation; stigma; long wait times; high fees; and, a limited awareness of available services. Researchers have also written about the barriers that LGBTQ+ community members experience both as they attempt to access grief and mental health supports. Bristowe, Marshall and Harding (2016) found that lesbian, gay and trans\* people grieving the death of a partner faced negative interactions with healthcare providers, legal and financial issues surrounding the recognition of their relationship, and general disenfranchisement, as many had been made to conceal the nature of their relationship for fear of social and professional implications. They also felt there was a shortage of appropriate and representative professional supports; those that accepted

their relationship status and relied less heavily on heteronormative (and even homophobic) values and principles. Likewise, the most commonly endorsed barriers by transgender individuals seeking to access mental health services included: cost; hearing about others' negative experiences; a readiness to discuss personal matters with others; a fear of medicalization, services and consequences; and, the stigma associated with service access (Shipherd, Green & Abramovitz, 2010). While this literature spans only a few of the groups referenced in our larger *Crossroads* project, altogether, the commonalities in the barriers experienced by racialized, newcomer and LGBTQ+ groups suggests that the current state of mental health services in North America is routinely falling short of serving marginalized people.

After reviewing the literature, we returned to the Canadian Census to estimate the number of bereaved children and youth under the age of 18 who identify as part of a minority or marginalized group. Tables 1 and 2 summarize the key findings. It is important to state however, that these numbers are estimates only, based on the reported percentages of the Canadian population identifying as belonging to one of these groups. As these estimates are based on the number of parental or sibling deaths in census families in Canada — defined as a married/common law couple and their children, or a lone parent living with at least one child (Statistics Canada, 2019) — these numbers do not include the large number of children who are grieving deaths in wider family units (i.e. grandparents, aunts, uncles, cousins) and friend circles. **These figures must be interpreted with caution, however, given the limits inherent to extrapolating estimates from statistical reports.** The total number of bereaved children in Canada was calculated using the number of deaths in the Canadian population between the ages of 0 and 54, and not the total mortality rate, in an attempt to hone in on parent and sibling relationships specifically. These numbers would be much higher if we were to include the total Canadian mortality rate for all age brackets, which would likely include some parents, grandparents, and even great grandparents who live to be much older than 54 years of age. Furthermore, the numbers reflect only the number of Canadian children living in the home with the person who died; if we were to account for the deaths of siblings and parents who are not residing with a child, the numbers of bereaved children in each geographical region would be much higher than Table 1 reports. It is also true that the mortality rate within each of the reported geographical regions differs from that of Canada, however, in the absence of updated mortality data for Ontario, Toronto, Peel and Halton, mortality rates were projected by multiplying the Canadian total by the proportion of the population living in each of those regions.

**Table 1**

*Estimates of Children and Youth under the age of 18 who were bereaved by the death of a parent or sibling living in their home in 2016*

	<u>Canadian</u> <u>Estimate</u>	<u>Ontario</u> <u>Estimate</u>	<u>Toronto</u> <u>Estimate</u>	<u>Peel</u> <u>Estimate</u>	<u>Halton</u> <u>Estimate</u>
# of Bereaved Children	39,723	15,206	2,725	1,764	731

**We must also be extremely prudent in analyzing and interpreting the bereavement statistics for each of the minority groups in Table 2.** To be clear, these numbers were calculated in a manner similar to the bereavement statistics for each geographical region: a percentage was generated by dividing the number of Canadians identifying as a member of these groups by the total Canadian population (these percentages are reflected in the left-most column of Table 1). These percentages were then applied to the total number of bereaved children in Canada. However, these national averages work poorly as estimates for minority groups given the starkly different socioeconomic circumstances and demographic profiles of these groups in Canada. For example, the statistic for Indigenous groups would be much higher given the infant mortality rate is twice as high as it is amongst non-Indigenous groups, Indigenous adults are twice as likely to die from "avoidable" and "unavoidable" causes than non-Indigenous adults, and suicide rates are more than three-times those in white communities (Kumar & Tjepkema, 2019; Park, Tjepkema, Goedhuis, & Pennock, 2015; Sheppard et al., 2017).

These numbers also do not include young people whose family members identify as LGBTQ+, living with a disability, or newcomers; instead, given their method of calculation, they reflect only the number of children and youth who may identify as a member of these groups themselves. Other influencing factors include differences in family size amongst these groups (the average number of racialized, newcomer, Indigenous, or low-income children living in a home may differ from the national average), and the proportion of marginalized individuals living in a specific geographic region (the national averages are not representative of community size in Ontario, Toronto, Peel and Halton). Also worth clarifying is the non-mutual exclusivity of these estimates. Given we remain unaware of the proportion of the Canadian population that identifies as belonging to two (or more) of these identities simultaneously (i.e. visible minority and newcomer, or Indigenous and living with a disability), we cannot make any statements or assumptions regarding the number of young people who exist as the intersection of these identity categories. Thus, a number of children and youth reflected in this table may be identified or counted multiple times in different categories.

**Therefore, the results presented in Table 2 should be read as significantly underestimating marginalized Canadian young people who are bereaved each year.** These population estimates affirm the need for well-informed, culturally-sensitive, and appropriate grief support and information for diverse families, and emphasize the importance of including these groups in our scholarly and professional understandings of grief. The limits inherent in providing these estimates also points to the need for much more accurate and focused analysis in future research studies on marginalized grief.

**Table 2**

*Estimates of Marginalized Children and Youth under the age of 18 who were bereaved by the death of a parent or sibling living in their home in 2016*

<u>Minority Group</u>	<u>Canadian Estimate</u>	<u>Ontario Estimate</u>	<u>Toronto Estimate</u>	<u>Peel Estimate</u>	<u>Halton Estimate</u>
Visible Minorities: 22.5%	8,938	3,421	613	397	164
Newcomers (including immigrants and refugees) : 16.25%	6,455	2,471	443	287	119
Indigenous individuals: 5.00%	1,986	760	136	88	37
LGBTQ+ community: 11.25%	4,469	1,711	307	198	82
Living with a disability: 4.10%	1,629	623	112	72	3
Low-income: 9.38%	3,726	1,426	256	165	69

## **Phase IIa: Partner Interviews**

As described in the sections above, all of the CYGN Network partners were asked about their experiences working with marginalized grievers and their organizations' capacity to do so. A full list of interview questions can be found in Appendix B. A number of themes and sub-themes arose within partners' narratives, including: the insufficiency of their intake processes; barriers that prevent organizations from better serving marginalized groups; barriers that inhibit diverse clients from

accessing formalized grief support; and the variety of strategies available to reduce barriers for oppressed communities. These are summarized in the mind-map in Figure 2 and described more fully in the paragraphs below. For confidentiality purposes, the partners are not identified using references to their organization or position. Instead, each partner participant was assigned a number and are referred to by that number throughout this report.

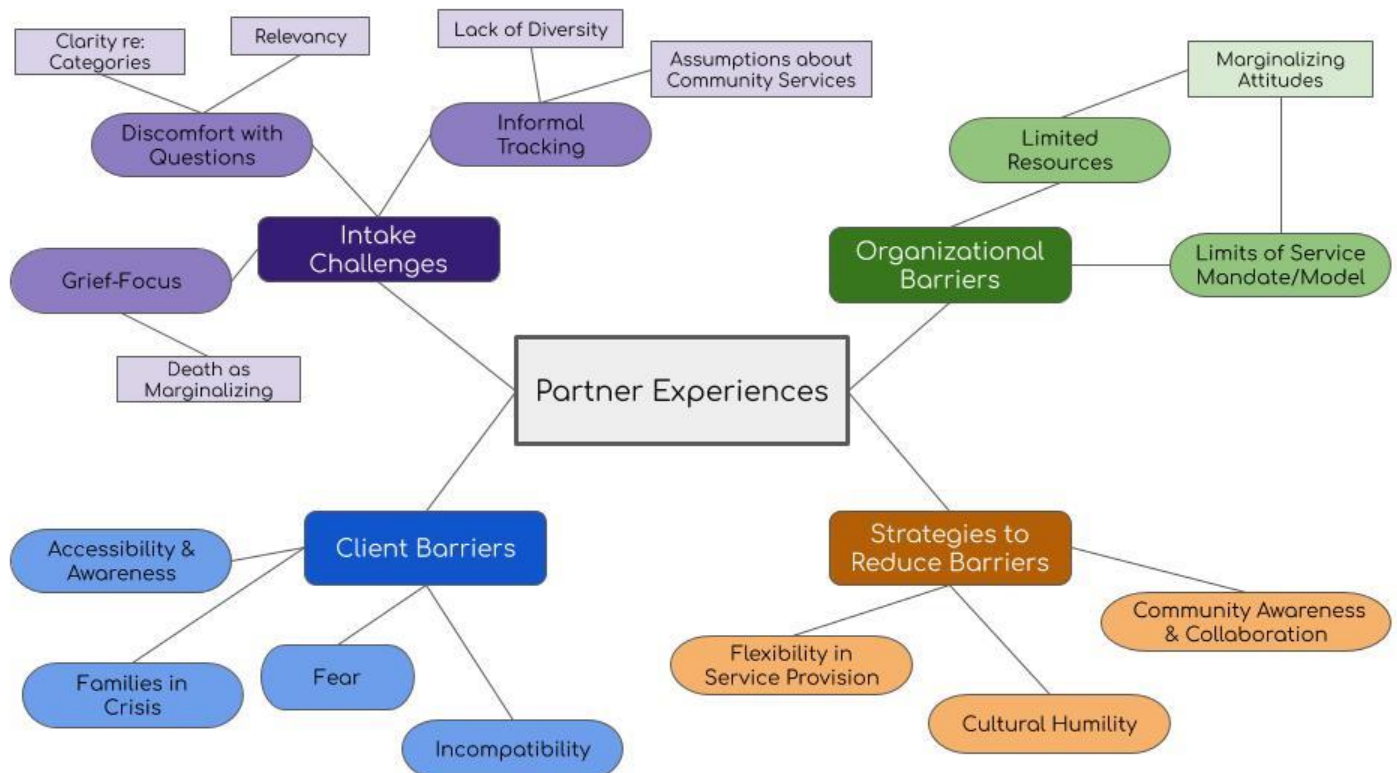


Figure 2: Relevant themes that emerged in partner interviews.

**Intake challenges.** A large portion of the partner interview focused on organizations' referral and intake processes. Across all interviews, there was a high degree of consistency in the referral sources, and the types of questions asked of referring clients. For example, the majority of partner organizations are referred to by: healthcare professionals (including doctors and paediatricians, nurses, hospice organizations, and hospitals); education professionals (including school social workers, teachers, principals and other administrators); funeral homes; and other social services or mental health organizations (including places like ErinOak, Reach Out Centre for Kids, Children's Aid, and Victim Services). However, the majority of clients make their way to our partner organizations on their own, either through word of mouth from friends and family, or Internet searches for services in

their area. This pattern suggests that the CYGN organizations do have a public profile in their communities.

Further more, all partners highlighted that their intake forms or interviews involved questions related to: basic information (i.e. names, addresses, birthdates/ages), information about the person who is dying or has died (i.e. name, familial relationship to children), the type of illness or death that has occurred in the family (i.e. cancer, ALS, sudden medical, suicide, homicide), and when the person died (or their prognosis if the person is palliative), and a history of the person's illness (if applicable). Most of the organizations ask questions about communication patterns with children (i.e. what does the child understand about the illness or death?), other services the family may be receiving within their community, and the other major life stressors that have impacted the children, youth or family unit (i.e. multiple deaths, divorce, changing of schools). Some of the organizations also ask a variety of other questions, including: whether there are mental health concerns, communication problems, behaviour or mood changes, disturbances in sleep or eating patterns, increased dependency on substances, motivations for attending the program/service, histories of trauma, the funeral or burial rituals that have taken place, the child's involvement in the person's care or death rituals, and whether the school environment is aware of the death. However, these questions are not a routine part of the intake procedures for the majority of organizations; while some partners referenced asking these as part of the intake or first session, they clarified that these were not formal components of their on-boarding procedure.

It seems only natural that the majority of questions in the intake process **focus on the experience of grief**, given they help clinicians better understand clients, assess clients' readiness to participate in clinical interventions, and determine the strategies and therapeutic modalities best suited for a client's care plan. There is also a substantial amount of literature that focuses on the relationship of these demographic variables (specifically the age of a child experiencing a family death, the type of death experienced in the family, and the time elapsed since the death occurred) to the future outcomes of grieving children and youth. In their interviews, some partners even went as far as to suggest that these grief-related experiences are important decision-making factors for clients and service-providers, because they can serve to increase feelings of either isolation *or* understanding in both the therapeutic alliance and in relationships with fellow clients. For example, when describing the programs offered at her centre, Participant 1 stated:

**We try to offer specific loss groups. In terms of their experiences, whenever we can, if we have a large enough critical mass to offer a suicide loss group or a homicide loss group, we would offer to families those specific loss groups, or they are welcome to be fully included in the mixed loss groups. We try to offer choices as much as we can in terms of**



letting the families step into a group that they think is going to be most helpful for them given their experiences...We group first and foremost by age and stage of development. It makes sense for children to be in a group with other high school kids, with other middle school kids, with other younger children. And I think parents appreciate being grouped with other parents of young children; parenting very young children when someone has died is a unique experience, so I think they almost seem to gravitate more towards that grouping than their specific loss...We try to find the greatest number of commonalities among the group participants as we can.

When discussing how MAID (medical assistance in dying) deaths were on the rise in her client community, Participant 6 made reference to the appropriateness of certain groups for individuals who had experienced specific deaths:

Certainly for me, being able to support them, cause it's not unlike...if you wanted to compare it to a suicide loss group, because it's such a specific death. A suicide loss doesn't always mix well with just a normal cancer group because it's...it's the circumstances behind it and there's such a thing as disenfranchised grief that can also be around it and just all those social norms. So for MAID...it's the same thing; a lot of people are reluctant to talk about MAID or that their loved one died by it. It's not that they're embarrassed or ashamed by it, they just could not tolerate someone judging their loved one for using MAID...It is the type of death, and to a certain extent the age group, where they are in their lifeline and stuff like that.

Similarly, when describing the clients who reach out to her for service, Participant 4 suggested:

I've got a number of people who are like, I need to see a therapist who is a parent because I can't imagine talking to someone who is not a parent about how to do this with my kids and being able to trust that, right? I've had a number of people call and be like, well, have you had a parent die? Or something like that, cause they actually want to know that their grief support person actually gets what it's like to go through grief. So, I think that the representation piece is important to some people...but I think that along those lines, I get people who want to come because they know I'm also a parent...I think it resonates for them when they ask me, "Have you had a parent die?" And you say yes.

It is clear that there is a high value assigned to the grief-specific information collected during referral and intake. The grief professionals interviewed here have a refined understanding of how marginalizing bereavement can be for children, youth and families. Therefore, they strive to establish and maintain



a sense of safety and community for their clients who may feel different or alone by attuning themselves and catering their programs and services to their clients' grief experiences and needs, which are outlined as early as possible.

However, when examining protocols around tracking client diversity, only three of the eight partners interviewed referenced questions directly related to clients' culture and/or spiritual beliefs, and none of the organizations currently asked targeted questions related to clients' household income, sexuality, or immigration status. Instead, information about clients' social and economic circumstances is **informally tracked**, usually after a number of interactions, in conversation with family members or through direct observation of their living conditions. For the purposes of the interview questions, partners drew on estimates of these populations from memory or personal knowledge of families they had worked with, only periodically recording this information in client files or organization databases. Moreover, unlike the statistics on referrals and grief experiences, partner participants relied heavily on rough estimates when asked how many of their clients identified as part of a marginalized community. The estimates provided in conversation with the partners are summarized in Table 2 below. In addition to the categories provided in Table 3, we also asked partners to estimate the number of children and youth who had previous involvement with the criminal justice system and child protective services. These estimates ranged from Unknown - 30% for both categories, with an average estimate of 10% each.

**Table 3**

*Estimates of Marginalized Children and Youth receiving service within CYGN partner organizations*

<u>Minority Group</u>	<u>CYGN Estimated Range</u>	<u>Average Estimate</u>
Visible Minorities	Unknown - 80%	22%
Newcomers (including immigrants and refugees)*	Unknown - 75%	17%
Indigenous individuals	Unknown - 5%	2%
LGBTQ+ community**	Unknown - 15%	6%
Living with a disability***	Unknown - 20%	11%
Low-income	Unknown - 45%	16%

\*Includes children and youth who are first and second generation immigrants

\*\*Includes families where a parent or sibling also identifies as LGBTQ+

**Table 3**

*Estimates of Marginalized Children and Youth receiving service within CYGN partner organizations*

<u>Minority Group</u>	<u>CYGN Estimated Range</u>	<u>Average Estimate</u>
-----------------------	-----------------------------	-------------------------

\*\*\*Includes mental health concerns such as anxiety and depression

As seen in the Table above, a number of partners responded that they could not provide an estimate, as their organizations did not currently track these demographic variables. Nonetheless, some estimates, particularly those for visible minorities and newcomers, were as high as 75 and 80%. These estimates both originated, unsurprisingly, from Peel Region — Brampton specifically — where it is estimated that 25% of the Greater Toronto Area's almost 2.8 million immigrants reside, and where 73% of the community identifies as a visible minority (Peel Data Centre, 2017). Other areas served by the CYGN did not report estimates that were quite as large, consistent with the much smaller proportion of visible minorities; according to the Canadian census, Oakville's population is comprised only of approximately 30% visible minorities (Statistics Canada, 2017b). Regardless of local differences and the large variance in estimates provided from one organization to the next, the average estimates provided by the CYGN as a whole for these two marginalized groups hovered around the national averages provided in the Canadian Census. This was unlike the other categories we enquired about: the average estimates provided for families living in low-income conditions or with a disability were estimated far higher than the Canadian averages recorded in Table 2, while those provided for Indigenous clients and LGBTQ+ clients were significantly lower.

The majority of approximations provided by partners with regard to these categories were extremely small, suggesting that many of the organizations were lacking noteworthy diversity in their clientele. Still, without accurate tracking and reporting, we remain unable to make claims about how services at CYGN *actually* compare to the national averages, and how our partners in different geographical regions are serving (or missing) these populations. Furthermore, without thorough demographic information, we have limited understanding about how these categories intersect and overlap in various geographical regions, and few opportunities to explore the grief experiences of individuals who occupy these identity categories. Without this information, we are restricted in our ability to accurately evaluate our programs and clinical models and determine how they align with or overlook the needs of *all* clients, including marginalized grievers.

Interestingly, when asked why their estimates were what they were, many of the service providers interviewed suggested that these groups were accessing bereavement services and support in other

smaller, informal, community networks — including cultural groups, faith groups, within family and friendship circles — rather than in larger, more formalized institutions. Participants 2, 4, 6, and 8 all referred to these community-based supports in their interviews (quotes are attributed to each provider in the order listed above):

**I'd say it's quite low because I do find certain groups tend to go to their own faith groups for bereavement support.**

**I think there's also been a huge breakdown of community in white, middle class North America. We don't live in tight-knit communities; we live in bigger houses with smaller families, and I honestly think that like, in some ways, it's probably strengths-based where...I think what you pay for in counselling, to a degree, you get from within your community. When people are more attached to spiritual or religious institutions, that is the go-to.**

**I do think, we wonder sometimes if some of the bigger groups that we have out there in the different cultural mix, if they perhaps have their own support systems already in place, when it comes to dying, they already have their own practices that they do and they have their...I don't know, their hospitals or wherever it is that they have, they already do it themselves, they don't necessarily need to come here.**

**I did go to a presentation in Halton region one time and they talked about specific agencies within that community that do...they have done a lot of work with the LGBTQ populations, so maybe they are doing to other agencies that deal with that specifically? I don't know.**

While an awareness of the importance of community in these subgroups is important, the assumption that grief support is actively sought out and received in these communities is a precarious one. Without accurate and intentional information gathering — be it with various community organizations themselves to determine what supports exist for grief and bereavement, or with old and new clients to assess the other services they have accessed — organizations are simply presuming that people are connected to a safe and accessible community *and* have access to honest and well-informed bereavement support. In essence, these assumptions can be interpreted as a way of organizations evading their responsibility to serve marginalized groups within their neighbourhoods, and account for the small numbers of diverse clients being seen each year. In simply hoping that immigrant, racialized, LGBTQ, poor, disabled, Indigenous families are receiving support elsewhere, organizations may not be otherwise motivated to assess whether their service mandates, programs and resources are accessible to and aware of these communities' needs, or reach out to these individuals with more intention and sensitivity.

An important pattern that emerged throughout the interviews with service providers was an **air of discomfort** asking demographic questions of clients. Firstly, there seemed to be a lack of clarity around the definition of each of these identity categories. A number of service providers had questions regarding who would and would not be included within each of the labels, and there was a large variance in how providers defined each group. For instance, when asked the proportion of clientele who identify as a visible minority or as part of a racialized group, Participant 1 responded:

**I'm not even really sure I know what that means...we do have families who in terms of their appearance, you know, they are not quite Canadian, right? But there are folks and families that are maybe second generation Canadian. So, for all intents and purposes, they consider themselves Canadian, although they may look very much like an Indian family...I'm always a bit unclear about how to kind of compartmentalize people into these categories.**

In the same manner, when responding to the question regarding low income, she stated:

**We don't ask a lot of questions about finances. So much so that I'm not even sure what is considered poverty, in terms of the poverty line, or in terms of income to numbers in the family.**

In regards to questions about clients who have had contact with the criminal justice system, Participant 4 commented:

**Having contact as in like, am I working with people who are navigating the system? On either side of it? I mean anybody that I would be working with is only in contact with it as like, they are the victim's family. Somebody has been murdered or something like that.**

She had comparable clarifying questions when asked about clients living with disabilities. Of course, this matter is particularly complicated by the fact that many of the CYGN partners work alongside individuals who are dying and their families, which can cause significant challenges with physical mobility and function, communication, memory and other cognition:

**I mean, if we're taking disease into account and stuff like that, I have a lot of people with cancer and ALS who I am working with...would that be included, if that's the actual illness that brought them to me in the first place? Or not so much?**

Similar questions surfaced about other disabilities (i.e. mental or physical challenges, whether anxiety or depression could “count” given their association with the process of grieving), clients who have had contact with child welfare and protective services (i.e. whether there was a history of involvement or ongoing involvement, or whether it mattered whether the child was currently living in their family home, the homes of kin, or foster care), immigration (i.e. whether the child or youth themselves had to be an immigrant or if they could be first/second generation), and sexuality (i.e. whether the child or youth had to identify themselves as belonging to the community, or whether their family members could also identify).

In addition to the confusion around categorical definitions, and tied to the grief-focused intake processes described above, a number of partners questioned the relevancy of demographic questions. Many of the participants described how questions related to grief were critical to the support they could provide clients, but that the issue of an individual's race, sexuality, immigration history, disability, income status and history of involvement with the law or child protective services was not always central to determining service pathways or the nature of their clinical work. There were also concerns that adding these demographic questions to the intake procedure may pose a barrier to families trying to access support; forms become much longer, harder and more uncomfortable to complete for clients. Participant 1 described:

**[We don't collect] a lot stats that I think relate to this particular subject matter. I think we try to balance our need for information for our own purposes, as well as for our donors, the things that we need information for. We try to balance that with the sensitivity around the people who come here and we really don't want to be overwhelming them with an application form for services that is going to be pages and pages long. So, as much as there is stuff we'd like to collect, we are careful about that. And really, we only take what we need. And in terms of what we need, to give them an experience that they need to have here, and to be supported through their grief, there's not a lot that we need.**

Participant 8 communicated a similar concern, even after her organization had implemented some demographic, health equity questions in their intake process:

**The health equity questions that we started doing a couple of years back, the questions around LGBT and around finance and around housing, the challenge for us is again, when you're going in and dealing with vulnerable populations who are, in most cases, living with dying, we don't necessarily have a huge amount of time and we don't necessarily see the value in asking those questions to them, right? I mean, yes, there's potentially value after the fact in how people are supported, but to that particularly family, unless its an issue**

**that they raise and it's identified as an issue to them, we're not trying to create barriers that might make them question whether or not they want to use this service.**

Even in instances where questions about a client's identity or personal experiences were included in intake assessments, some providers explained that they did not ask these questions because it felt disruptive to the flow of the session, or feared that it would incite discomfort or anger from the client.

Reflecting on these two specific patterns, it is possible that the lack of clarity regarding category inclusion contributed to the large range of estimates provided by the organizations in this phase of the project. Variations in service providers' responses may well have stemmed from the way interview questions were structured in the protocol itself, which is certainly a potential limitation of this portion of the study overall. There is also something respectful and sensitive about service providers and organizations wanting to protect their clients from undue stress or distress, given the vulnerability already associated with experiencing the dying or death of a family member. Posing questions about someone's race, sexuality, income and disability, especially when they feel extraneous to accessing grief support can be interpreted as prying, imposing and even threatening.

However, these themes also point to the need for a more widespread and systemic understanding of how these categories are defined from a social justice perspective, and their importance when working with vulnerable clients. The general discomfort with asking these questions, the unfamiliarity with what constitutes these categories and their relevancy may altogether point to a need for hospice, palliative and bereavement care professionals to investigate how and why these categories are defined within the relevant literature, commit to defining these categories in a more clear and meaningful way within their field, and explore how these questions can be asked of clients. Although we may be protecting clients from potential embarrassment or unease, we are doing a greater injustice by overlooking these categories, as we are consequently discounting experiences that may be pertinent or relevant for clients and their family. Without implementing some foundational structure or process for asking these types of questions, we may never understand how and why these types of questions and experiences are salient, or just how much client diversity we are able to capture. The experience of one's race, immigration history, sexuality, disability, and family structure are all deeply personal, and multifaceted experiences that impact each individual in unpredictable and unknown ways. How people choose to identify with or distance themselves from these categories is integral to how their world is perceived, and may (or may not) be salient to their experience of grief. Therefore, asking the questions in open, yet direct and clearly defined ways, and allowing the client to answer in the way that best suits them, may support individuals to feel empowered and seen in their clinical encounters, and can support a larger conversation that sheds light on the aspects of a client's identity that are most significant to them and to their grief. In turn,

organizations can establish an intake and clinical process that feels comfortable and safe for service providers and clients alike, while developing a more fulsome understanding of the intersection of marginalization and grief.

**Organizational barriers.** Given the focus on exploring organizations' capacities to work with marginalized grieving young people, some of the interview discussions focused on the limitations and barriers that prevent groups and providers from conducting this research themselves. Across the board, participants spoke of the **lack of sustainable funding** available in the province and their geographical region. This lack of funding has a direct impact on the number of staff working within each organization, the amount of training available to these staff members, the quality of research and consultation that can be conducted around the issue of marginalization, and the frequency of evaluations and assessments that can be completed in relation to the available services and resources. Drawing on the narratives of a few network partners, Participant 1 reflected on this challenge at length:

Going back, last year actually, we had a placement student with us who had an interest in kind of understanding why we looked so white here because he is from another cultural background and he asked some very interesting questions and had insights into maybe why we don't see people, see the level of diversity within our community that is representative of the community in which we sit. So he did, as part of his time with us, he did a little bit of outreach into the multicultural and multi-faith communities throughout Halton and Peel and did some surveys with some different people and brought back some information which was a really great start, but he just didn't have enough time. We realized how much time that takes, not only to collect information, but to build the kind relationships with people where they are going to be comfortable to give you the information. So, we knew that we had only scratched the surface and we all knew that in our twenty years, we are still pretty small. We still only have a really small staff and an army of volunteers that help us, but certainly not the kind of resources that we need to go deep into that kind of research...I feel that as an organization, we've got a ways to go in terms of really feeling like we have done the kind of work that we need to do. And like many organizations, it's just really a resource issue...it's having to deal with the day to day operations of this place, really stretching our resources to the limit.

Participant 2 echoed these sentiments when she was discussing what her organization would need to be able to offer more groups to more individuals:

We have to be careful because we are non-profit, so we're always looking for funding. That's huge...more staff and more funding. I can only spread myself so thin. Every time I come up with an idea, my director says, "I have to make sure you're not getting burnt out." You know? I'm one of those people that's like, "Let's do this, let's do that." And for burnout reasons, she has to say, "Do we really have time? Or do we have the resources to do this?"

Participant 6 also felt challenged by the manpower available to keep her organization's programming alive each year:

The biggest thing is having the manpower to run the support groups and also to have the people who are trained specifically for the needs of specific groups. And that goes across the board for everything that we do. The biggest drawback for sure is space, it's the cost of stuff. Even if you go to a church, some people don't want to go to a church because its a church, but trying to find...if you have to pay for space to run groups, the organization can't do it. So, the biggest thing for us is having skilled, trained volunteers and enough facilitators to be able to run groups.

When asked what future initiatives her organization might engage in to continue increasing awareness and accessibility in certain communities, Participant 8 cautioned:

I don't know. At this point, we just have to find money for [the program] to continue. So, as far as new initiatives, I'm not sure. I think it's really about building empathetic and compassionate communities...but outside of looking for funding for current initiatives, we don't really have any paths...that we want to try to do anything more.

It is important to note that all of the service providers interviewed understood the importance of offering more programs — to different populations, with more frequency and in different locations at different times, especially to marginalized grievers — but stated that precarious funding meant their sights had to be set on simply keeping their centres open. Many spoke about relying on the generosity of volunteers and placement students to achieve certain goals, positions that often come at the expense of extremely high turnover. This complicates organizations' ability to conduct research and undertake work that takes a significant amount of time and relationship building.

To accommodate for limited resources, many organizations had implemented **service mandates and models** intended to move people through their system quickly and efficiently. Yet, these limitations also have the unintended consequence of limiting which clients can be seen and how their support service might look. For example, Participant 4 ran an extremely busy practice, and to



ensure that she is able to take new clients on, she remains unable to work with families who require significant levels of support:

**[Clients] are basically coming in through [intake coordinator] who does all of the admin and intake, and basically, she is just checking out, finding out what the needs are, what's the situation, how frequent of services do you think you need?...My practice is very busy and if you need a lot of ongoing support, I'm probably not the right person, right? So, I was kind of, and still am, kind of reaching out from that, too, because I can't see a lot of people who need weekly support with just me.**

In a similar manner, Participant 2 felt that complicated grief was a challenging diagnosis to support with limited resources, especially because her organization relied so heavily on volunteers in the community to provide bereavement support:

**[Something that would make a client ineligible would be] complicated grief, because we are not counsellors, we do bereavement support...if we feel that they are not suitable for our program, we will certainly find them resources that are. So, everybody is eligible to come in and go through an assessment, but they may not always come into our program, depending on what their needs are...grief is a speciality, and even if someone has an MSW or psychotherapy degree, it's still a unique type of need. Oftentimes, we will refer them to private counsellors or Halton Family Services, sometimes back to their family doctor, and trying to help the family doctor understand what it is that they need...I mean, all loss is complicated in its own way, it's just how they're coping with it. If they have a concurrent disorder, if they have a substance misuse disorder, then we usually try to encourage them to get help for that and once they have that, we can help them. Oftentimes, the complicated grief may be due to another factor, so we will refer to other agencies or community organizations that would deal with that piece.**

Participants 7 and 8, who worked within the same organization each reflected on the limits of their service model, but from different perspectives. Participant 7 focused on time limits with clients, stating:

**We're short term, right? We see the clients for so many visits and then if I find that there's more complex trauma or a child is needing extra support...then I will refer on to more long term care.**

Participant 8 added:

**We are never signing up for long-term counselling. It's very specific to grief, so again, if grief is part of the presentation of what that person's care plan is, then we are flexible as long as grief is the primary reason for the health, the issues that are manifesting, right? But we will refer out. If we go and there is mental health and addictions and all kinds of other elements that grief is a piece of, then we're either trying to work collaboratively with a group or we are referring out to try and get that predominant issue that's creating the mental health issues dealt with prior to us going in.**

While a short-term structure and boundaries regarding clinical diagnoses can be helpful in terms of mitigating the often overwhelming demand for grief and bereavement resources, these restrictions can leave certain groups of individuals without access to effective and comprehensive support. Though the literature on marginalized and bereavement has yet to explore these linkages at length, the experience of poverty, immigration, and discrimination due to sexism, racism, and ablism can certainly amplify the complexity of grief experienced by certain individuals, potentially leading to other mental health concerns, including anxiety, depression, substance misuse, complicated grief. Furthermore, given the relationship between one's social and economic status and various forms of violence experienced personally and inter-generationally, it is not unlikely that certain marginalized groups are sometimes subject to more traumatic forms of grief, including those unrelated to death. As such, these conditions — and the way they uniquely manifest in people's lives — may preclude specific children, youth and families from receiving care within various grief and bereavement institutions because they require more intense, frequent or consistent support. When we consider the lack of social services available in many regions, and the absence of formal grief training that endures within other existing community groups, families who cannot be effectively held within the CYGN can remain overlooked and under-served.

Taken together, the limited resources and restricted service mandates can communicate **marginalizing attitudes** to communities on the fringes who are in need of grief support, albeit unintentionally. By not asking questions that capture client diversity, being unable to offer resources, programs and information that relate to various communities, and referring certain individuals to external agencies, organizations' intentions can be misconstrued as not valuing the needs and experiences of marginalized groups. This concern was captured in the interview with Participant 3, who previously worked alongside a number of different marginalized groups, including men living with HIV, migrant workers, and indigenous communities in Asia:

This is a complain of marginalized groups in and of itself, right? It's like, well, people in dominant agencies or mainstream agencies will say, "It's nice to do it, but we really don't have the time or the resources to do it." That's not an adequate response to marginalization. Like, it doesn't take very much to ask, right?...Yeah, we can't be everything to everybody, but that tends to be something that I find in marginalized communities, people get really, really upset about cause it's just another way of saying, you're not that important...we would love to serve other folks, or deliver it in this way, we just can't...that whole proposition and way of talking, I think in itself its a form of marginalization. It marginalizes people cause it say's you're not really that important. And I know maybe we're doing things in a way that isn't culturally sensitive or in a way that is sensitive to your particular whatever, but that's too bad, we're making a choice. And it just replicates it, right? It replicates a dominant, mainstream way of doing things.

Despite the numerous discussions regarding budgets and staffing, this was the only conversation where this possibility was mentioned. To be clear, none of the CYGN partner organizations intended to further marginalize individuals who identify as racialized, newcomer, disabled, Indigenous, LGBTQ+, living in poverty or having contact with child welfare and justice systems. In fact, every organization interviewed as part of this project was working hard to abide by the network's mission and vision and ensure that *all* children and youth have access to well-informed support (discussed further in sections below). However, it is possible that potential, current or previous clients have felt excluded and unseen because of the lack of specific services or resources made available to them as a consequence of inadequate funding, staffing and skill. This in turn can increase feelings of disenfranchised grief (Doka, 1989); by failing to recognize their needs and experiences, the grief and bereavement community may be conveying the message that their losses are not socially supported, and that they are somehow illegitimate grievers. Not only can these feelings of disenfranchisement heighten individuals' feelings of isolation and amplify the complexity of their grief response, it can also decrease the likelihood that they will seek out additional or different support services in fear of encountering similar attitudes.

**Client barriers.** While not a primary focus of the interviews, many partners did touch briefly on the barriers that clients might experience as they attempt to access formal grief support. Many of the partners drew on specific examples from their professional encounters with clients when describing these barriers, suggesting that they had firsthand experience mitigating these issues alongside families. One barrier that surfaced frequently was clients' **lack of awareness** of various services. Many providers acknowledged that community members were still unaware of the services available to them, or were unsure of where and how to access grief support. Participants 1, 2, and 5 were

worried that people in their neighbourhoods still did not know that their organizations existed, or how to identify appropriate services:

**A lot of people don't know about us; they don't know that we are here.**

**You know, not knowing where to turn, how to do it. People who come from disadvantaged backgrounds may not even know how to start looking for help.**

**Its the access to the knowledge; how are they going to get to us if they don't know about us?**

Many providers expressed that schools, healthcare providers, religious groups, funeral homes and other community centres had limited knowledge of grief and bereavement resources (despite the many education efforts described in sections below), and therefore, children, youth and families were not being referred in an efficient or timely manner.

Yet, even when clients were aware of the organizations, services and resources available to them, there were often concerns related to the **accessibility** of the information. Providers' acknowledged that clients often felt challenged by the centre-based services that required them to travel into offices for appointments and groups, and the timing of certain programs (i.e. 1:1 counselling appointments during the day, groups available only on specific weeknights, too early or late in the evening). Others lamented only being able to offer services and resources in English, which prevented clients' from being able to understand important information or participate meaningfully in clinical interventions. Though translation services were available to many service providers, almost half described how complex and awkward client interactions can become when using these services, especially as they attempt to relay all communication — which is often sensitive and highly emotional — through a third party. Participant 9 reflected on some of these challenges:

**I think language is a huge barrier, I see that quite frequently. We do have access to translation funds but what I sometimes find is that with an extra adult in the room, kids especially, they're already intimidated, it's already an awkward conversation, so having another adult in the room, who is kind of being that liaison between the two of us, it doesn't work as well. They don't seem as open to talking or things get lost in translation.**

Even when information was provided in electronic format, sent to families for review at a later time, or available on an ongoing basis via organization websites, other restrictions (such as timing and technological availability) made access difficult. As Participant 9 commented:

I've had marginalized youth who really don't have access to a computer or the ones that know how to use the computer, have struggled with accessing [resources] because it's just not something that they are privy to or have access to. There's no computer in the home, or they have several young children so the only time that they would be able to do anything is late at night when the kids are in bed and they can't leave the house to get to the library. There's lots of good information, it's just making sure that it's accessible across the board.

In addition to concerns regarding awareness and access, many providers worried that the fundamental clinical models that informed their programs and services were **incompatible with other social and cultural views** on grief and bereavement. For example, Participant 1 considered the implications of valuing open and honest communication with young children:

There might be aspects of our model that for certain cultural groups, it perhaps doesn't align well with their values or beliefs...the open sharing that kids are encouraged to do in group outside of their families...i think there might be some groups where they don't really understand the value of that for children and maybe it makes them a little uncomfortable.

Similarly, Participant 4 suggested that individuals of certain cultures and socioeconomic status were more comfortable with the idea of counselling than others:

Going to therapy...it tends to be that in some cultures, and I say like, white, middle-class cultures, it tends to be way more open to that than other cultures...i do think there's possibly an element of the idea of counselling and therapy being considered more acceptable and more the norm in some communities as opposed to others, right?

A number of service providers believed that many cultures outside of North America were unwilling to receive clinical support for grief because it is considered a "normal" or "natural" part of the life cycle. Some believed that there was still stigma attached to receiving social support, or that families were hesitant to receive help from clinicians who don't identify with the same cultural or religious background.

Related to this idea of stigma, more than half of the CYGN partners stated that **fear** could impede clients' willingness to receive help, including fear of the unknown (i.e. being unsure of what to expect from service) and the fear of openly grieving in front of another unknown person. Participant 1 also

hypothesized that some individuals may fear being misunderstood by providers or other clients, especially in a peer-facilitated group setting. She cited an example of a previous client:

**I think oftentimes, fear of judgement and shame; those are the two biggest ones. I think we have taken pause from people who are interested in the support groups, say from the Islamic community, or people they are referring from the islamic community, and i have heard on a few occasions that they really desire a group with the people from the islamic community. I'm not sure why that is...I don't know if it's a fear of judgement, or feeling like people from different groups are not going to understand you or be able to relate to you. Maybe they're afraid those connections wont be made.**

Service providers also believed that clients might experience a fear of judgement or lack of safety if other institutions were involved in their care plan or referral process. In cases where there had been previous involvement with the criminal justice system (i.e. a homicide or other sudden death) or involvement with the child welfare system, partners found that families were skeptical about beginning service or undergoing routine assessments. This was especially true for service providers who conducted sessions in clients' homes. Participant g felt that she had to work harder to separate her organization from other referring institutions such as Police Services and Child Protective Services, so that her clients could feel comfortable interacting with her:

**The one thing I'm finding with marginalized families, specifically the ones that Im working with who have experienced a crime and that's what the loss is regarding, whether thats murder or something like that, a sudden loss, I'm finding they tend to slip through the cracks a little bit. A lot of the times, families aren't necessarily comfortable with having someone come into their home, especially if places like CAS are making the referral; it can be very intimidating. So, separating, as much as we need for these referrals, separating ourselves from [CAS or the police]; we're there to help, we're not there to judge, we're not there as part of the system who might be investigating or whatever.**

As a result of this lack of trust, some families fail to follow through with service, or client-clinician rapport is not effectively established.

Finally, all of the partners acknowledged the challenges associated with working alongside families who are grieving a death. Understanding that the death of a parent or child can serve as a particularly destabilizing experience, clinicians recognized that a number of families referred to their services were still **"in crisis"**, attempting to navigate unanticipated changes to their family structure and living conditions, while establishing new routines. Death can also bring about a variety of secondary losses

that impact a family's functioning, including: the loss of an income, home, financial security, friendships and extended family relationships, or sense of community. These changes can pose significant barriers to caregivers who are attempting to identify and secure clinical services for themselves or their children. Participants 4 and 8 reflected on these difficulties:

**It's just access...this is the type of work where somebody is either dying or has died, so. You've got families like in crisis at that time and so, I just think you've got this whole extra layer of barriers. Like, now you're working three jobs and figuring out how to be a single parent; how the hell are you going to get your kid even to the free program?**

**Think of all the conflicting priorities in the family, right? I always think back to one of the families that there was seven kids in the whole, Vietnamese, dad was dying, sole breadwinner, so the mom of course had no idea where she was going to live, how she was going to support these seven kids, she didn't drive, he was the only person that drove. You think of all the social determinants of that situation that are creating barriers for that family - how do you think those kids are going to get support? There's no way. She doesn't...she has to keep a roof over her head, she's got to get food in their mouths and supporting their long-term mental health is not something she's even thought about right now, right? She's just trying to get through to get through today and survive.**

Even when families are referred to services by healthcare professionals, educators, funeral homes or friends and family, partner agencies found it difficult to connect with families to share information and resources.

While recognizing client barriers is an important part of providing effective service, it is important to keep in mind that service providers' responses provide only one perspective. It is likely that families children and youth in marginalized communities experience many more barriers than those listed above. We did ask similar questions to members of the wider community who are working with marginalized individuals in non-grief specific ways to supplement the responses provided by our CYGN partners (see Phase IIb). However, a critical area of future study would be to investigate these barriers from the perspective of clients themselves by conducting interviews, focus groups and other collaborative research with various communities.

**Strategies to Reduce Client Barriers.** Acknowledging that many clients encounter barriers when attempting to secure services, every CYGN partner interviewed spoke of strategies they and their colleagues utilize to facilitate access for as many families, children and youth as possible. In addition to offering all of their services for little to no cost, this included adopting a **flexible model of service**

**provision** wherever possible, engaging actively in **community awareness and education** campaigns, and exercising a **culturally humble, client-centred approach** in interactions with all clients, including those who are marginalized.

While all of the partner organizations spoke about their service mandates and models (as described in previous sections), they also discussed their adaptability and amenability to meet the needs of clients. For some partners, this involved making exceptions around what clients were able to be seen, where they could be seen, and for how long. Participants 1 and 2 referred to their organizations' policy on catchment areas, stating:

**Geographically, I mean our technical catchment area is Halton and Peel, but we are not strict on borders, as long as the family can commit to attending their group regularly and they can get here for that, we don't turn anybody away.**

**We do have a catchment area, but because support groups specific to that area so great, i've had people come to Oakville as far as Hamilton, Bolton and Brampton. So, we will allow people to come from out of the area as long as they are willing to come to our Centre.**

Participant 1 then continued to explain that for some families, even managing to get to their centre for group sessions was difficult, so her organization implemented an "accessibility fund" to support people (living within or beyond the catchment area) to attend:

**We do offer support in terms of transportation and accessibility for people to get here...we have an accessibility fund that we offer, and we have a few families where I know, in one case, a couple of parents have a visual impairment and they don't drive, so we have some funds that were donated to help people access Uber or Lyft or other ride share services. We've also helped kids and teens to get here on train passes.**

Participant 2 also recognized that coming into a Centre for a counselling session may not feel as comfortable, safe, or feasible for some members of the community, so she began texting with clients to facilitate access to bereavement care:

**I find with young people...they don't want to sit here talking to me, a middle-aged woman, they don't want to do that. But they'll text...And I do a lot of texting that way, they love to text.**



Even Participant 8, whose service mandate included exclusively in-home visits, made flexible arrangements for clients who were not comfortable being seen in their space, including school visits and meetings in community spaces such as libraries. Her organization even provides the options of in-office visits for these clients.

Participant 5 spoke at length about making exceptions about service eligibility requirements for clients, referring more specifically their insurance coverage:

**There has been talk about whether eligibility needs to include an OHIP card and that is up in the air at this point. We are required to have an OHIP card for residents [in hospice] but it hasn't been put down on paper with regard to OHIP for community services, because if we're going into a home and you know someone was palliative in the home, just because they don't have an OHIP card, we're not going to talk with them about their grief? No, that's not the case.**

She similarly described policies around age requirements for various programs:

**On our flyers, we say six to twelve cause that's what we've found works, but we will extend that depending on the developmental capacity of the children. You know, there are some really keen five year olds and there are some thirteen year olds or fourteen year olds it might be appropriate for. It's a case by case basis.**

Participant 9 likewise found herself making accommodations for clients who fall outside the upper age limit for her child-focused services, particularly adults living with a cognitive delay. She felt compelled to see and work with these clients because of the lack of appropriate services available in the community:

**I will take on referrals where an adult is having a parent who is dying or has died, but their development, they are developmentally like eight years old. I got a referral last week. I will take them on as clients to kind of help navigate that experience for them. Like, there's not a lot out there and it wouldn't necessarily be part of our mandate to service these clients, but I do, and we've kind of navigated how to support them, because when I was doing research into other options for them, I had a really, really hard time finding supports for them within the community.**

In addition to these types of exceptions, Participant 9 strived to make service as beneficial she could for families by extending the "short-term" model of care as far as possible:

We are intended to be short-term. I would say the average is probably six to eight sessions, with some families needing only two or three, some families only needing consults over the phone to help parents navigate parenting and what to expect from their child and how to handle those situations, and then some people need far more. I know our mandate says eight to ten sessions is what we should be able to offer, so when I go in and address the families and they're doing okay but we know that there are special occasions coming up or that things will get a little wavy, I will extend sessions or I'll see them every month instead of every two weeks so I can see them for a longer period of time. And if there's a family that has a lot of different issues going on, we do have the ability to extend them a little bit and do more than eight to ten sessions because some families are only using a couple and others might need fifteen.

Ultimately, partners did the best they could to ensure that anyone who was making strides towards accessing grief and bereavement services could receive it. They did not want their organizational mandates, geographical location, budgetary limitations, or staff resources to serve as an additional barrier.

Organizations also wanted to ensure that they maintained a strong public profile in their communities, and that all potential referring agencies or professionals were aware of the services they offered. Service providers recognized that many families in their service areas were likely unfamiliar with their services, and that they alone could not connect with everyone in need of clinical support. Therefore, many organizations invested a fair amount of time doing targeted outreach in their communities, interfacing with other institutions who also had contact with children, youth and families, both before and after a death had taken place. For example, Participant 2 spoke about different awareness initiatives her organization developed through a dedicated outreach coordinator staff:

We have an outreach coordinator and she does community outreach, she reaches out to special interest groups to let them know about our services and also to encourage them to use our services...we do reach out, we do workshops, we do a lot of training, we go to these communities to let them know that this is what we do. We go to different churches and faith groups. We have gone to the board of education to talk about what we do...I think it's really important to get out to the community what the resources are. A lot of family doctors may not know that they can refer clients, so it's really getting the education out to people that can refer people to these organizations, to these resources...It's letting people know, cause like you said, marginalized people don't always know how to access

**these, but there's got to be somebody that's watching that marginalized person in some way...somebody that's hopefully there that can advocate for them.**

Even when there was limited staff available to perform these outreach initiatives, counsellors themselves would ensure that information was being distributed to the community as frequently as possible. Participant 9 took this upon herself when her organization's services expanded:

**In the beginning, we do have some outreach volunteers that will spread the word for us...when we were first moving into the Halton region, I was driving to churches, I was driving to funeral homes, I was driving to doctor's offices and dropping off information and letting these organizations know that we exist in Halton to be able to then share with their families.**

Participant 1's organization held a specific annual event, inviting diverse service providers and community members to learn more about their programs and services, as well as skills and tools for working with bereaved youth:

**We have really tried to do more in terms of building knowledge and awareness outside of the four walls of [organization name]. So, the grief symposium that we do, the consultations we offer to families, we recognize that not every family that needs support is going to be able to know about this place, so being able to engage other professionals that work with children and families: police services, victim's services, school teachers, child and youth workers, social workers, people that work in funeral homes, people who work for other agencies. You know, if we look at people from all those disciplines, those are the people that are going to be crossing paths with children and families and I think if we can help to make them a little bit more informed and aware and knowledgeable about what this experience is like for kids, building that community capacity is probably the best way to address barriers.**

Participant 4 felt strongly about developing the teaching and training component of her organization, recognizing the potentially large amount of output that can be created through community education initiatives:

**A big part of why I feel so strongly about doing the consulting work that I do...I think a lot of the things we've created, particularly through Virtual Hospice are amazing...it's reaching far more people that way. I feel like I'm so passionate about teaching and I think very much that some of the projects through CYGN when we were first looking at the**

formal versus informal, really solidified it for me. The informal, increasing capacity within our communities is so important because that's where we can get to all the kids who are in schools, in a certain teacher's class, and things like that. That is going to have a far bigger trickle down effect or ripple effect than just individual counselling...There really needs to be a shift where it's like, a lot more partnering with schools and a lot more education of the informal supports. I mean, that includes all the probation officers...just making sure that the information supports people on the front lines who are coming in contact with people, that they are well-resourced and aware and know how to show up in that way.

Participant 8 even felt that community education and awareness was central to her organization's vision and mission:

The broader vision of [organization name] is about getting resources into schools and there places so that people who aren't getting to formal support...our philosophy is and always has been about making sure that people have the information to serve their clientele better. We spearheaded the network, Victim's Services, the work we've done with them through the network and individually, but getting them the information to try and make sure people are getting access to service. Going into the schools, the grief kits that we've created to support teachers that are having the conversation with kids, and connect them to resources.

Overall, it was clear in all of the partners' narratives that there was a strong, underlying commitment to building compassionate and caring communities around grief and bereavement. In this way, the collaborative was attempting to practice or embody the principles of the Irish Bereavement Pyramid, which "recognizes the essential role of family and community in supporting bereaved children and young people" and demonstrates that "most bereaved children and young people can be met from within their family and community" (Irish Childhood Bereavement Network, 2014).

However, some partners, including Participant 3 and 6 used these outreach opportunities to also engage in knowledge exchange. By working in partnership with various community groups — including faith organizations, cultural centres, or other social service providers with different foci — their organizations were able to share information for working with certain individuals. Participant 6 described how impactful a faith-based initiative was at her organization:

We did have a community coordinator for a couple of years...their job was to get out there and really promote not just the hospice care, but talking about death and dying and that kind of thing. Really spearheading and encouraging death cafes and that kind of

stuff...one of her roles was to connect with every faith group in Halton. It was amazing how many, I think we had a meeting once and had forty-two different people come to present all of these faith communities. It was amazing. And from there, we were asked to create a conversation starter. So, if you were a volunteer going into the community and working with someone who is doing or someone who is a caregiver, or someone who is bereaved, what do you say? It really gave us a huge contact list, so if we had someone come in and we, their faith and we think, wow, we actually don't know...it gave us a huge contact list to call if ever we had an individual or family come through here that we weren't familiar with.

Participant 3 also named a number of groups that her organization was excited to partner with and learn from both in the past and future:

I don't know how many staff have reached out to an organization because of their work with a particular client, I just know that recently, there have been a couple where folks have reached out to some agencies...like Women's Health in Women's Hands, and they're a great partner to have because their work in racialized communities, with racialized women and newcomers, their practices are playing with different kinds of ways of taking CBT models of therapy and looking at how we kind of adapt that into various culturally appropriate communities?...And there's lots of communities...that we could be partnering with. Centre for Victims of Torture, we have contact there to look at refugees, the trauma that is experienced by refugees, right?...We are about to do a training with Elizabeth Fry Society, so that may open us up to a population of folks in contact with the law, right? That's one of the areas where we can really start to build some alliances...just to work, doing a training in a community that we're not familiar with, that we haven't worked with, is an opportunity to ask those questions and that builds on our expertise and reflectiveness. It demonstrates to others that we are willing to not come into the community and say, here's our model, here's how we do this.

These women were aware and appreciative of the impact of these knowledge exchange opportunities: not only did the community organizations learn more about how to work with grieving children, youth and families, and the resources available to them, but the interviewees could also extract certain skills, strategies, tools that would help them work alongside marginalized groups in new and meaningful ways.

Finally, and perhaps most importantly, all partners demonstrated that they valued and worked from the premise of cultural humility. Rather than operate in manner consistent with theories of cultural

competency — which assume that healthcare professionals and other service providers can learn all there is to know about what it means to identify as a different culture, sexual orientation, religion and/or socioeconomic status (Cuellar, Brennan, Vito & de Lion Siantz, 2008; Isaacson, 2014; Racher & Annis, 2001) — the CYGN partners sought constantly to consider a person's lived experience from their perspective (Tervalon & Murray-Garcia, 1998). No partner made assumptions about what grief meant or felt like to a person who identified as racialized, newcomer, LGBTQ+, disabled, or living in poverty based on theories and previous experiences. Instead, clinicians always attempted to learn how clients understood their experiences, and respect how these experiences impacted their grief journey. They each had unique ways to describe this approach. Participant 1 referred to it as a "humble", "teach me" approach:

**In a country like Canada, we cannot expect that we are going to know everything we need to know about values, beliefs, and rituals of our families. There are families that have been here for generations; what their parents believe and value is going to be different from their children, from their children's children. So, we really don't need to worry ourselves about thinking we need to know everything about everyone. In fact, we take a humble approach...we don't expect that we are the expert in anybody's grief; we expect the griever to be the expert of their own grief and so we employ a "teach me" model. Our group facilitators are trained to facilitate children and families sharing their unique experiences of grief with us. That includes their culture beliefs, religious beliefs — many things that are called into question after someone dies. We take the position of just wanting to learn about what they find helpful and what they believe, and other participants may learn from that or take things away from that, but we are just here as interested and inquisitive learners.**

Participants 2 and 7 used the term "client-centred" to describe the process of asking questions and learning about individuals' experiences:

**It's also making everything be client-centred. Take your ego out of it and make it client-centred. They're the most important thing. I hold space for people. So, I will sit and I will listen. I don't have answers for them; I can sometimes facilitate them coming to their own decision in the way I ask a question, but for the most part, like with grief, you can't take someone's grief away and I let them know that. And I will say to people, you are the**

expert on your own grief, not me, so tell me. Tell me about your grief, teach me about your grief, I'm here to learn.

I'm totally client-centred. I am always assessing what it is they're needing and I ask a lot of questions when I first meet a family to get a better understanding of what their goals are, but also what their religion and culture have to say. I'm always asking questions, I'm always doing research, doing webinars, whatever I can to find out more information about the family and their needs, so I can tailor the work that I do with the kids. I'm not shy to ask a lot of questions.

Participant 3 referred to the work as "anti-oppressive":

Doing that kind of work is really, really, very important...We have to say we're not experts in everything; we are experts in children and youth's grief. How that gets sliced when people are..when you intersect that with race, or with people's experience of homophobia, that's a whole other piece that we need to learn from clients. Being prepared to ask the question. It demonstrates that we are taking an anti-oppression perspective in our work. And clients will tell us — sometimes they will say, it doesn't impact me, and it may not. Sometimes that's just where they're at and they don't see it themselves, but just ask them. To be able to find ways to talk to them about the other ways in which these things may or may not be affecting their experience of grief, right? ...We want to make sure that someone comes in and says, 'Yes, I'm Muslim,' and people don't go into gear like, "Oh yeah, there's this toolkit, this is what we do." Cause we don't know how people sit with their identity, and whether they practice or if they don't practice, if they follow certain things or not.

And finally, Participant 4 preferred to refer to her work as "being curious" with clients:

When I'm actually working with an individual, it's exploring what their experience is and not assuming that I understand their experience, even though they may identify as LGBT or they have had a parent die, or they do have kids, right? I'm very conscious of how much our lens of the world influences things and how easy it is to apply that to other people. I think curiosity is the word that I would use the most; I'm always just curious about other people's experiences and interpretations and I try to weave that right into the fabric of the work that I'm doing with people...I love the concept of cultural humility as opposed to cultural competence...again, that curiosity and being open and willing to learn, and

sometimes even mess it up a little bit and being able to apologize and say, “Okay, I’d love to learn.”

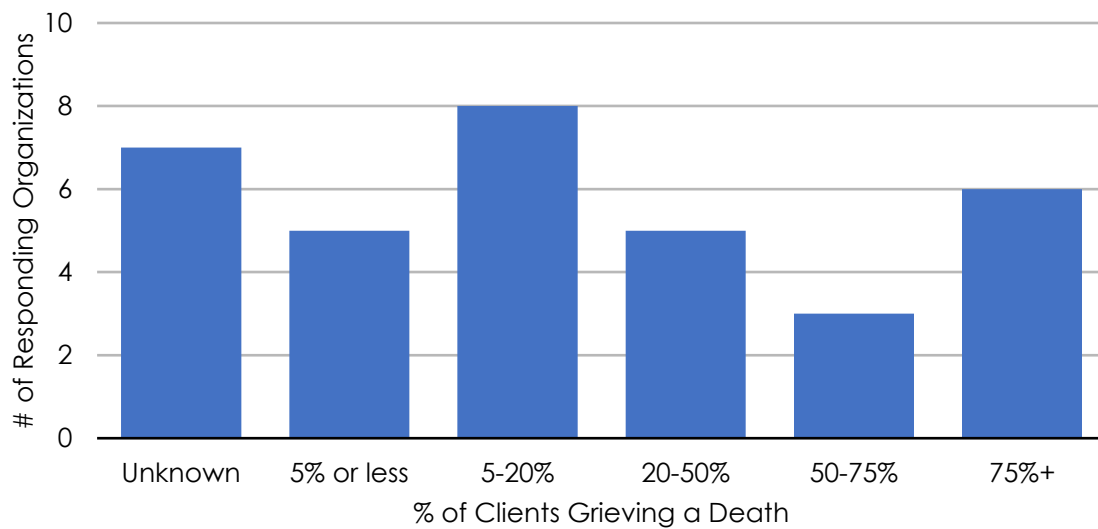
Whether or not they used the term “cultural humility”, participants recognized the need to collaborate with children, youth and families, and appreciated that one-size models of care were not suited for all clients. They recognized that it is impossible to be completely knowledgeable about groups that we do not personally identify with, and aimed to constantly occupy the role of learner rather than “expert” when interacting with clients (Levi, 2009; Isaacson, 2014). Altogether, the flexibility, community education and cultural humility that guided CYGN partner organizations in their work with clients illustrated that they were committed to doing what they could to reduce barriers for all clients, including those who may also be marginalized in one or more ways.

### **Phase IIb: Community Survey**

CYGN partner narratives were supplemented using the findings from our community survey, distributed to hundreds of organizations working with diverse communities of youth and families outside the realm of grief (e.g. children’s mental health, homelessness, poverty, newcomer centres, LGBTQ+ organizations). We inquired about the impact of grief on these communities: estimates of the number of clients who were grieving a death; other types of grief that clients were experiencing; the barriers that providers experienced in navigating grief with clients; and, the barriers that clients experienced as they attempted to access formal grief and bereavement care. We followed these questions by asking organizations what formal grief support institutions could create or offer to support them in their work.

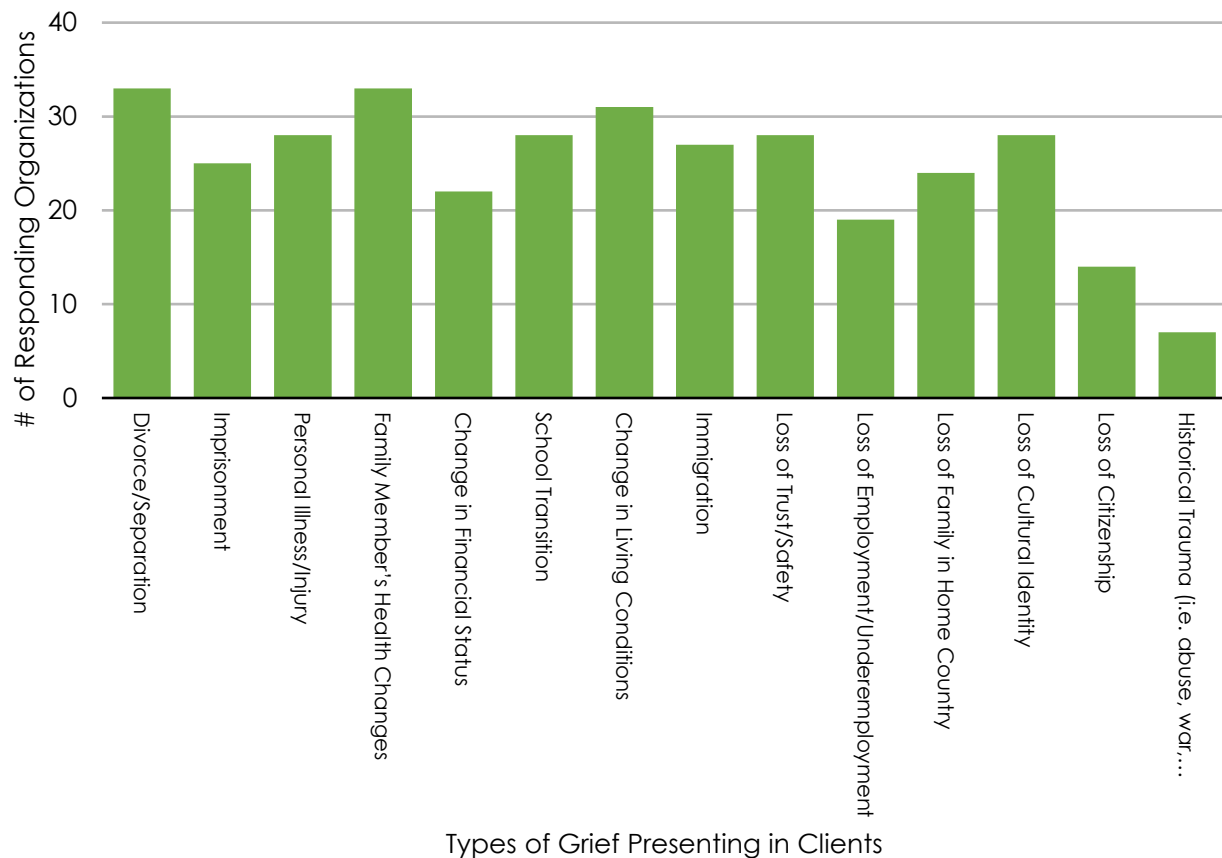
Just as there was a vast range of responses from CYGN partners attempting to estimate the number of marginalized clients in their care, community organizations’ responses regarding the number of grieving clients varied greatly. Figure 3 depicts counts that range anywhere from less than 5% to well over 75%, with a substantial number of respondents stating they could not estimate how many clients were grieving. Still, the average estimate provided was 37.8%, suggesting that a substantial portion of clients using community services *not* specializing in bereavement were, in fact, grieving a death, even if this was not the primary reason for reaching out to the organization.





*Figure 3.* Organizations' estimates of the number for grieving clients.

However, there was much more consistency in the responses related to the other types of grief that clients were experiencing. Figure 4 illustrates the number of organizations that identified other salient forms of grief in their clients. While not directly probed in the survey, we can assume that some of these auxiliary forms of grief may be related to the death that clients are already mourning (i.e. grief due to family member's health changes, changes in financial status, school transitions and living conditions). It is also possible that these types of grief are interrelated, in that they are created by the same circumstance (i.e. divorce and separation could be related to changes in living conditions, grief due to immigration may be directly related to loss of family in home country and cultural identity). Taken together, these estimates demonstrate how multifaceted and prevalent grief can be.



*Figure 4.* Other types of grief identified by community organizations.

When asked how grief impacted their work, community members' responses clustered into one of two major themes: service providers in other agencies felt that underlying and unresolved grief either **disrupted the therapeutic alliance or process** in some way, or that it **influenced the emotional and mental state** of the young people they were working with. Regarding the therapeutic alliance, many providers felt that grief of any kind made it particularly difficult to prioritize therapeutic or service goals; youth and families were unable to determine what their most pressing need was or identify resources and services that would be most helpful. Providers who participated in the survey detailed that grief often layered on to other presenting challenges such as anxiety, depression, feelings of discrimination and/or rejection. However, many providers detail that their clients are often not even aware of how grief is influencing these experiences. Thus, they are called to work harder to support clients in making the connections between their grief experiences and other challenges, and this can be difficult in the context of the services provided. For example, some of the responses include:

**Most of our clients have several issues they are dealing with and grief compounds these issues.**

**[Grief] is often a factor that colours their world view and sense of social safeness and belonging.**

**If the grief is what the client wanted to work on, that would be our treatment goal. But at times, it's supporting the client to realize how grief may be impacting their overall well-being.**

**It adds complexity to the counselling interaction, adding another layer to explore within a single-session context can be challenging. Young people also present grief in many ways and may not identify it by name, but rather by the feelings that stem from their experience.**

Grief also complicated youth's ability to engage meaningfully in service. For some, this was related to youth's lack of "trust in adults" or "having their guard up", specifically service providers. As one respondent detailed:

**Grief can present as hostility towards staff or shutting staff out which can make it difficult to understand what the family needs.**

But for others, it was related to low levels of participation in service, stemming from a "drop off in attendance to meetings" or what providers' labelled a "lack of motivation" and "readiness for change".

Moreover, almost all respondents believed that grief had a significant impact on the overall functioning of young people. Providers referred often to youth's "state of mind" when accessing service, highlighting that grief can produce or exacerbate mental health issues and emotional dysregulation. They detailed how many of their clients experienced "decreased self-esteem", hopelessness, "feelings of social rejection" and "isolation and social withdrawal" as a result of grief experiences. Other providers experienced an increase in youth's negative behaviours, including: feelings of "intense anger", "acts of aggression and revenge", "risk-taking behaviours", and an attitude of "disregard" for others and/or the consequences of their actions. As a result, providers found it difficult to both communicate with and relate to young people from a clinical perspective, and connect youth with other helpful services and resources such as peer-support programs, and other community initiatives.

Community service providers also listed a number of **professional and systemic barriers** that complicated their work with marginalized grievers. Similar to the CYGN partners interviewed, participants felt limited by: available funding; their organization's clinical/service models (i.e. how long sessions can be provided, age limits, how/where clients are seen); and accessibility to families (i.e. their geographic location, long wait times for their services). However, the most commonly cited barriers that community organizations experienced in relation to clients' grief is a lack of training and comfort, and, relatedly, grief being beyond their organizational mandate. Some providers felt that their agency lacked "specialized counselling opportunities to deal with grief" while others cited a "lack of knowledge and expertise" related to clients' needs. They were concerned about being able to "adequately provide support" given "staff are not specifically trained to do grief work." According to one service provider:

**Our agency does not provide counselling or programming in this area. If it is identified, our agency would refer the client to an agency who could provide services needed in their area.**

These feelings of uncertainty and anxiety around working with grieving clients was perhaps best captured by one respondent who simply stated: "We are not grief workers." This theme suggests that while community organizations serve diverse groups of clients, presenting with a vast array of needs, including mental health, homelessness, immigration, criminality, abandonment, isolation, and poverty, they still rely heavily on the work of formal grief support services — such as those represented in the CYGN — to provide informed and professional support to clients who are grieving a death.

Unfortunately, access to these formal supports is not always guaranteed to clients. In fact, the barriers that community organizations identified as limiting client access to grief support were almost identical to those described by CYGN partners. They include: limited financial resources; accessibility of grief services (including the location of the service and the wait times to receive support); inflexible service formats (i.e. ages of individuals served, short-term service provision, in-office visits, regular commitment requirements, time of service, family vs. Individual appointments); and, a lack of awareness of the services available in the community. In addition to these barriers, a few community organizations also commented on the cultural appropriateness of grief supports. While for the most part, specific groups and needs were not identified, many providers indicated that cultural-sensitivity was missing from formal grief supports, and this value manifested in a variety of ways for respondents. For example, one provider suggested that grief institutions were sometimes experienced as "non-welcoming spaces" for certain groups. Another requested that grief services adopt "a different understanding of what grief looks like." Still, others reflected:

**Our client group often needs services in languages other than English and French.**

**Youth from different cultural backgrounds look for counsellors that they can connect with. Having grief counsellors with the knowledge, skills and experience of different cultures will help, and make more youth willing to access formal grief support.**

These responses suggest that while cultural humility is central to the vision and mission of many of our CYGN partners, there are other, more discernible ways in which a commitment to serving people of all cultures may be demonstrated, even before a clinical relationship or interaction begins.

Finally, there was significant alignment in relation to the need and desires of community organizations. When asked what formal grief supports could offer or do to reduce barriers to resources and programs, the majority of respondents proposed initiatives that improved overall access both for clients and service providers alike. These included: reducing wait times for grief services; lowering cost for services/resources or making them free; offering community (or in-home) visits for clients rather than in-office visits; opening more service locations within other communities across Ontario; and developing/launching web-based services and resources that can be downloaded by families remotely. Other popular suggestions focused on establishing improved relationships with diverse groups of service providers and clients. Many respondents felt that the CYGN and other grief agencies could launch more awareness and education campaigns to showcase the work that they do and establish a public profile in communities outside their geographical area. This included distributing flyers and posters, attending public speaking events and conferences, posting and sharing on social media, and reaching out to other community organizations to share their mission and vision. Another popular suggestion included collaborating with community groups, and participating in professional trainings and consultations.

A number of survey participants noted that they would like to attend a professional training event to learn more about providing grief and bereavement support to their community. In reverse, many providers offered to share their own expertise, knowledge and skills related to working with marginalized groups with formal grief organizations to enhance cultural awareness and sensitivity. In this way, community organizations are craving more than simple training manuals and programs; rather, they are willing and wanting to engage in meaningful knowledge exchange with grief professionals to enhance the work of both parties. While some of these suggestions are current and priority initiatives within the CYGN (as described above in Phase IIa), community organizations did offer additional avenues for consideration.

### Phase III: Exchange Events

In total, 124 evaluation forms were completed from all four of our Knowledge Exchange Events: 50 from the Halton District School Board audience, 15 from the Hospice & Palliative Care Ontario Conference, and 59 from our webinar with Andrea Warnick Consulting. Audience members and survey respondents represented diverse sectors, captured in Table 4 below, suggesting that grief and bereavement is of interest to a number of professionals who work with or care for children and youth in both direct and indirect ways.

**Table 4**

*Proportions of professionals represented in evaluation survey*

<u>Profession</u>	<u># of Respondents</u>	<u>% of Respondents</u>
Social Workers	20	16%
Child & Youth Workers	17	13.6%
Speech-Language Pathologists	16	12.8%
Psychologists	13	10.4%
Hospice & Palliative Care Workers	13	10.4%
Certified Child-Life Specialists	9	7.2%
Clinicians & Therapists	8	6.4%
Nurses	5	4%
Volunteers	4	3.2%
Educators	6	4.8%
Other Healthcare providers (i.e. physicians and personal support workers)	4	3.2%
Other (i.e. parents, artists, spiritual care workers)	9	7.2%

Overall, responses to the Knowledge Exchange Event presentations were positive, suggesting that community professionals did benefit from participating. A summary of the evaluation survey results is captured in Table 5. More than 75% of respondents either agreed or strongly agreed with all but two of the response items, demonstrating that the presentation content was useful in supporting the audience's understanding of grief and bereavement, and expanding the tools and knowledge they relied on when supporting grieving young people. Results also demonstrate that participants felt the content was relevant to their work and presented in an accessible way, and that the majority of professionals intended to apply what they had learned in the session. However, two specific items had less positive responses: only 62.3% of respondents agreed or strongly agreed that the Exchange Event increased their confidence when working with or supporting a grieving child or teen, and only 67.8% believed that the workshop provided them with strategies and tips to reduce barriers that exist for groups of grieving young people.

**Table 5**

*Proportions of audience responses to Knowledge Exchange evaluation form*

<u>Response Item</u>	<u>Strongly Disagree</u>	<u>Disagree</u>	<u>Neutral</u>	<u>Agree</u>	<u>Strongly Agree</u>
Today's workshop increased my understanding of grief and bereavement.	1.6%	4%	15.3%	58.1%	21%
Today's workshop increased my understanding of how I can support a grieving child or teen.	3.3%	2.4%	8.9%	61.8%	23.6%
Today's workshop increased my confidence in working with/supporting a grieving child or teen.	3.3%	2.4%	32%	46.7%	15.6%
Today's workshop gave me tools, knowledge and resources that will support me in my work with grieving children and teens.	2.4%	0%	9.7%	45.2%	42.7%
Today's workshop increased my familiarity with grief supports that exist in my community.	1.7%	5%	15.7%	38.8%	38.8%

**Table 5***Proportions of audience responses to Knowledge Exchange evaluation form*

<u>Response Item</u>	<u>Strongly Disagree</u>	<u>Disagree</u>	<u>Neutral</u>	<u>Agree</u>	<u>Strongly Agree</u>
Today's workshop helped me understand different barriers/challenges that young people may face when grieving.	2.4%	3.3%	15.5%	58.5%	20.3%
Today's workshop provided me with strategies/tips to reduce these barriers in my work with grieving youth.	2.4%	5.6%	24.2%	50.8%	17.0%
Today's workshop was relevant to my work.	4.1%	2.5%	13.1%	41.8%	38.5%
Today's workshop was easy to understand/presented in an accessible and engaging way.	4%	1.6%	8.9%	44.4%	41.1%
I plan to apply what I learned today in my work.	3.4%	0%	12.6%	41.2%	42.8%

These patterns highlight important areas for future work. While many professionals working alongside children and youth may feel equipped with knowledge, tools and resources to support expressions of grief, the confidence to engage actively with young people in these conversations and support them may not be so easily imparted. Rather, as our CYGN partners often advise, this comfort is cultivated slowly, often with many hours of practice. Unfortunately, while many of the professionals involved in the Knowledge Exchange events may have encountered a child or youth who is grieving, there are often less likely to be solely responsible for providing them support. In fact, many professionals in our sessions indicated that they prefer to refer to formal grief organizations and professionals for this care. Thus, it may be advisable to extend our Knowledge Exchange sessions to provide additional information over longer sessions of time and with more frequency, to enhance professionals' confidence. Though these Exchange Events were not intended to serve as formal trainings, it is possible that offering more regular and structured sessions with professionals that are more interactive in nature (i.e. offer more practical, scenario-based exercises) would be beneficial.



The same is true regarding education about the strategies to reduce barriers for marginalized grievers. While this topic was discussed briefly during the Knowledge Exchange events, it was not a primary focus of the presentations. It is also possible that audience members, similar to our CYGN partners, may feel particularly limited or restricted by the larger social and political forces that structure their organization or profession. Therefore, they may feel unable to effect these types of changes. Moving forward, we recognize the importance of not only educating professionals as to the barriers that their clients may face when attempting to access grief support, but also sharing the many ways that they can work to reduce these barriers. This includes small scale efforts that can be made on a personal level, and larger scale changes they can advocate for both within their organization and the institutions or systems to which they belong. We may also want to integrate specific examples of initiatives that our CYGN partners are undertaking (described above), as well as models from other collaboratives or industries (i.e. education, healthcare, hospice care). Together, this may comprise a list of potential avenues of action for audience members and tangibly demonstrate the possibility of transformation.

Interestingly, the patterns that emerged in respondents' quantitative responses were also reflected in their qualitative responses. When asked the most important lesson learned in the Knowledge Exchange events, the majority of attending professionals felt being familiarized with available resources was the most critical takeaway. This seems closely tied to the level of agreement indicated on the survey: 87.9% of respondents agreed or strongly agreed that the presentation gave them tools, knowledge and resources to use in their work with grieving young people. Other extremely popular responses included: how to support a grieving child or youth (including things to say/not say, do/not do), and the statistics on marginalized grievers in Canada. The percent agreements on these items were also high: 85.4% agreed the workshop increased their understanding of how to support a grieving child or teen, and 78.8% agreed that it helped them understand the barriers that some young grievers may face when accessing support.

By the same token, when asked about what the CYGN could create or offer to support them in their work with grieving young people, the majority desired more trainings and accessible resources, as well as more information and research on diverse groups of clients. These needs can be mapped directly on to the discussion above regarding areas for improvement: with additional training and resources, professionals in other sectors can feel more confident in their ability to provide support to grieving youth, and additional research on diverse groups can facilitate a better understanding of the barriers that impact certain individuals and how these can be eradicated in our work. The CYGN hopes to continue to pursue these initiatives in the years to come, and share new resources, educational opportunities and research with the wider community.

## Recommendations:

### Adopting a Health Equity Approach to Grief & Bereavement Care

Taken together, the data collected through our literature review, original data collection with CYGN partners and community organizations, and our knowledge exchange events highlights the need for additional information and evidence-based strategy related to working with marginalized grievers. While researchers and bereavement professionals in our Network continue to make significant strides to learn about the needs of specific communities, many individuals may continue to feel unseen and irrelevant in the theories used to guide our work, the assessment tools used to make service decisions, the resources developed and disseminated, and the programming provided within our agencies. To date, we understand little about the social experiences, motivations, desires and limitations of individuals who are accessing our services, but we understand even less about those who aren't. As such, it is imperative that the CYGN and wider grief and bereavement field begin to consider making a strong and visible commitment to diversity and inclusion by adopting a **health equity approach** in their work.

The United States Department of Health and Human Services (2011) defines health equity as "the attainment of the highest level of health for all people" requiring "valuing everyone equally with focused and ongoing societal efforts to address avoidable inequities, historical and contemporary injustices, and the elimination of health and healthcare disparities." In Canada, the National Collaborating Centre for Determinants of Health (NCCDH) draws on the definition provided by Whitehead and Dahlgreen at the WHO Collaborating Centre for Policy Research on Social Determinants of Health (2006): ensuring "all people can reach their full health potential and should not be disadvantaged from attaining it because their race, ethnicity, religion, gender, age, social class, socioeconomic status or other social circumstance" (2013a, p. 1); no matter how someone identifies, where they live, and what resources they have available, they are able to receive high-quality care that is "safe, effective, patient-centred, efficient and timely" (Health Quality Ontario, n.d., p. 5). Fairness underlies the principle of health equity: fair distribution of health resources, fair access to healthcare opportunities, and fairly administered support to individuals in need of care (Krieger, 2001). However, the concept of fairness in health equity differs from the idea of equality wherein all individuals receive the same amount of resources and support to achieve healthy outcomes. Instead, health equity frameworks advocate that some members of a population need more or different services to achieve the same level of health as others. According to De Souza and Iyer (2019), adopting a health equity approach involves organizations giving reexamining the way their programs and services are developed and delivered to marginalized groups and acknowledging the environmental conditions that maintain disparities in health and healthcare access. More specifically, on a program level, organizations must: make attempts to understand differences in healthcare access amongst the

population; experiment with strategies to mitigate these differences; and evaluate the implemented strategies to determine how they impact specific subgroups, both intentionally and unintentionally (Liburd, Giles, & Jack Jr, 2013). At a larger system's level, organizations must also: examine how visions, missions priority actions are determined; how partnerships are cultivated and perceived; and, how leadership functions to model its commitment to diversity and inclusion (Liburd et al., 2013). In their report, *Healthcare and the Competitive Advantage of Racial Equity*, De Souza and Iyer (2019) offer specific strategies and "internal catalysts" for advancing equity and inclusion in healthcare. These actions are similar to those put forth by the NCCDH (2013b). As such, we felt they were appropriate to recommend as next-steps or considerations for the CYGN given the results of this project.

The first broad strategic action includes **collecting and analyzing high-quality data**. As evidenced in the Findings section above, few of the CYGN partners were currently compiling, storing and interpreting quantitate or qualitative information about their current or prospective clients. However, companies leading the charge in equity, diversity and inclusion "collect and track data on patient race, ethnicity, and language" to take appropriate action to improve service delivery (De Souza & Iyer, 2019, p. 15). CYGN partners must be able to reliably document this information about clients, as well as other factors and lived experiences, such as their history of migration, income, sexuality, ability, and involvement with child welfare and/or the criminal justice system. While sensitive in nature, these demographic profiles are immensely beneficial in a number of ways. Primarily, they allow partners to understand who the services are and are not reaching. When paired with other assessment measures and tools (i.e. grief and depression indexes), these numbers may also help to clarify who is/is not benefiting from their services, and the relationship between people's intersecting social circumstances, their needs, and their health outcomes (NCCDH, 2013b) — in this case, their adaptation to grief and improved functioning overall. With this information in hand, partners are able to more accurately determine if there are gaps in the resources and services available to their clients, and make informed decisions about priority areas for improvement and development. An example of this strategy at work comes from one of our partners, Heart House Hospice, who learned through a client chart review that they were rarely serving hospice clients of South Asian descent despite being located in a geographical region comprised primarily of South Asian residents. Equipped with this information, Heart House began to make strategic decisions to attempt to draw in clients from this cultural group: they engaged in targeted outreach in the community, focusing on spaces and programs where the South Asian community gathered; they intentionally recruited hospice volunteers from a variety of South Asian communities to ensure that clients could communicate in languages they felt most comfortable with; and, they commenced cultural and religious training for their staff and volunteers to ensure that the hospice and bereavement needs of South Asian clients could be more effectively met. Collecting and using reliable data can also support decision making

by providing a stronger case for resource (re)allocation, especially when they are limited; management and board members may feel more comfortable or compelled to invest in programs and services that promote equity and inclusion when there is striking data to accompany a recommendation or request.

Returning to partners' narratives however, the biggest limitations to the collection of demographic information included professionals' discomfort asking the questions, confusion regarding the relevancy of the questions, and a lack of clarity surrounding the defined categories. A potential solution to all of these challenges involves a network-wide adoption of a standardized, piloted procedure and tool that has proven effective in similar healthcare spaces. In 2013, Toronto Public Health, Saint Michael's Hospital (SMH), The Centre for Addiction and Mental Health (CAMH), and Mount Sinai Hospital (MSH) released their research project report on health equity data collection, *We Ask Because We Care*. This report documents the develop and testing of an eleven-item (8 required questions, 3 optional questions) socio-demographic questionnaire provided to clients at registration/admission. The questionnaire has been recommended for use and adopted in many institutions, and can be found in Appendix B of the [research report](#). The tool itself offers many advantages. The first is that it is rooted strongly in evidence: it was created in 2009 by a collaborative of equity practitioners working at SMH, MSH and CAMH who acknowledged the disparity in health data collection methods. Together, the team sought to determine the following: what social information should be collected from clients?; who should be asking clients for this information?; in what format should this information be collected?; and, how should patients and staff be informed about data collection efforts? Prior to developing the tool itself, the collaborative conducted a literature review and environmental scan to identify other countries and institutions that were involved in similar data collection efforts, how the general public felt about these data collection initiatives, best practices in personal data collection and the questions that were most critical to ask of clients. Once developed, staff and volunteers were trained on distribution, and education and awareness campaigns were commenced at the various healthcare sites. Secondly, through the pilot data-collection project, researchers concluded that 86.6% of patient respondents completed the survey while only 13.4% declined. Furthermore, the individual questions on the inventory had response validities that exceeded 95%. Taken together, these results suggest that collecting this information using this format is possible, and that clients are perhaps more willing to share this information than some healthcare professionals may assume. Third, the response items are standardized and use a "check one only" structure to bolster the quality of the data, ensure client's careful consideration of the options, and simplify statistical analysis, aggregation and comparison (Wray et al., 2013). This reduces the need for CYGN partners or other professionals to identify response items for clients, or interpret open-ended results.

However, staff's acceptance of demographic information collection is essential to the success of the questionnaire; should clients sense staff's discomfort or resistance, or if staff are hesitant and avoidant when asking the questions, they may be more unwilling to answer questions, or respond with "I don't know" and "Prefer not to answer" (Wray et al., 2013). Thus, it is important for any organization using the tool to educate their staff prior to formal implementation. Education efforts include: stressing the importance of collecting this information, providing additional information about the need for health equity, and allowing for many opportunities to practice administering the questionnaire, including chances to shadow another person collecting the data in real time. The majority of staff that participated in the pilot project believed that the collection process was "relatively easy" (Wray et al., 2013), demonstrating that implementing client surveys can be comfortable with adequate preparation. We would therefore advocate that organizations not rush to begin amassing data using the questionnaire, but rather, take their time to ensure staff and leadership personnel are properly informed about the tool's purpose and are ready to begin working with clients to collect the information. This will ensure a smoother process for clients and professionals, as well as more accurate and complete data.

Beyond quantitative data collection, we would advocate that the CYGN consider embracing qualitative methods as part of their client assessment process. For example, instituting an intake interview to better understand the specific needs of clients and families, their previous experience with programs and services, and the barriers they may have faced in their attempts to access and engage with formal service. Alternatively, organizations may consider implementing a mandatory exit interview or qualitative survey with clients to determine if their needs were met by participating in programs and services, what (if anything) was missing from their service, and thoughts about how to improve programming to ensure equity for future clients. Combined with the quantitative instruments listed above, interviews and qualitative assessments allow for additional and important nuancing; professionals may be able to analyze and speak to the relationship between social identity factors and grief needs, however, listening more attentively to the voices and lived experiences of clients allows for complex intersection to shine through and more individualized care to be offered. It prevents organizations from making stereotypical assumptions about what it means to be grieving *and* racialized, an immigrant, disabled, poor, gay or bisexual, etc., and instead allows professionals to come to an understanding of what is relevant and pertinent to the clients they are serving, without losing important statistical data about who their services are reaching. Data collected from pre- and post-service interviews also provides supplemental information to support decision-making and program planning.

An important caveat to consider however, is the fact that these initiatives work only to maintain a clearer picture of the children, youth and families who are accessing formal service at one of our

partner organizations. To date, we remain even more limited in our understanding of the experiences, needs and barriers of grieving families who are receiving care in other localities, and those who are not receiving any formalized support, which inhibits our ability to create a system, resources and services that truly caters to everyone. Thus, in addition to instituting changes to the client intake and discharge process, organizations should consider expanding their research efforts to explore the needs of these isolated communities (Health Quality Ontario, n.d.). Certainly, projects of this nature require creative research strategies, significant amounts of time and financial resources, and dedicated management staff; however, with targeted proposal writing and through intentional collaboration with other grief and non-grief specific organizations, funding and personnel can be secured to build on the findings of this report. Research methods may mirror those used over the course of the current project (i.e. literature reviews, interviews, qualitative surveys and knowledge exchange events), but may also expand to include unstructured interviews, storytelling, arts-based methods (such as poetry, visual art, music, creative writing, filmmaking) and even studies of blog posts and Instagram photos that allow participants to speak to their experiences and needs in unique ways. While the analytic process involved in these alternative methods is perhaps more complex and unfamiliar to researchers and professionals in the grief field, these methods of inquiry may prove more engaging, appealing and appropriate to marginalized groups, and produce more generative results that allow for interesting service innovations to emerge.

To facilitate research projects of this nature, and further strengthen our capacity to serve marginalized grievers, it is also imperative that the CYGN and other formal organizations look to **establish new and strategic partnerships** (De Souza & Iyer, 2019; Health Quality Ontario, n.d.; NCCDH, 2013b). These relationships can be established with other formal grief organizations in Peel, Halton, and Toronto, as well as those located across the province and country, to facilitate an improved awareness of existing programming and research initiatives. This level of collaboration has already commenced within the CYGN through their National Survey, distributed in Spring 2018 to organizations and private practitioners who had previously requested their grief resources. Click [here](#) for information about the survey itself, the findings and actions that resulted from this inquiry. More importantly however, the collective may want to consider engaging the individuals and spaces identified as critically supportive to marginalized populations in the current literature, including: religious and spiritual groups, ethnic/cultural centres, and prominent community leaders. It may similarly advantageous to build upon the process of this project by returning to those organizations who participated in the community survey and ganging them in a more meaningful way. As a reminder, participants included representatives from children's mental health organizations, LGBTQ+ services, immigrant and settlement groups, Indigenous healing lodges/networks, and charities/agencies that work with individuals living in poverty, those who are homeless, and involved in both the child welfare and criminal justice systems. At an even larger level, the CYGN

should consider formally enlisting the support of both the education and healthcare sector by on-boarding network partners who maintain ties to school boards, hospitals, community health centres, and local health integration networks with whom they have regular contact. One asset that makes these alliances a potential reality is the existing 3-tier partnership structure that the CYGN put into place in the Summer of 2019 (click [here](#) for more information about this initiative), which allows organizations and professionals to engage with the network at a level that is convenient for them. Providing groups the option to join the network as either a partner, associate or community member honours differences in organizations' capacities, while demonstrating the importance of both engagement by the organization and recognition by the network.

Bringing these groups to the CYGN table creates multiple, enduring knowledge exchange opportunities (Health Quality Ontario, n.d.). Firstly, by collaborating with organizations and professionals that work with high-risk, marginalized groups, the CYGN is called to more consistently bear the voices and experiences of these groups in mind, enhancing their capacity to provide grief and bereavement support. Together, grief and non-grief specific agencies can engage in important and informed dialogue about a community's needs and the barriers that they face. Moreover, best practices can be identified, and tools and resources can be evaluated, revised and created to address these. New agencies with different service mandates can also provide more straightforward and uncomplicated access to members of specific, more isolated social groups to allow the CYGN to hear personal stories and invite additional recommendations that further enrich resource development, and ensure "efforts reflect what is meaningful and matters to individuals experiencing inequalities" (Health Quality Ontario, n.d., p. 14). Reciprocally, inviting new organizations to the table bolsters their capacity to support grieving children and youth in their communities, consistent with the principles of the Irish Bereavement Pyramid described above (Irish Childhood Bereavement Network, 2014). By attending meetings, participating in discussions, and engaging in resource development, these community organizations can become more adept at providing grief and bereavement support to families they come in contact with, and doing so in a way that aligns with both the theoretical philosophies and practice framework that guide the CYGN's work as well as their own cultural practices and beliefs. Finally, these partnerships can improve service access overall; the more aware both the CYGN and community organizations become of one another, the more likely they are to refer to one another in their daily work. When working with a client who identifies as marginalized or disenfranchised in some way, grief organizations will be better able to identify, connect with, and work alongside groups that attend specifically to their needs. Similarly, when working with a client whose grief is central to their worldview or layering on to other social challenges, community organizations may feel increasingly comfortable to refer to the CYGN, recommend their resources, and cooperate to improve the client's health outcomes. Clients, too,



may feel more comfortable and safe accessing service within the CYGN or in the community when these partnerships are established and promoted.

De Souza and Iyer (2019) also recommend instilling a **philosophy of cultural humility** in all service delivery. As a reminder, cultural humility recognizes that it is impossible to know everything about specific cultural groups, and thus, requires professionals to commit themselves to assuming the role of learner in their relationship to clients, being curious about/open to learning about clients' belief systems, experiences and needs, becoming comfortable with the idea of "not knowing", practicing self-reflection to investigate the source of potential biases, recognizing how power and privilege influence the client-professional dynamic (Culturally Connected, n.d.). Certainly, improved data collection and partnerships may work (independently and in tandem) to increase cultural humility, given they support and encourage the CYGN partners to be respectful of and responsive to the beliefs, values, practices and needs of diverse groups. However, the principle of cultural humility also needs to be prioritized as a key clinical approach in interactions with clients, allowing children, youth and families to establish authority over their lived experiences (Health Quality Ontario n.d.). While professionals within the network are immensely proficient and well-versed in grief theory and literature, and considered "experts" in strategies that support the identification, normalizing and management of grief, it is vital that they recognize and acknowledge that they will always remain unaware of exactly how each individual client embodies grief and the impact it has on their lives and relationships. In this way, each client must be considered the expert of their own grief experience. Promisingly, the paradigm shift from cultural competence to humility has already begun to manifest in the daily practices of the CYGN. As described in the Findings section above, almost all of the partners demonstrated they were open to hearing and learning from clients' lived experiences, probing the aspects of their identity that were most salient to them and refraining from making assumptions about what grief looked or felt like to someone who identified in a specific way. The professionals interviewed were committed to practicing not only intersectionally, but using a "teach me", "client-centred", and "anti-oppressive" framework, agreeing that quality care was not rigid or prescribed, but flexible, fluid and responsive to the individual needs of clients.

Therefore, building on this encouraging pattern, the findings of this project point to organizations' continuing to demonstrate this responsibility, and engaging, whenever possible in additional trainings or education initiatives that further their understanding of cultural humility. Recommendations include incorporating information about cultural humility and relevant resources into staff and volunteer training manuals or programs, emphasizing the importance of this philosophy to each centre's work. The Ontario Public Health Administration also offers a cultural humility workshop that staff could engage in. The workshop — led by a social justice educator, equity and cultural humility specialist — intends to promote participants' understanding of cultural humility as a principle and



process, increase knowledge of oppression and intersectionality, and allow opportunities to practice culturally-humble interactions that can be applied to healthcare work (for more information about the course, visit the OPHA [website](#)). Given funding restrictions often serve as a barrier to organizations' participating in ongoing professional development, other free resources are available. For example, The Ontario Health Authority links to a 30-minute documentary on cultural humility on YouTube (Click [here](#) to view). Canadian Virtual Hospice (CVH) has also launched [LivingMyCulture.ca](#), an initiative undertaken in collaboration with 50 Canadian partners and professionals. This website includes short video clips of individuals living in 8 different cultures talking about the intersection of their culture, terminal illness, palliative care and grief. Finally, The Health Literacy Team at British Columbia Children's Hospital and the Population Health Promotion Team at British Columbia Women's Hospital collaborated to develop and launch [CulturallyConnected.ca](#), an electronic resource designed to support providers to consider culture in healthcare interactions. The intentions of the website is to educate viewers about culture humility so to create and maintain healthcare spaces that are culturally safe and promote the health literacy of all users. In addition to short introductory readings on cultural humility, cultural safety and health literacy, the website features animated case study videos, as well as a list of fundamental practices, strategies and techniques that are central to actualizing these practices in our work with clients. While not an exhaustive list, consulting these resources may prove beneficial in developing and refining our understanding and practice of cultural humility with grieving clients.

Finally, demonstrating and growing the commitment to diversity, equity and inclusion requires **embedding these principles into the culture of the organizations** that comprise the CYGN and the CYGN staff itself (De Souza & Iyer, 2019). Leadership and staff need to believe firmly in the concept of equity and inclusion, and strive for these benchmarks at all times. This involves, at the very least, acknowledging the reality that social identities and experiences such as race, income, immigration history, disability, and sexuality can be significant facets of an individual's grief experience, and that these can have powerful impacts on their willingness and ability to access formalized grief support. As a result, they must be willing to consider implementing the recommendations provided in this section of the report, as well as encouraging the flexible service provision initiatives described by their coworkers in the Findings section by contributing the moral, practical and financial support whenever it is possible. Directors and human resource departments should also model the principle of diversity in its hiring of staff and recruitment of volunteers, recognizing that diverse talent helps clients to see themselves reflected in an organization, and feel safer speaking to their experiences (De Souza & Iyer, 2019). Of course, we are confident in there CYGN's ability to engage in this recommendation, especially given the way they prioritized this project; when faced with decisions regarding next steps for programming, development and growth of the network, the collaborative elected to pursue research funding to learn more about increasing its capacity to work with

marginalized communities. This act, in conjunction with the initiatives service providers already described as taking place within the individual organizations, demonstrates the collaborative is making important strides towards realizing their vision and mission that *every* child and youth — including those facing social and financial barriers — has access to honest information and well-informed support when someone they care about is dying or has died.



## References

- Bristowe, K., Marshall, S., & Harding, R. (2016). The bereavement experiences of lesbian, gay, and/or trans\* people who have lose a partner: A systematic review, thematic synthesis and modelling of the literature. *Palliative Medicine*, 30(8), 730-744.
- Children & Youth Grief Network. (2018). *Crossroads of Grief Project: Grieving or bereaved children literature review 2015-2018 overview*. Guelph, ON: Ashpole, B. & Warnick, A.
- Cowles, K. V. (1996). Cultural perspectives of grief: An expanded concept analysis. *Journal of Advanced Nursing*, 23(2), 287-294.
- Cuellar, N. G., Brennan, A. M. W., Vito, K., & de Lion Siantz, M. (2008). Cultural competence in the undergraduate nursing curriculum. *Journal of Professional Nursing*, 24, 143-149.
- De Souza, R., & Iyer, L. (2019). *Health care and the competitive advantage of racial equity: How advancing racial equity can create business value*. Retrieved from <https://www.fsg.org/publications/health-care-and-racial-equity>
- Doka, K. J. (Ed.). (1989). *Disenfranchised grief: Recognizing hidden sorrow*. Lexington, MA, England: Lexington Books/D.C. Health and Com.
- Erevelles, N., & Minear, A. (2010). Unspeakable offenses: Untangling race and disability in discourses of intersectionality. *Journal of Literary & Cultural Disability Studies*, 4(2), 127-145.
- Garry, A. (2011). Intersectionality, metaphors, and the multiplicity of gender. *Hypatia*, 26(4), 826-850.
- Granek, L., & Peleg-Sagy, T. (2015). Representations of African Americans in the grief and mourning literature from 1998 to 2014: A systematic review. *Death Studies*, 39, 605-632.

Granek, L., & Peleg-Sagy, T. (2017). The use of pathological grief outcomes in bereavement studies on African Americans. *Transcultural Psychiatry*, 54(3), 384-399.

Health Quality Ontario. (n.d.). *Health Quality Ontario's Health Equity Plan*. Retrieved from [http://www.hqontario.ca/Portals/0/documents/health-quality/Health\\_Equity\\_Plan\\_Report\\_En.pdf](http://www.hqontario.ca/Portals/0/documents/health-quality/Health_Equity_Plan_Report_En.pdf)

Hirschmann, N. J. (2013). Disability, feminism, and intersectionability. *Radical Philosophy Review*, 16(2), 649-662.

Irish Childhood Bereavement Network. (2014). *The Irish Childhood Bereavement Care Pyramid: A guide to support for bereaved children and young people*. Retrieved from <https://www.childhoodbereavement.ie/professionals/childhood-bereavement-care-pyramid/>

Isaacson, M. (2014). Clarifying concepts: Cultural humility or competency. *Journal of Professional Nursing*, 30(3), 251-258.

Islam, F., Multani, A., Hynie, M., Shakya, Y., & McKenzie, K. (2017). Mental health of South Asian youth in Peel Region, Toronto, Canada: A qualitative study of determinants, coping strategies and service access. *BMJ Open*, 7, 1-11.

Kleinman, A. (1987). Anthropology and psychiatry: The role of culture in cross-cultural research on illness. *British Journal of Psychiatry*, 151, 447-454.

Krieger N. (2001). A glossary for social epidemiology. *Journal of Epidemiology and Community Health*, 55(10), 693-700.

Kumar, M. B., & Tjepkema, M. (2019). Suicide among First Nations people, Metis and Inuit (2011-2016): Findings from the 2011 Canadian Census Health and Environment Cohort (CanCHEC). Retrieved from <https://www150.statcan.gc.ca/n1/pub/99-011-x/99-011-x2019001-eng.htm>

Levi, A. (2009). The ethics of nursing student international clinical experiences. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 38, 94-99.

Liburd, L. C., Giles, W., & Jack Jr., L. (2013). Health equity: The cornerstone of a healthy community. *National Civic Review*, 102(4), 52-54.

McKenzie, K., Agic, B., Tuck, A., & Antwi, M. (2016). *The case for diversity: Building the case to improve mental health services for immigrant, refugee, ethnocultural and radicalized populations*. Report to the Mental Health Commission of Canada. Ottawa, ON: Mental Health Commission of Canada.

National Collaborating Centre for Determinants of Health. (2013a). *Let's Talk: Health Equity*. Retrieved from [http://nccdh.ca/images/uploads/Lets\\_Talk\\_Health\\_Equity\\_English.pdf](http://nccdh.ca/images/uploads/Lets_Talk_Health_Equity_English.pdf)

National Collaborating Centre for Determinants of Health. (2013a). Let's Talk: Public health roles for improving health equity. Retrieved from [http://nccdh.ca/images/uploads/PHR\\_EN\\_Final.pdf](http://nccdh.ca/images/uploads/PHR_EN_Final.pdf)

Park, J., Tjepkema, M., Goedhuis, N., & Pennock, J. (2015). Avoidable mortality among First Nations adults in Canada: A cohort analysis. Retrieved from <https://www150.statcan.gc.ca/n1/en/pub/82-003-x/2015008/article/14216-eng.pdf?st=Jp4HeZF>

Peel Data Centre. (2017). *2016 Census bulletin: Immigration and ethnic diversity*. Retrieved from <https://www.peelregion.ca/planning-maps/CensusBulletins/2016-immigration-ethnic-diversity.pdf>

Racher, F. E., & Annis, R. C. (2007). Respecting culture and honoring diversity in community practice. *Research and Theory for Nursing Practice: An International Journal*, 21, 255-270.

Sheppard, A. J., Shapiro, G. D., Bushnik, T., Wilkins, R., Perry, S., Kaufman, J. S., Kramer, M. S., & Yang, S. (2017). Birth outcomes among First Nations, Inuit and Metis populations. Retrieved from <https://www150.statcan.gc.ca/n1/pub/82-003-x/2017011/article/54886-eng.htm>

Shipherd, J. C., Green, K. E., & Abramovitz, S. (2010). Transgender clients: Identifying and minimizing barriers to mental health treatment. *Journal of Gay & Lesbian Mental Health*, 14, 94-108.

- Statistics Canada. (2017a). *Canada [Country] and Canada [Country] (table). Census Profile*. 2016 Census. Statistics Canada Catalogue no. 98-316-X2016001. Ottawa. Released November 29, 2017. <https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/prof/index.cfm?Lang=E> (accessed October 18, 2018).
- Statistics Canada. 2017b. *Oakville, T [Census subdivision], Ontario and Ontario [Province] (table). Census Profile*. 2016 Census. Statistics Canada Catalogue no. 98-316-X2016001. Ottawa. Released November 29, 2017. <https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/prof/index.cfm?Lang=E> (accessed June, 2019).
- Statistics Canada. (2018). Mortality: Overview, 2014 to 2016. Retrieved from <https://www150.statcan.gc.ca/n1/pub/91-209-x/2018001/article/54957-eng.htm>
- Statistics Canada. (2019). Dictionary, Census of Population, 2016: Census family. Retrieved from <https://www12.statcan.gc.ca/census-recensement/2016/ref/dict/fam004-eng.cfm>
- Stroebe, M., & Schut, H. (1998). Culture and grief. *Bereavement Care*, 17(1), 7-11.
- Tervalon, M., & Murray-Garcia, J. (1998). Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. *Journal of Health Care for the Poor and Underserved*, 9, 117-152.
- United States Department of Health and Human Services. (2011). *Health Equity & Disparities*. Retrieved from <http://www.minorityhealth.hhs.gov/npa/templates/browse.aspx?lvl=1&lvlid=34>.
- Whitehead, M., & Dahlgreen, G. (2006). *Concepts and principles for tackling social inequities in health: Levelling up Part 1*. World Health Organization Collaborating Centre for Policy Research on Social Determinants of Health: Copenhagen, Denmark.
- Wray, R., Hyman, I., Agic, B., Bennett-Abu-Ayyash, C., Kanee, M., Lam, R., Mohamed, A., Tuck, A. (2013). *We ask because we care: The Tri-Hospital + TPH Health Equity Data Collection Research Project Report*. Retrieved from <http://www.stmichaelshospital.com/quality/equity-data-collection-report.pdf>

## Appendix A

### Immigrants & Refugee Literature

- Casado, B. L., Hong, M., & Harrington, D. (2010). Measuring migratory grief and loss associated with the experience of immigration. *Research on Social Work Practice, 20*(6), 611-620.
- Kokou-Kpolou, K., Menick, D. M., Moukouta, C. S., Baugnet, L., & Kpelly, D. E. (2017). A cross-cultural approach to complicated grief reactions among Togo-Western African Immigrants in Europe. *Journal of Cross-Cultural Psychology, 48*(8), 1247-1262.
- McKenzie, K., Agic, B., Tuck, A., & Antwi, M. (2016). *The case for diversity: Building the case to improve mental health services for immigrant, refugee, ethnocultural and radicalized populations*. Report to the Mental Health Commission of Canada. Ottawa, ON: Mental Health Commission of Canada.
- McLellan, J. (2015). Religious responses to bereavement, grief and loss among refugees. *Journal of Loss and Trauma, 20*, 131-138.
- Miller, L. D. (2013). "I am not who I thought I was": Use of grief work to address disrupted identity among Hispanic adolescent immigrants. *Clinical Social Work Journal, 41*, 316-323.
- Saito, C. (2014). Bereavement and meaning reconstruction among Japanese immigrant widows: Living with grief in a place of marginality and liminality in the United States. *Pastoral Psychology, 63*, 39-55.

### Racialized Communities Literature

- Ellis, R. T., Granger, J. M. (2002). African American adults' perceptions of the effects of parental loss during adolescence. *Child and Adolescent Social Work Journal, 19*(4), 271-284.

- Granek, L., & Peleg-Sagy, T. (2015). Representations of African Americans in the grief and mourning literature from 1998 to 2014: A systematic review. *Death Studies*, 39, 605-632.
- Granek, L., & Peleg-Sagy, T. (2017). The use of pathological grief outcomes in bereavement studies on African Americans. *Transcultural Psychiatry*, 54(3), 384-399.
- Islam, F., Multani, A., Hynie, M., Shakya, Y., & McKenzie, K. (2017). Mental health of South Asian youth in Peel Region, Toronto, Canada: A qualitative study of determinants, coping strategies and service access. *BMJ Open*, 7, 1-11.
- Jenkins, E. J., Wang, E., & Turner, L. (2014). Beyond community violence: Loss and traumatic grief in African American elementary school children. *Journal of Child and Adolescent Trauma*, 7, 27-36.
- Johnson, C. M. (2014). The loss of friends to homicide and the implications for the identity development of urban African American teen girls. *Clinical Social Work Journal*, 42, 27-40.
- Lawson, E. (2014). Disenfranchised grief and social inequality: Bereaved African Canadians and oppositional narratives about the violent deaths of friends and family members. *Ethnic and Racial Studies*, 37(11), 2092-2109.
- Lopez, S. A. (2011). Culture as an influencing factor in adolescent grief and bereavement. *The Prevention Researcher*, 18(3), 10-13.
- Sharpe, T. L., Joe, S., & Taylor, K. C. (2012-2013). Suicide and homicide bereavement among African Americans: Implications for survivor research and practice. *Omega*, 66(2), 153-172.
- Umberson, D., Olson, J. S., Cronsoe, R., Liu, H., Pudrovskaya, T., & Donnelly, R. (2017). *Death of family members as an overlooked source of racial disadvantage in the United States*. Proceedings of the National Academy of Sciences of the United States of America, 114(5), 915-920.



## Disability Community Literature

- Artman, L. K., & Daniels, J. A. (2010). Disability and psychotherapy practice: Cultural competence and practical tips. *Professional Psychology: Research & Practice*, 41(5), 442-448.
- Brownrigg, S. (2018). Breaking bad news to people living with learning disabilities: A literature review. *British Journal of Learning Disabilities*, 46, 225-232.
- Chow, A. Y. M., McEvoy, J., Chan, I. K. N., Borschel, M., Yuen, J. H. L., & Lo, J. Y. M. (2017). Do men and women with intellectual disabilities understand death? *Journal of Intellectual Disability Research*, 61(12), 1130-1139.
- Clute, M. A., & Kobayashi, R. (2012). Looking within and reaching out: Bereavement counselor perceptions of grieving adults with ID. *American Journal of Hospice & Palliative Medicine*, 29(8), 583-590.
- Irwin, L., O'Malley, G., Neelofur, S., & Guerin, S. (2017). An exploration of clinical psychology's response to parental bereavement in adults with intellectual disability. *Journal of Applied Research on Intellectual Disabilities*, 30, 1065-1075.
- Lord, A. J., Field, S., & Smith, I. C. (2017). The experiences of staff who support people with intellectual disability on issues about death, dying and bereavement: A metasynthesis. *Journal of Applied Research on Intellectual Disabilities*, 30, 1007-1021.
- MacHale, R., McEvoy, J., Tierney, E. (2009). Caregiver perceptions of the understanding of death and need for bereavement support in adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 22, 574-581.
- Mappin, R., & Hanlon, D. (2005). Description and evaluation of a bereavement group for people with learning disabilities. *British Journal of Learning Disabilities*, 33, 106-112.
- Rodriguez, M. A. A., Fernandez, L. C., & Sanchez, L. E. G. (2018). Evaluating the characteristics of the grieving process in people with intellectual disability. *Journal of Applied Research in Intellectual Disability*, 31, 999-1007.

Thorp, N., Stedman, J., & Lloyd, H. (2018). "I carry her in my heart": An exploration of the experience of bereavement for people with learning disability. *British Journal of Learning Disabilities*, 46, 45-53.

### **Impoverished Communities Literature**

Goldsmith, C. (2012). 'It just feels like it's always us': Young people, peer bereavement and community safety. *Journal of Youth Studies*, 15(5), 657-675.

Upton Patton, D., MacBeth, J., Schoenebeck, S., Shear, K., & McKeown, K. (2018). Accommodating grief on Twitter: An analysis of expressions of grief among gang involved youth on Twitter using qualitative analysis and natural language processing. *Biomedical Informatics Insights*, 10, 1-9.

### **LGBTQ+ Community Literature**

Bristowe, K., Marshall, S., & Harding, R. (2016). The bereavement experiences of lesbian, gay, and/or trans\* people who have lost a partner: A systematic review, thematic synthesis and modelling of the literature. *Palliative Medicine*, 30(8), 730-744.

Broderick, D. J., Birbilis, J. M., & Steger, M. F. (2008). Lesbians grieving the death of a partner: Recommendations for practice. *Journal of Lesbian Studies*, 12(2-3), 225-235.

Curtin, N., & Garrison, M. (2018). "She was more than a friend": Clinical intervention strategies for effectively addressing disenfranchised grief issues for same sex couples. *Journal of Gay & Lesbian Social Services*, 30(3), 261-281.

McNutt, B., & Yakushko, O. (2013). Disenfranchised grief among lesbian and gay bereaved individuals. *Journal of LGBT Issues in Counselling*, 7(1), 87-116.

Shipherd, J. C., Green, K. E., & Abramovitz, S. (2010). Transgender clients: Identifying and minimizing barriers to mental health treatment. *Journal of Gay & Lesbian Mental Health*, 14, 94-108.

## Indigenous Community Literature

- Dudgeon, P., Wright, M., Paradies, Y., Garvey, D., & Walker, I. The social, cultural and historical context of Aboriginal and Torres Strait Islander Australians. In N. Purdie, P. Dudgeon, & R. Walker (Eds.), *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice* (p. 25-42). Commonwealth of Australia.
- Hanssens, L. (2008). Clusters of suicide...The need for a comprehensive postvention response to sorrow in Indigenous communities in the Northern Territory. *Aboriginal & Islander Health Worker Journal*, 32(2), 25-33.
- Hanssens, L. (2011). "Suicide (echo)clusters" - Are they socially determined, the result of a pre-existing vulnerability in Indigenous communities in the Northern Territory and how can we contain cluster suicides? *Aboriginal & Islander Health Worker Journal*, 35(1), 14-23.
- Nicolai, S. S., & Saus, M. (2013). Acknowledging the past while looking to the future: Conceptualizing indigenous child trauma. *Child Welfare*, 92(4), 55-74.
- Parker, R. (2010). Australian Aboriginal and Torres Strait Islander mental health: An overview. In N. Purdie, P. Dudgeon, & R. Walker (Eds.), *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice* (p. 3-11). Commonwealth of Australia.
- Spiwak, R., Sareen, J., Elias, B., Martens, P., Munro, G., & Bolton, J. (2012). Complicated grief in Aboriginal populations. *Dialogues in Clinical Neuroscience*, 14(2), 204-209.
- Walker, R., & Sonn, C. Working as a culturally competent mental health practitioner. In N. Purdie, P. Dudgeon, & R. Walker (Eds.), *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice* (p. 157-180). Commonwealth of Australia.
- Wanganeen, R. Dealing with loss, grief and trauma: Seven phases to healing. In N. Purdie, P. Dudgeon, & R. Walker (Eds.), *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice* (p. 267-284). Commonwealth of Australia.

Zubrick, S. R., Dudgeon, P., Gee, G., Glaskin, B., Kelly, K., Paradies, Y., Scrine, C., & Walker, R. Social determinants of Aboriginal and Torres Strait Islander Social and Emotional Wellbeing. In N. Purdie, P. Dudgeon, & R. Walker (Eds.), *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice* (p. 75-90). Commonwealth of Australia.

## Appendix B

1) Tell me about the community or populations that you serve within your organization:

- a) How do you think people learn about your service? Who are the biggest referrers to your service?
- b) Are there eligibility requirements? Anything that makes clients ineligible for services?
- c) What is your process for on-boarding/intake of clients?
- d) What information do you collect about clients? How is this information used/stored?
- e) Is there any information you don't collect? Any information you wish you did collect?

Part of this project is learning a bit more about how marginalized grieving youth access/receive service, and the capacities that organizations have to serve them. This includes youth who are personally/part of a family that is racialized, immigrant, refugee, Indigenous, identity as part of the LGBTQ community, living in poverty, lives with a disability, or have had contact with the criminal justice/child welfare system. We hope to apply for more funding to continue this research so that we can work alongside these communities in a fulsome way to understand the lived experience of grief and marginalization, but wanted to use this opportunity to understand how grief organizations work to serve these communities.

2) Using your best estimate, what percentage of your clientele would identify as:

- a) Racialized/part of a visible minority?
- b) Immigrant or refugee?
- c) Indigenous
- d) Having contact with the criminal justice system?
- e) Having contact with the child welfare system?
- f) LGBTQ+
- g) Living in poverty?
- h) Living with a disability?

3) Why do you think these estimates are what they are (as low or as high as estimated)?

4) What specific initiatives, if any, do you have in place to make your service accessible/sensitive to these communities?

- a) What do you think are a few ways you/your organization might increase your accessibility/sensitivity to these communities?
- b) What would your organization need to do this work?
- c) What efforts have you tried that have been successful? Unsuccessful?
- d) Do you measure/assess the barriers that your clients face in accessing or engaging with your service?

4) What specific resources/skills, if any, do you use to tailor your service to their experiences/social identities?

- a) What has been successful/unsuccessful about these modification attempts?

5) In your opinion, what barriers do you think exist for marginalized, grieving individuals or families who are looking to access grief support?

- a) Do you think there are specific barriers for any of the communities listed?
- b) How might the community of grief education and bereavement support work to reduce these barriers?
- c) What about the grief community produce/develop to increase your capacity to reduce barriers and/or serve diverse communities?

6) Have you/your organization participate in any trainings related to cultural sensitivity/humility or work with any of these populations?

- a) If yes, what was your experience with these trainings?
  - What was helpful? Unhelpful?
- b) If no, why?
  - What trainings might you want to engage?

7) Has your organization partnered or worked with any other organizations (local, provincial, national, international) to improve access to grief support and information?

- a) If so, who? What was your experience like working with these groups?
- b) If no, are there groups/communities you would like to partner/work with?

8) Phase II of this project involves speaking with community organizations working alongside marginalized communities in non-grief specific ways and learning more about how grief impacts their work and their clients, and what they may require from grief-focused organizations to better serve their community. Do you have any contacts or suggestions you could recommend for us to reach out to in this second phase?

g) We are hoping to build off of the learnings from this project and continue developing resources/delivering information to increase the capacity of organizations to serve marginalized grieving youth and families. Do you have any ideas for initiatives or projects that we should undertake?

a) How might your organization support this initiative?

