Ethics and Research with Young People in Challenging Contexts

Knowledge Synthesis Report 2014

www.cyccnetwork.org/ethics

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The views expressed in this report are those of the authors and do not necessarily represent those of the Government of Canada.

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Executive Summary

I. Introduction

Children and youth in challenging contexts, both in Canada and overseas, face common threats to their mental health. These challenges can be better addressed when researchers, service providers, practitioners and communities pool their knowledge and resources, and share their lessons learned of what works best for improving the mental health of young people. If these groups continue to work within their occupational and disciplinary boundaries, they will fail to mobilize the full potential of evidence documented by researchers, the practice-related knowledge of service providers and practitioners, and the local knowledge of communities.

The CYCC Network was developed in response to this need. In the summer of 2013, the Network released three thematic knowledge synthesis reports on the topics of violence, technology, and youth engagement.

Violence against children and youth, in particular, is a complex public health problem that affects communities worldwide, and can lead to potentially devastating consequences for young people and their families if left unaddressed. To tackle this problem, a coordinated effort to share and document best practices for addressing young peoples’ mental health needs is urgently needed. Without opportunities to share this knowledge, there is a risk of delivering potentially ineffective interventions that are difficult for young people and their families to access or relate to. Additionally, poorly-researched or evaluated interventions often ignore the structural barriers (e.g. access to mental health practitioners, stigma, narrow focus on a single problem, and the coordination of mental health services offered by different service providers) that shape young peoples’ mental health and wellbeing. In light of these challenges, the knowledge synthesis report on violence explores the effective strategies that help children and youth in challenging contexts who have been exposed to violence, in order to help them overcome trauma and feel safe in their families, schools, and communities.

Recent years have seen an explosion of new, innovative programs that focus on improving the lives of vulnerable young people through the use of technology. The internet has opened doors of opportunity to reach these children and youth in more effective ways with the information and support they need to lead healthy lives. Today, mobile phones are one of the most prolific mediums through which interventions can be delivered. While the rapid developments made in technology present many opportunities, the expansion of this field has not been mirrored in the development of research and evaluation of those innovations. There is a need for more evidence to support the use of technology as a means of intervention with children and youth in challenging contexts. In response to this gap, the knowledge synthesis report on technology reviews innovations in technology that are known to be effective in helping children and youth in the most challenging of contexts, to nurture resilience, prevent
mental health problems, and build a special place for themselves in the collective life of their communities.

Finally, there has been an increasing recognition that youth engagement is central to any best practice or intervention that involves young people. Valuing youth engagement puts the focus on the positive contribution that youth make to programs and their effectiveness. Programs and services that acknowledge the independence and agency of at-risk youth provide opportunity for young people to give feedback on the relevance and appropriateness of the programs that serve them. Additionally, youth engagement can promote a sense of empowerment on an individual level, and facilitate healthy connections between young people and their community. Despite these benefits, however, there remains a gap in our understanding of the implications of engaging vulnerable youth. In order to better understand and optimize youth engagement, different strategies need to be explored that identify their appropriateness for youth living in different challenging contexts, representing all genders and age categories. With these gaps in mind, the knowledge synthesis report on youth engagement explores strategies that have been shown to work in engaging children and youth in challenging contexts as full members of their communities and in ending feelings of disempowerment and abandonment.

As a next step to this process, the Network is launching four new knowledge synthesis reports in 2014. These reports explore the themes of violence prevention, ethics, information-seeking behaviour, and supportive environments.

While children and youth are always particularly vulnerable to violence, young people living in contexts that are devoid of programs and services which focus on protection become significantly more vulnerable. The purpose of the knowledge synthesis report on violence prevention is to examine the ways in which complex emergencies and disasters expose children and youth to violence, and to highlight promising practices that foster the resilience in these challenging environments. Given what we know about the impacts of violence and the prospects for prevention, identifying contexts where protection services are non-existent must be a primary objective of child protection advocates and practitioners. Disasters and complex emergencies are contexts that expose children and youth to increased risks of violence. Due to the lack of services available in these contexts, immediate action is required.

Social research conducted with youth in challenging contexts attempts to gain insight into the lives and perspectives of a wide variety of young people. While there are risks associated with such research, there are also potential rewards both for participants in research and society at large. The knowledge synthesis report on Ethics explores the ethical approaches and issues in conducting research with children and youth in challenging contexts. This shift towards including youth in research has the potential to give young people a greater opportunity to voice their views and perspectives in an effort to influence both policy and practice. There remains a need to translate existing rights into workable ethical practices. In addition, the move toward including the voices of youth has created a number of ethical dilemmas that challenge researchers, practitioners, and REBs.
Youth experience mental health differently, depending on their cultural, social and economic positioning. It should come as no surprise that these same factors also influence the way in which young people find information and support related to mental health. Studies have shown that young adults in Canada have higher rates of mental health concerns compared to other age groups, and yet they have lower rates of accessing mental health services. This knowledge synthesis report attempts to shed light on the information-seeking experiences of youth. There is a need to provide mental health information in various formats in order to take the many different needs of youth into account. It is important to engage youth in the creation of spaces and activities that support mental health knowledge. Ultimately, this will serve to increase youth mental health literacy and the capacity of youth to recognize disorders and risk factors and to seek the necessary and relevant support.

And finally, the last knowledge synthesis report reviews the effectiveness of supportive service environments that have been used to help children and youth with complex needs. These include children/youth with intellectual disabilities, children/youth with severe emotional and behavioural disorders, aboriginal children/youth, homeless youth and refugee or displaced children/youth. Mental health being at the centre of the complexity, these children and youth have multiple serious issues that compromise their physical, mental and emotional well-being and development. In order to best meet the needs of these young people, interdependence between different services and systems is an important principle. Effective models identified fall within three categories: child/youth focused, family-centred, and community-based interventions. It is because of the complex needs of these young people that the provision of services from different disciplines across various service sectors is crucial.

II. The Goal of the Knowledge Synthesis Reports

Ultimately, the seven knowledge synthesis reports are interconnected in ways that can help to form a comprehensive strategy for researchers, practitioners, service providers, and communities to address the needs of vulnerable children and youth in Canada and overseas. In synthesizing evidence from researchers, practitioners, service providers, and communities, these knowledge synthesis reports bring together disciplinarily-specific approaches and lessons learned in working with vulnerable and at-risk children and youth. The goal of the CYCC Network is to create an integrated and sustainable community of researchers, practitioners, communities, policy makers, and young people working together to share and improve programs that support the wellbeing and positive mental health of children and youth in challenging contexts.
Section 1: Introduction

I. Ethics in research with vulnerable youth

There is a growing recognition of the importance of listening to children’s voices, recognising the value of their interpretations of their own experiences, and of the value of incorporating these interpretations into social research (Grugel, 2004; Powell, Fitzgerald, Taylor & Graham, 2012). The recognition of the value of youth input into research is embodied in the growth of emancipatory research methods, and is reflected in the United Nations Convention on the Rights of the Child (UNCRC) which states that:

“The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child’s choice.” (UNCRC, 1989)

Understanding children as active participants in the production of knowledge as it relates to their own experience is rooted in the idea that children should be able to “express their views freely in matters affecting their lives, and to have their views given due weight in policy and practice” (Abebe, 2009, p. 453).

Ethics has been defined generally as a “a set of moral principles and rules of conduct” (Morrow & Richards, 1996, p. 91). In the context of research, ethics has been framed as the “application of a system of moral principles to prevent harming or wrongdoing others, to promote the good, to be respectful, and to be fair” (Sieber, 1992, p. 14). National guidelines (such as the Canadian Tri-council Policy Statement on Research with Human Subjects) are often assumed to
minimize the risks of participating in research and make certain that potential benefits are weighed against any potential risks. However, there is evidence to suggest that the activities of Research Ethics Boards (REBs) do not necessarily produce ethical research with children and youth (Bray & Gooskins, 2006; Wyn, 2011). In some cases expectations regarding ethical protocols in research with children can undermine attempts by researchers to produce research which could empower youth by including their voices (UNICEF, 2012; Swauger, 2009; Bray & Gooskens, 2006; Clacherty & Donald, 2007; Daley 2013; Dyer & Demeritt, 2008; Halse & Honey, 2007; Matutina, 2009; Meade & Slesnick, 2002).

Requiring social research to subscribe to standardized ethics procedures can prevent qualitative researchers from meeting the ethical standards that are promoted by youth, feminist, critical race, queer, and cultural studies (Swauger, 2009; Bray & Gooskins, 2006; Liebenberg, personal communication, December 17, 2013). A great deal of social research (especially that which employs emancipatory methods) does not fit neatly with REB-required ethical practices (Hastadewi, 2009; Dyer & Demereit, 2008). Institutional ethical requirements often consider the maintenance of anonymity and the necessity of securing parental consent for under 18s to be of primary importance (Halse & Honey, 2007). Requiring that standard protocols be followed without taking the context of research into account can minimize the voices of youth, prioritize the consent of adult gatekeepers and control the ways in which youth can be involved in the dissemination of research (Spyrou, 2011; Clacherty & Donald, 2007). In this way, the implementation of conventional research ethics frameworks has the potential to diminish the voices of the most marginalized (Liebenberg & Ungar, 2011), while maintaining and reproducing dominant voices within academic and policy discussions informed by research.
II. The Knowledge Synthesis Report on Ethics in Research

The purpose of this knowledge synthesis report is to examine the literature that is relevant to conducting ethical research with children and youth in challenging contexts. This report is a synthesis of the existing academic and non-academic research and will offer peer-reviewed recommendations for steps that can be taken to work toward the development of an ethical framework that is amenable to producing high quality, ethical research with children and youth in challenging contexts. Such a framework will assess ethical issues on a case by case basis, incorporating contextual elements into the discussion.

Including the voices, experiences and interpretations of youth in social research has received growing recognition from many researchers in recent years (Hill, 2005). Some research has successfully engaged youth and provided avenues for them to be heard and make a difference to our understanding of what the needs and priorities of youth are (Abebe, 2009). In general, arguments for recognizing the rights of children to play an active role within research are growing. The United Nations Convention on the Rights of the Child states that:

“The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child’s choice.” (UNCRC, 1990)

This shift towards including youth has the potential to give young people a greater opportunity to voice their views and perspectives in an effort to influence both policy and
practice. Several authors have argued that there remains a need to translate existing rights into workable ethical practices (Powell et al., 2012; Bell 2008).

In addition, the move toward including the voices of youth creates a number of ethical dilemmas which challenge researchers, practitioners and REBs. Including the voices and perspectives of youth in research is far from a straightforward goal. Sustaining youth involvement in research has the potential to create challenges which are highly dependant upon the context in which research takes place (Abebe, 2009; Boyden & Ennew, 1997).

III. Children and Youth in Challenging Contexts

Consultations were held with organizations and individuals involved with the CYCC Network to decide what populations of children and youth to include in the definition of children and youth that forms the basis of this report. The groups selected for inclusion are:

- Children and youth affected by war
- Child soldiers
- Children and youth in military families
- Refugee children and youth
- Children and youth affected by natural disasters
- Immigrant children and youth
- Children and youth subject to maltreatment
- Children and youth in alternative care
- Children and youth in institutions
- Youth in juvenile detention
- Aboriginal children and youth
- Homeless children and youth
- Youth gangs
- Child labourers
- Children and youth in the workplace
- Children and youth who have been trafficked
- Children and youth living with health-related challenges
- Children and youth living with chronic illness
- Children and youth living with mental illness
IV. **Organization of this Report**

Section 2 outlines the key terms and concepts used in the report, including the different forms of knowledge, best practices, and resilience. The methodology used in the synthesis process is then presented. This methodology includes a scoping review of the literature, a services scan, meetings with Network Partners and experts in the field, and data analysis. The section concludes with a discussion of the limitations of the report.

In Section 3 of the report, an overview of several aspects of debate on research ethics with children and youth is presented. The historical origins of research ethics, the formalization of research ethics within academic institutions and the particular effects of institutional ethics upon vulnerable youth involved in research will receive attention. Each of these topics is complex and has received lengthy treatment in the academic literature. The account given here is necessarily abridged, and readers interested in learning more are encouraged to review the sources cited.

Section 4 provides an overview of substantive ethical issues, the way in which ethical research boards address each of these issues, and how this affects children and youth involved in research. Specific themes addressed are: informed consent, payment and compensation, privacy and confidentiality, and harms and benefits. The organization of the discussion presented in this report is a reflection of the prominence of these issues within the academic discourse.

Section 5 presents some key findings from each of the themes discussed in section 4, with some final points for consideration.
Section 6 presents a comprehensive list of recommendations for developing a collaborative and multi-level approach to mental health care for at-risk children and youth. This section provides some practical tips for working with children and youth in challenging contexts, and identifies next steps for moving forward.
Section 2: Methodology

I. Background of Knowledge Synthesis Reports

In 2012, the CYCC Network published three knowledge synthesis reports that addressed key topics identified by the principle investigators on this project. These topics included: violence, youth engagement, and technology (these reports are available on the CYCC Network website). A second round of knowledge syntheses were carried out to address the following questions:

1. What strategies exist to prevent violence toward children and youth displaced by natural disasters and complex emergencies?

2. What are the ethical approaches and issues in conducting evaluations of interventions with children and youth in challenging contexts?

3. How do youth access mental health information and which pathways are likely to be most helpful?
4. What kinds of services and supports work best for children and youth with complex needs in challenging contexts?

Together, these seven report topics are all linked together by one guiding question: What works for Canada’s most vulnerable young people (see Figure 1).

Figure 1: Seven Knowledge Syntheses
II. Types of Knowledge

Different types of knowledge are challenging to synthesize, as they continue to be divided along disciplinary and geographic lines. Advocates of evidence-based practice, for instance, prioritize “the use of treatments for which there is sufficiently persuasive evidence to support their effectiveness in attaining the desired outcomes” (Roberts & Yeager, 2004, p. 5). Based on the assumption that empirical, research-based evidence is the most reliable for practice (Proctor & Rosen, 2006), this evidence is generally categorized hierarchically in accordance with the scientific strength of derived outcomes, with meta-analyses or replicated randomized controlled trials ranking among the most authoritative evidence. Case studies, descriptive reports and other unsystematic observations rank among the weakest (Roberts & Yeager, 2004). Qualitative evidence in particular is not always given weight among the advocates of evidence-based practice. In many cases, the results of experimental designs are prioritized where randomized control trials (RCTs) are held up as the “gold standard” (Oktay & Park-Lee, 2004, p. 706). It is also important to note how the evidence is shared. Making information accessible and understandable to different audiences is a key knowledge mobilization principle.

These types of knowledge may be usefully conceptualized as residing within a circle of evidence. Figure 2 depicts how the CYCC Network has conceptualized these different types of knowledge and how they interact. The purpose of the diagram is to demonstrate the relative amount of knowledge that exists within each category. In other words, a great deal of local knowledge is largely undocumented, and there is extremely little evidence that meets the criteria necessary for quantitative meta-analyses. By selecting only the inner most circle, it is
likely that best practice knowledge relevant to populations of at-risk young people may be overlooked.

**Figure 2: Circle of Evidence**

Community ownership increases towards the outer perimeter of the circle, as interventions are matched to the unique needs and customs of communities. However, our understanding of the fluidity among these forms of analysis and the resultant balance between scientific rigor and community ownership remains limited. In the diagram, the gaps between the types of knowledge represent the intersections of these forms of knowing that have not yet been fully explored.

For the purposes of this report, the CYCC Network defines best practices and promising practices as follows:
Best practices- or promising practices- are interventions that reflect what we have learned from evidence-informed practice. They identify, and employ the right combination of program elements to ensure targeted outcomes, and match these interventions to the local needs and assets of communities.

III. Knowledge Synthesis Process

In order to capture these different types of knowledge, these reports followed three methodological steps (Figure 3) which are described in detail in this section:

Step 1- Scoping Review

Step 2- Environmental Scan

Step 3- Case Studies

a. Scoping Review of the Literature: A focused search and review of the academic literature

A scoping review is a search tool used to ‘map’ or identify the extent and nature of the literature that currently exists in the field of interest (Arksey 2003; Mays et al 2001). The purpose of scoping this field of academic literature was to be as comprehensive as possible in finding evidence-based practice. Relevant articles were retrieved through key databases including Proquest Social Services Abstract, Proquest (general), EBSCO and PAIS International.
All sources that pre-date 2000 were excluded from this report, with the exception of foundational reports and studies, for the sake of making the scoping exercise reasonable. Some of the search terms used include: youth, mental health, stigma, information seeking social media, social networks, search, and health literacy. The full list of search terms used for this report can be found in Appendix C.

This scoping review involved a clear research question and an evaluation grid for the sources found. The evaluation grid was developed by the team at the CYCC Network, outlining six criteria that were looked for in all the resources gathered: relevance, peer-reviewed, number of citations (three categories indicating 1 to 3, 3 to 10, or more than ten citations), rigorous methodology, sample size, internal validity, and external validity. A detailed description of these criteria is presented in Appendix B.

The scoping review was limited to literature demonstrating evidence-informed practice, practice-based evidence, and/or local knowledge. This includes studies demonstrating meta-analytic or meta-ethnographic findings, randomized controlled trials, participatory action research, and examples of community development with youth populations. The goal was to identify themes that repeated in the literature regarding lessons learned, gaps in knowledge, and ways that service providers could work more effectively in the future.

b. Environmental Scan: Capturing Practice-Based Evidence

Leading from the scoping review, an environmental scan was done to capture the practice-based evidence that was outside the academic literature (Chrusciel 2011). For this report, an environmental scan was done to search and review the “grey literature” found on
websites as well as unpublished information from within organizations. The internet has greatly facilitated the production, distribution, and access of grey literature.

This search for grey literature was done using Google search. The first 50 sources that came from this search were viewed, as Google searches are set up to sort for relevance of results (Google Basics 2014). The limit was set at 50 to keep the search manageable. Google searches were one strategy to capture these resources. The programs and services of CYCC network members were included in this scan. All search terms used for this report can be found in Appendix 3. The results were assessed according to their relevance to the report topic. Relevance was defined as having addressed the key concepts embedded in each research question.

c. Case Studies: Capturing Local Knowledge

As a way of capturing local knowledge for this report, the experiences of researchers were incorporated throughout the report. The approaches that researchers take to navigating through the ethics process will not necessarily be found in published work. Through informal conversations, the findings in this report reflect the local, informal knowledge that exists in the research community, specifically among those who do research with young people. The experiences of service providers with research, gathered through the working group described below, also helped inform the focus of the report.
IV. Consultations

Throughout the development of the knowledge syntheses reports, there were key groups that helped guide and inform the process of these reports: the knowledge mobilization steering committee, a working group of service providers located in Halifax, NS, and the Network’s youth advisory committee.

a. Knowledge Mobilization Steering Committee (KMbSC)

The knowledge mobilization steering committee (KMbSC) was a group of 18 Network Members from different sectors, including students and youth, who provided expert direction in the development of the knowledge synthesis reports. Within the committee, 2-3 members functioned as the co-leads for each report. They were responsible for directing the research assistants in their searches and writing for these reports, and also helping to develop the recommendations from this research. This committee met regularly throughout the development of these reports.

b. Service Providers Working Group

In an effort to ensure that the reports meet the needs of different stakeholders, the CYCC Network organized a series of working lunches, in partnership with Phoenix Youth Programs. Phoenix is a non-profit community-based organization working with street-involved youth in Halifax, Nova Scotia. This was an open invitation sent to services providers from across the city who work with youth in some capacity. Meetings were held to discuss the progress of the reports, what themes were being identified, and what recommendations were being identified through the research. This was an opportunity for service providers to provide
feedback on the focus of the reports and the relevant findings. There were four such meetings held during the development of these reports.

c. **CYCC Network Youth Advisory Committee (YAC)**

The CYCC Network’s Youth Advisory Committee (YAC) was involved in the progress of the reports by providing feedback to the research assistants. A few members of the YAC were engaged in the report process as co-leads, giving direct input into the progress of the reports. A one-day in-person meeting was held in Ottawa after the completion of a first draft for the purpose of reviewing the findings and recommendations arising from the reports. Feedback was gathered by the research assistants and project managers, and integrated back into the second draft of the reports.

V. **Limitations**

The limitations encountered in the search of the literature consist of the following:

1- The experiences of researchers interacting with REBs, youth participating in research and researchers conducting research with vulnerable youth are not well-represented in the literature.

2- There is research included in this review that engages youth who do not fall within the CYCC definition of vulnerable youth. While the focus was on at risk children and youth, some programs that service them are not specific to one population, but include vulnerable young people in services that are accessible to all youth.
Section 3: Research Ethics in Context

I. Introduction

While thinking on ethics has multiple origins and derivations, at the heart of most ethical systems is the belief that it is possible to arbitrate between what is right and wrong. While ethical arguments can be applied to most facets of human activity discussion of ethics within research has given rise to particularly lively debate amongst academics (Hursthouse, 2013). The foci of this debate vary widely and include issues such as when and how an individual can consent to participate in research (Gallagher, Haywood, Jones & Milne, 2010), how participants should be compensated for participation in research (Alderson & Morrow, 2004), and how data collected through research should be used (Hastadewi, 2009).

Ethical issues are rooted in the particular challenges of a given research context. While it is possible and necessary to generalize from specific instances, the dilemmas that researchers encounter are rooted in specific histories, and social, economic and political contexts. Discussions of ethics with regard to research should thus not be entered into with the goal of producing a theoretical ethical perfection, but with the goal of producing analysis which can inform the conduct of increasingly ethical research. Ethics is, overall, “about how to deal with conflict, disagreement and ambivalence rather than attempting to eliminate it” (Gorin et al., 2008, p. 278, cited in UNICEF, 2012).

In this section of the report, an overview of several aspects of debate on research ethics with children and youth is presented. The historical origins of research ethics, the formalization of research ethics within academic institutions and the particular effect of institutional ethics
upon vulnerable youth involved in research will receive attention. Each of these topics is complex and has received lengthy treatment in the academic literature. The account given here is necessarily abridged, and readers interested in learning more are encouraged to review the sources cited.

II. Origins of Research Ethics

Ethical thinking has historically been thought of as “the sum of human aspiration or honour in interpersonal life, for respect in face-to-face encounters, and fairness in the collective treatment of people” (Stake & Rivzi, 2008, p. 526). From the inception of formal research ethics, they have been regarded as a subset of this larger aspiration to fair and respectful interpersonal encounters. Research ethics has been presented as both a philosophic framework and regulatory set of activities that is essentially concerned with protecting human participants from the risks that they may be exposed to by participating in research. It is often viewed as a way of both developing a standard definition of what constitutes ethical research, as well as a mechanism of ensuring that research practices meet the standard implied by this definition (Gallagher et al., 2010; Powell et al., 2012, UNICEF, 2012).

The notion of research ethics that informs the design and activities of research ethics boards is rooted in medical professional codes such as the Hippocratic Oath of the 5th century BC (Alderson, 2005). While the philosophic roots of institutional research ethics run deep, the institutional expression of aspirations to conduct research ethically has a relatively brief history. Following the Second World War the Nuremberg Code (1947) was developed as a response to atrocities committed in the name of medical experimentation by the Nazi regime (Lifton, 1986).
The horrors committed by the Nazis had a definitive role in shaping the Nuremberg Code. In general terms the code stressed the risks of participating in research and the importance of unpressured consent, and, perhaps most directly relevant to this report, assumed that children are too immature to consent to participation in research (Alderson, 2004).

Recognition of more recent cases of abuses committed in the name of research have accelerated the development of institutionalized research ethics and have increased their impact within universities. One notable example of such research, the Tuskegee syphilis experiments, studied the untreated progression of syphilis on African American sharecroppers between 1932 and 1972 (Flicker, Travers, Guta, McDonald & Meagher, 2007; Ungar & Liebenberg, 2011). Despite the fact that effective treatments for syphilis were available, researchers conducting this study made no attempt to offer these treatments to research participants, nor did they make it clear that participants could withdraw from the study whenever they chose. Reflection on the treatment of participants in this experiment, along with other experiments of a similar nature, helped to illustrate the need for a manner of ensuring that research with humans is conducted in a just an ethical manner (Ungar & Liebenberg, 2011).

Research Ethics Boards (REBs) are often framed as a mechanism through which members of the public, and in particular members of the public deemed to be vulnerable, can be protected from the risks of participating in research (Ungar & Liebenberg, 2011; Greig, Taylor, & MacKay, 2007; Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada [Tri-Council], 2005). In this sense, REBs serve as a practical expression of some rather
complex debates about what sorts of research can be justifiably conducted with humans as subjects.

III. The non-objectivity of institutional research ethics

This brief examination of this history of REBs illustrates that they do not come from nowhere; they are rooted in a specific historical, political and social context. “The implicit theoretical framework of most review bodies today is, therefore, located in Euro- American realities” (Liebenberg & Ungar, 2011, p.25). As Blackstock (2007) illustrates, there are significant differences between the epistemological assumptions which underlie Western and Indigenous world views. These include differences in understandings of time, the role of the individual, the value of ancestral knowledge, values and beliefs. An uncritical application of research ethics with Western origins can serve to obscure other ways of understanding the world.

This finding has several potential implications for research conducted with vulnerable children and youth. Unstated assumptions that underlie research ethics frameworks can result in biases which run counter to the stated goals of most research ethics frameworks. For example, assumptions about the nature of childhood (that children are vulnerable, in need of protection and can be protected by researchers) (Morrow & Boyden, 2013) can lead to overly protective regimes of research ethics, rooted in assumptions about the nature of childhood rather than the realities of the children involved in research. In some cases, this orientation can
serve to exclude marginalized groups, and to systematically and persistently omit specific phenomenon and experiences (Swauger, 2009).

It has been argued that excluding vulnerable youth from research, although done in the name of conducting ethical research, is unethical and not in the interests of those populations that REBs are purported to protect (Swauger, 2009). Several sources in the literature argue that the challenges presented by institutional ethics are rooted in biases toward positivist research, and against the interpretative and qualitative methods frequently employed by social scientists (Wyn, 2011; Christians, 2007).

Wyn (2011) investigated the experiences of qualitative researchers interacting with the ethics boards in the course of their research. Frustration with ethics boards who attempted to apply ethical standards befitting of positivist research to non-positivist research was a frequent experience amongst those who participated in the study. This study suggests that many researchers who work in disciplines such as sociology or anthropology have encountered difficulties justifying their work to ethics boards made up of predominantly positivist researchers. As one participant noted:

“The single ‘big lesson’ that was finally learned was that you could not resist the rise of the IRB, you could only make sure you got representative people on it—that is, anthropologists everywhere learned it was best to get an anthropology faculty member to serve on the IRB, or an academic from a kindred discipline such as a Sociology, Women’s Studies, Geography, etc. I think these ‘unsung heroes’ of anthropology should be recognized for making an important contribution to the evolution of the
‘consciousness’ of the IRBs. ... Today, you hear far fewer horror stories. There are
conflicts and disagreements, but these are almost always worked out with discussion.”
(Wyn, 2011, p. 104).

Similarly, Christians (2007) argues that the development of institutional research ethics constitutes a push towards the development of a universal conception of what constitutes ethical behaviour. While the activities of REBs are relatively new, as Christians notes, the idea of a universal ethics which lies at the root of some conceptions of research ethics is similar to that conception of ethics which has given rise to colonial projects throughout the world (2007, p. 438). The argument that REBs necessarily work to promote a singular vision of what constitutes ethical behaviour is attenuated by the examples provided by Liebenberg & Ungar (2011), and by Wyn (2011), in which the positivist biases of REBs were productively challenged by researchers. The larger point deserves consideration, particularly as relates to research that places western researchers in non-western contexts.

IV. Institutionalization of Research Ethics

The assertion of a rigid framework of ethics can also be the source of more immediate problems in social research. Brunger and Burgess (2005) and Halse and Honey (2007) note that ethical review procedures are normally envisioned as linear processes which follow a pattern of submission, review, revision, research and reporting. Discussions of ethics which accept this conception of ethical review are often organized around improving this linear process. However, as Brunger and Burgess (2005) note, there are significant shortcomings with thinking of ethical review procedures in a linear way which are unlikely to be addresses without more
profound changes to the model. Understanding ethics review as a formulaic process can have
the impact of obscuring the fact that research often takes place within shifting social
environments in which the most ethical course of action may change according to
developments in the research site. According to Brunger and Burgess (2005), this realization
outlines the need for an understanding of research ethics governance that acknowledges that
research is subject to complex social influences, and that these influences “inevitably shape
even the standards, practices and structures of research ethics” (p. 70).

The role that technology plays in the lives of many adults and youth, and the impact that
it has had on common conceptions of privacy and confidentiality, serve to illustrate the
difficulties that institutional frameworks have in reacting to a rapidly changing social context.
According to Burbeles (2009), the place that technology has in the lives of many people
necessitates a different framework for thinking about ethics, particularly with regard to privacy.
Burbeles argues that the assumptions upon which traditional analyses of threats and
protections with regard to privacy are based are no longer valid. Assuring the privacy of
research participant, long an element of most institutionalized ethics frameworks, may not be
feasible or preferable. According to Burbeles, “many of the elements of typical human subjects
review (privacy, anonymity, the right to “own” information about one’s self) need to be
rethought; as do the procedures by which the well-being of research subjects is, we hope, to be
served” (Burbeles, 2009, p. 538). Hull, Lipford and Latulipe’s (2011) analysis confirms that the
widespread use of social media has stimulated a fundamental shift in the way that young
people conceive of privacy within their own social relations.
One theme outlined in the literature is that institutional ethics procedures can and are used to limit the liability of researchers and institutions, rather than to protect vulnerable research participants or promote a thoughtful reflective research progress (Homan in Gallagher, Finley & Gough, 2009; Tilley & Gormley, 2007; Guillemin, Gillam, Rosenthal & Bolitho, 2008; Powell et al., 2012).

The crux of the argument here is that, as ethical oversight processes have developed and become embedded within research institutions, the emphasis of institutional ethical oversight has become placed on protecting institutions from liability rather than protecting the interests of those involved in research. The thoughts of a participant in Wyn’s (2011) study of the experiences of qualitative researchers with ethics procedures serve to outline this point:

“At my home institution ... it’s more or less commonly accepted that the process has nothing to do with ethics and everything to do with legal liability. ...Conversations about ethics are hugely important when doing ethnographic work, and my dissertation research proposal had a significant section devoted to them. But the REB process was the least helpful thing I did concerning issues of ethics.”

(Wyn, 2011, p. 105)

This argument may appear cynical: certainly it is possible that an ethical framework can be used to both promote ethical research practices and to insulate an institution from liability. In addition, this argument does not suggest that researchers themselves do not engage in critical thinking on ethical issues related to the research they conduct. However, as the insights provided by Wyn (2011) and Gallagher et al. (2010) suggest, institutional research ethics
processes may not always provide a helpful framework within which to engage in discussion about ethics in research.

Gallagher et al. (2010) notes that a focus on formalities and legalities has the potential to make researchers more concerned with the products of consent, rather than the ensuring that participants have understood the research project, their role within it and possible implications to the fullest extent possible. Framing consent as an event or an outcome has been thoroughly criticized and an alternative perspective, one that conceives of consent as an ongoing process, has been put forward (Oakes, 2002; Leakey 2004). In this alternative conception, the immediate steps to indicate consent (signing a consent form or giving verbal consent) are a necessary but not sufficient condition for ensuring that consent to participate in research is genuine.

The requirements of institutional ethics processes are often onerous and are a significant step in the research process. This position is supported by the comments of one researcher who took part in a study examining the implications of formal research ethics:

“I think ethics committees have become so bound up in the procedure part of it and the legal ramifications of not doing their jobs that they’ve actually forgotten what research is about... I don’t think they’re sort of really concerned about the ethics, I think they’re concerned about the legal constraints or the legal implications of what research might mean. You know, the possibility of being sued or whatever, rather than their responsibilities to researchers and participants and the ethics of both.”

(MacKinnon et al., 2008, p. 16)
Ungar and Liebenberg (2011) provide a brief example of a circumstance in which they were able to convince a university REB that, in the context in which they were researching, the requirements of the REB would expose participants to additional risk and that as a result, alternative requirements should be applied. Working with youth in rural Colombia who could have possibly come into contact with members of rebel groups during their daily lives, the authors noted that requiring youth to carry consent forms to and from their parents could put them into danger. There was some possibility that a child carrying official looking papers would be perceived as in collaboration with government forces and thus likely to be harmed in some way by rebels. In this case the study authors were able to convince the relevant REB that forgoing the need for written consent and instead relying on verbal consent was sufficient to both ensure consent to participate in research and to not expose research participants to additional risks (Liebenberg & Ungar, 2011). This anecdote shows that, although REBs may be structured in a way that creates particular ethical difficulties for research with children and youth, the possibility for challenging the biases, which exist within many REBs, is present.

V. Discourse of Ethics

While the literature review produced no evidence that demonstrates the prevalence of the following opinion, anecdotal evidence suggests that within many institutions research ethics have become “unassailable as a concept of principled good” (Wyn, 2011, p. 95). In this account, ethics becomes a “magically efficacious word” (Wyn, 2011, p. 95) which has taken on meaning of its own. “Ethics” ceases to be a reasoned process that evaluates and attempts to
minimize the negative impacts of research on participants. Instead, it becomes a label which must be obtained in order to deem a given piece of research acceptable within an institution.

Halse and Honey (2007) describe this idea in terms of the development of an independent ‘institutional discourse’. They argue that the institutionalization of ethics has moved it away from a process of thinking critically about the impacts of the actions of researchers upon the subjects they engage with (and the general population) and toward a system which discourages critical debate, replacing it with a system which is self-reinforcing and which ensures its own momentum. Conceiving of research ethics as both an ideology and instrument of “governmentality” (Foucault, 1986), the authors hold that research ethics has “generated its own discursive systems, meanings, and representations of the world, evolving into a particular sort of institutional discourse” (Halse & Honey, 2007, p.336). The force of this discourse of ethics has moved “beyond the realm of scholarly research and the academy, weaving itself in general and specific ways through the nooks and crannies of institutions and into national policies, legislation, and law and into their supporting infrastructures. It is a discourse that has potentially profound implications for the moral imperative to respect others” (Halse & Honey, 2007, p. 341). With the solidification of this discourse, ethical review can become a system with its own moral reference points which can be detached from the actual experiences of researchers and participants in research.

VI. **Institutional Ethics and Youth in Challenging Contexts**

Many of the insights into the impact of research ethics on vulnerable youth comment upon issues that are not exclusive to vulnerable youth, but are relevant to social research more
generally. While these general critiques are relevant, the literature search also returned a number of sources which comment directly upon ethics in research with children (Liebenberg & Ungar 2011; Gallagher et al., 2010; Leakey, 2004; Bray, 2005; Morrow, 2009). Taken together these sources suggest that:

1) Research with children and youth in challenging contexts frequently involves particular ethical difficulties;

2) Institutional research ethics have potentially negative repercussions for children and youth involved in research;

In any research endeavour the way in which relevant concepts are defined is likely to have ethical implications. In research involving children and youth, the understanding of children and youth that underlies this research is important (Morrow & Boyden, 2013).

Alderson (1996) argues that, if ethical thinking with regard to research with children is to be honest, it must be acknowledged from the start that many adult researchers start from the assumption that adults are "superior, beneficent and rightly in charge of knowledge and resources"(p. 115).

Theoretical frameworks for understanding children are often left implicit in the design of research (Morrow & Boyden, 2013, p. 2897). Despite the fact that the way in which childhood is conceived often goes unexamined, separate bodies of academic work have developed multiple conceptualizations of children. As Morrow and Boyden's (2013) overview shows, these conceptions have been quite diverse. While conventional sociology and anthropology have tended to view children in terms of how they become inducted into their cultural groups (Montgomery, 2009), more recent studies have emphasized the agency of
children and have given recognition to children's accounts of their own experiences (Morrow & Boyden, 2013, p. 2897).

One notable aspect of this shift towards accounting for the agency of children is the recognition that experiences of childhood are unique, and that there is considerable diversity in the types of experiences that children have, both within similar and different contexts. In a study which involves analysing the experiences of students with disabilities in an integrated classroom, Alderson (1996) argues that considering the role of children with disabilities serves to outline the process of social construction, and how this is involved in constructing children as “able” or “disabled.” Alderson notes that:

"The relationship between children’s acknowledged difficulty and socialized assumptions about their appropriate education was at times unclear... In integrated schools, children at the far end of the autistic spectrum, without speech and with communication disorders, or children severely lacking cognitive skills—far from being the most ‘different’ one could imagine—came to be seen as a paradigm for the way that we perceive and approach all children. They are at the boundary which tells us how all children may be treated as ethical beings and (in this sense) as equals in the research process, as children generally tend to be seen as having limited communication. To some extent everyone shares these limitations. Children help to create the ethical framework of the research, and the risks of misinterpreting them are no greater than with adult subjects."

(Alderson, 1996, p. 155)
Alderson’s work with children with disabilities outlines a possibility which complicates thinking on research ethics. Creating principles intended to guide research with children can have the unintended consequence of shoring up a particular definition of childhood. This definition may be rooted in an understanding of childhood which has little to do with the actual experiences of children, and more to do with the assumptions that are necessarily built into any broad definition. While this is a rather abstract conclusion, it is one which may have profound implications for ethics in research with children and youth. This realization forms the basis for a vision of creating ethical research with children that Alderson outlines. In Alderson's vision, "The first step in creating ethical research standards that respect children's worth and dignity is to consider questions of power, stereotyping and children's status" (1996, p. 115).

If this position is taken into account it follows that conducting ethical research with children depends upon developing an understanding of the network of power within which a child forms their own sense of dignity and worth. Within this conception, if research with youth is to be considered ethical, then the starting assumptions of what constitutes childhood must be unravelled and reassembled in a way which takes into account the social context within which a child grows. Ethical research practice depends upon breaking down stereotypes of what children are, and what their experiences are, and replacing them with children’s own conceptions of who they are and how they interact with their social and economic contexts.

**VII. Participatory Action Research and the perspectives of youth in research**

Developments in the study of childhood have lead to an increase in the recognition of the importance or children’s participation in research, with some researchers arguing that the
application of participatory methods has the potential to both increase the ethicality of research and the scientific validity of research with children and youth (Powel et al, 2012; Sime, 2008).

Youth participation, often framed as youth engagement, has been the focus of a significant amount of both academic and program work. Participatory Action Research (PAR) has been framed as a solution to several dilemmas faced by social science researchers working with vulnerable populations. Rather than a clear method for how to do research, PAR is better regarded as a guiding philosophy; PAR emphasizes the political aspect of knowledge production and aims to create knowledge which is useful for adult education and socio-political action. As Olga (2013) notes, many proponents of PAR share in the analysis that social oppression is rooted not only in material conditions, but also in the production of knowledge. Creating an alternative for creating knowledge thus takes a stand against the "ways in which the elite monopolize the production and use of knowledge for its own benefits" (Olga, 2013, p210).

The literature shows that there are many way to engage youth in either programming or research. As a previous report on youth engagement published by the CYCC details, both the form and methods that can be used to engage youth vary widely (Zinck, Ungar, Whitman, Exenberger, LeVert-Chaisson, Liebenberg, Ung & Forshner, 2013). Youth engagement may be most productively regarded as “a process; an attitude and approach that by nature facilitates meaningful involvement and ownership on the part of the youth” (Zinck et al., 2013, p. 4).

Different modes of engaging youth can produce different results in terms of participation. While some modes of engaging youth, like incorporating youth in decision making, may result in a high level of participation, other modes of engaging youth, such as
consulting them, may be said to offer a lower level of participation. The point to be taken from this is that participation is not black and white; it must be regarded as a process that can be used to address ethical issues in research with youth and does not constitute a simple solution. Similarly, different levels of engagement with youth are likely to produce different ethical challenges.
Section 4: Analysis of Ethical Issues

1. Introduction

The following section provides an overview of substantive ethical issues, and of the way in which each of these issues addressed by institutional ethics boards affects children and youth involved in research.

Discussion is based around four themes:

1. Informed Consent
2. Payment and Compensation
3. Privacy and Confidentiality
4. Harms and Benefits

The choice of these themes deserves comment: These four themes were chosen because the literature which discusses issues related to research ethics is organized around them. Two comprehensive literature reviews which address issues related to ethical research with children have been organized around these issues (Powell et al., 2012; UNICEF, 2012). Further to this, a great deal of the original research on ethics has coalesced around the above-mentioned issues.

As discussed earlier, a discourse of ethics is firmly rooted within research institutions. While acknowledging the existence of a discourse of ethics as described by Halse and Honey (2007), and providing criticism of the role that this discourse plays in determining the ethicality of research, basing a discussion of research ethics in the academic literature cannot avoid using
some of the terms dictated by this discourse. The organization of the discussion presented in this report is a reflection of the prominence of these issues within the academic discourse. Arguably, given that the driver behind organising the discussion around these four ideas is an institutional discourse, it does not mean that these topics are not important to youth involved in research. The extent to which these issues are relevant to youth is dependent upon the extent to which the prevailing discourse reflects the issues that are practically important to youth involved in research. It is perhaps better to regard the four ethical themes as an indication of the issues that are important to researchers, rather than issues that are necessarily important to youth.

II. **Informed Consent**

The literature on informed consent addresses issues such as: how consent should be obtained, debates on children’s competence to give consent, who should provide consent for a child to participate in research and the nature of freely-given consent (UNICEF, 2012, p. 34; Powell et al., 2012).

Gallagher et al. (2010) outline four broad principles which can be used to guide inquiry into issues related to informed consent:

1. Consent involves an explicit act, for example, verbal or written agreement.
2. Consent can only be given if the participants are informed about and have an understanding of the research.
3. Consent must be given voluntarily without coercion.
4. Consent must be renegotiable so that children may withdraw at any stage of the research process.

(Gallagher et al, 2010)

As Gallagher et al. (2010) note, the process of providing the information necessary to ensure that consent is informed can be thought of in terms of three interactions: 1. Information is provided to potential participants by researchers; 2. Information is interpreted an understood by the potential participant; 3. The potential participant makes a decision regarding their participation in research.

While informed consent appears to be quite a simple concept, further review of the literature shows that it is quite complicated, and that negotiating it presents a set of complicated ethical challenges. Informed consent has been conceived as “the invisible act of evaluating information and making a decision, and the visible act of signifying the decision” (UNICEF, 2012, p. 27; Alderson & Morrow, 2011; Fisher, Hoagwood, Boyce, Duster, Frank, Grisso, Levine, Macklin, Spencer, Takanishi, Trimble & Zayas, 2002). Although the mechanics of ensuring informed consent are important (for example whether consent is written, how information is communicated), as Sieber (1994) notes, consent is perhaps better conceived as a process of both communication and decision rather than as the signing of a consent form or legal document (Sieber, 1994, p. 5; UNICEF, 2012).

Perhaps the most prominent lesson emerging from the literature is that consent is not negotiated within a cultural or social vacuum; the social and economic context as well as the cultural biases of both researcher and participant play a role in how the process of ensuring informed consent is negotiated and how the elements of this process are interpreted (Marzano,
Understanding informed consent as a “universal concept” which can be uncritically applied across contexts masks the fact that any interpretation of consent or of the information provided to ensure that consent is informed happens within a social environment that has its own dynamics, inequalities and oppressions (Marzano, 2007).

In a literature review which draws upon findings from research conducted in a variety of cultural settings, Powell et al. (2012) echo the argument that ethical decisions are made within a cultural context and that this context plays a role in determining how issues of informed consent should be approached. An example that illustrates the cultural embeddedness of concepts which are a part of institutional ethics frameworks is provided by Suaali & Mavoa (2001).

In Maori communities certain pieces of knowledge are regarded as being collectively owned. Collective ownership is a direct challenge to liberal, individualized conceptions of consent. Most institutional research ethics frameworks consider in the first instance, consent to be one of a collection of rights that belong to the individual. From this perspective, the Maori claim to collective ownership is invisible. Without making any claim on the ethicality of collective versus individual rights, it is possible to say that an ethics framework which has the individual at its core has its own cultural biases, and contains within it the possibility of erasing (things) that are culturally meaningful to others (Powell et al., 2012; Suaali & Mavoa 2001).

Certainly, culture is not the only element that shapes the context within which ethical decisions play out. As Pittaway, Bartolomei & Hugman (2010) note, the socio economic
circumstances of potential participants may play a role in negotiating consent. Research with people living in refugee camps provides a particularly striking example of this:

“When I go into a horrendous camp situation as a white researcher, the people are so desperate for any form of assistance they would agree to anything just on the off-chance that I might be able to assist. It makes asking for permission to interview them or take photographs a farce... What does ‘informed consent’ mean in an isolated refugee camp with security problems and no proper interpreters?”

(Pittaway et al., 2010)

a. Informed consent and research with children and youth

Discussion of informed consent as related to research with children and youth has generated a significant amount of debate and has resulted in the development of a large body of literature (Powell et al., 2012, p. 13).

The analysis developed by Gallagher et al. (2010) provides a helpful lens through which to consider issues related to informed consent in research with children and youth. The authors start from the premise that a principle like informed consent - no matter how clear it appears, is “more complicated and ambivalent in practice than we might think” (p. 472). This assertion supports one of the major findings of this report - that standardized institutional approaches to research ethics are not sufficient to ensuring ethical research with children and youth. If this finding is taken seriously it is not sensible to continue to offer concrete solutions that are meant to apply across research contexts. Instead, it may be more productive to consider ethical issues
related to research as they play out within a given social and economic context. At a time when ethical requirements for research with children are becoming increasingly formalized and bureaucratized, it may be productive to offer questions that can be used to develop complex conceptions of what constitutes informed consent within a specific context (Gallagher et al., 2010, p. 472; Abebe, 2009; Powell et al., 2012; UNICEF, 2012).

The literature suggests that it is important to consider elements of the context in which consent takes place. This by implication means that neither the consent of a gatekeeper nor written consent should be understood as either necessary or sufficient to ensuring informed consent. In most environments people, and perhaps especially youth, are subject to peer group dynamics, institutional hierarchies and pressure from personal relationships with guardians, parents and teachers (Powell et al., 2012).

**b. The role of gatekeepers in informed consent**

Parents and guardians are frequently used as proxies who are capable of giving informed consent on behalf of youth involved in research. While the use of gatekeepers may increase the ethicality of research in some situations, as Coyne (2010) notes, using gatekeepers in this way perpetuates “the view of children as potentially vulnerable [which] may be a stereotype that masks individual children’s abilities, competencies and understandings and which ignores work which clearly demonstrates that children have a contribution to make and want their voices to be heard” (2010, p. 454).

In addition to being based on unreliable premises, mandating the use of gatekeepers without sensitivity to context can have a host of negative practical impact, notably the exclusion of youth who do not have access to such gatekeepers (Coyne, 2010, p. 454). In many
contexts gaining active parental consent is not possible either due to low rates of literacy or difficulties identifying parents (Abebe, 2009; Clacherty & Donald, 2007; Hutz & Koller, 1999). Further, in some contexts engaging parents in consent discussions may not be appropriate as research deals with topics that require the privacy and protection of the participant for example; sexuality (Valentine, Butler & Skelton, 2001) or drug use (Langhinrichsen-Rohling et al., 2006). Cases in which research is conducted with street involved youth or youth who have run away from home may also challenge involved parents in consent processes (Powell et al., 2012; Meade & Slesnick, 2002; Vakaoti, 2009; Runnels, Hay, Sevigny & O'Hara, 2009).

A hierarchy of gatekeeping, although envisioned as a way of protecting children, often increases barriers to youth participation in research (Morrow & Richards, 1996; Powell & Smith, 2009; Powell et al., 2012). When children are viewed as especially vulnerable, or when a research topic is viewed as extra sensitive, youth are often regarded as needing extra protection. Overcompensating by providing extra protection to youth can have the effects, not of ensuring that their participation in research is more ethical, but of excluding them from research on the basis of potential risk (Powell et al., 2012; Graham & Fitzgerald, 2010) or denying them the right to express views and opinions on matters of concern (Powell & Smith, 2009).

Drawing on experience conducting research with self-identified lesbian or gay youth, Valentine, Butler and Skelton (2001) provide an illustrative case in which requiring parental consent can have particularly negative consequences for vulnerable youth involved in research. Parental consent is often required by research ethics boards for participation of under 18’s in research. If the subject of a study of a sensitive topic is revealed to parents then the sexual
orientation of the relevant youth could be shared with parents. Requiring parental consent from these youth would either force them to come out to their parents or, more likely, exclude them from research.

Certainly, gatekeepers can play a role in ensuring that research with youth in conducted in an ethical manner. As UNICEF notes, research with children invariably entails working across a large power imbalance which separates researchers and children and which frequently involves the parents or guardians responsible for those children as gatekeepers (UNICEF, 2012, p. 48). Although if this is the case there is danger in taking an approach which diminishes the agency of youth to consent to their own participation in research. Demanding that a gatekeeper consent on behalf of a young person could have the implication of reducing their ownership or voice within the research, as well as (more pragmatically) working to exclude youth who do not have ready access to a gatekeeper from research.

c. Written consent and research with children and youth

Requiring written consent for participation in research is a position frequently taken by REBs (Leakey, Lunde, Koga & Glanz, 2004). While this position is taken in the name of ensuring that research conducted with children is ethical, the literature review revealed several issues that suggest that requiring written consent does not necessarily do this. Ungar and Liebenberg (2011) outline several issues which arise when written consent is required of youth to participate in research. Citing work conducted by the International Resilience Project the authors note two instances in which obtaining written consent from participants could be argued to be inappropriate. Writing about field sites in South Africa and Tanzania, project personnel argued that power inequities between researchers and participants could be
exacerbated by requiring youth with some level of literacy to ask their mostly illiterate parents to sign a document so that they could participate in research. In another field site in Colombia project personnel argued against requiring written consent as it was thought that bringing legal-looking documents home from school could put the youth in danger of being harmed by paramilitaries wary of collusion with government authorities.

Obtaining written consent forms from research participants was required by the REB of the university at which the International Resilience Project is located (Liebenberg & Ungar, 2011). Despite this, the International Resilience Project succeeded in convincing the REB that consent procedures could be altered to take into account the contexts in which the research was carried out. In the end, the REB agreed to waive the need for written parental consent in instances where the youth was over 14 and where there was valid concern over the potential impacts of requiring written consent. This argument was made using the United Nations Convention on the Rights of the Child as well as UNICEF’s (2002) research guidelines which assert that parental consent “is not an adequate standard in light of the rights of the child” (Liebenberg & Ungar, 2011, p. 5).

Although in some circumstances obtaining written consent for participation in research may constitute an ethical research practice, assuming that obtaining written consent is sufficient to ensuring that consent is genuine is problematic. Further, assuming that written consent is itself an ethical practice can pose problems. Research always takes place within some context and that context often affects the way that obtaining consent plays out. Generally, ensuring genuine informed consent is significantly more complicated than the dominant ethical paradigm suggests (Gallagher et al., 2010, p. 474).
Such an approach can serve as a barrier to participation in research, especially for marginalized populations like youth who live independently of their parents or who experience severe conflict with their guardians (Ungar & Liebenberg, 2011, p.3).

III. Payment and Compensation

The review of the literature produced a number of sources that speak to the issue of whether and how to compensate youth for participation in research. While there is no consensus on either of these questions amongst researchers, there is a growing argument that the time and experience of research participants should be acknowledged and compensated for, just as the time and experience of adult researchers is compensated. Further to this, the argument that the context in which research takes place should play a role in considering how to approach payment or compensation to youth research participants is growing in prominence (Powell et al., 2012; Alderson & Morrow, 2004; Young Lives Case Study, 2012).

While there is a case to be made for compensating youth for the time that they spend engaging in and contributing to research, the review of the literature suggests that the form that compensation takes, as well as the way in which a given form of compensation interacts with a context should be taken into consideration in decisions on compensation. Some authors argue that in some circumstances giving payment for participation in research constitutes bribery or coercion. They argue that, particularly for potential research participants who experience economic need, providing a cash incentive could compromise their consent or encourage them to take risks that they wouldn’t otherwise take (Dickert & Grady 1999, Rice & Broom, 2004, p. 168; Alderson & Morrow, 2011, p. 68).
While several relevant concerns are outlined within the literature, much of the debate is based on the assumption that some form of compensation is just, and that the important part is deciding upon a form and amount of compensation that is just within a given circumstance. Porter et al.’s (2010) statement regarding the ethicality of compensating youth for participation in research perhaps best sums up the dominant position. Porter et al. argue that it “is insulting and denigrating to children and their contributions to suggest that they, unlike adults, can be adequately compensated for their work by receiving training, experience, acknowledgment in publications and token gifts” (Porter et al., 2010, p. 224).

**a. How to compensate for participation in research?**

Payment for participation can be framed in several different ways, with each framing producing different expectations of both quantity and quality of payment. The Young Lives project, an international study of childhood poverty which is located in the UK and involves 12,000 children in 4 countries over 15 years attempts to take local social and economic considerations into account when deciding how much to pay youth for participating in research and what form remuneration should take. Working with children in Peru, India and Vietnam, researchers compensated children with cash or small gifts, depending on the age of the child. Norms of reciprocity and norms of the community in which participants live we seen to influence people’s decision of whether or not to participate, and as such affected the choices of researchers (ERIC Case Study: Harms and Benefits; Morrow, 2009).

Following Rice and Broom (2004), Powell et al. (2012) present the following models that can be used to guide researchers’ choice of how to think about frame incentives:
1. Market model – participants are provided with a direct incentive to take part.

2. Wage payment model – participation requires time and effort from the child. Compensation is framed as a way of easing the burden associated with research participation.

3. Reimbursement model – payment is framed as a reimbursement for financial outlay by the child or their family. Payment is given based upon expenses incurred.

(Powell et al., 2012; Rice & Broome, 2004, p. 165).

b. Dilemmas related to payment for participation in research

An ERIC case study (ERIC Case Study: Payment and Compensation) outlines a number of ethical dilemmas surrounding payment for participation in research that were encountered by researchers. In locations of acute poverty such as the Young Lives study locations, researchers were often perceived as similar to aid workers, and were thus expected to provide resources in a similar manner. As a research project Young Lives did not provide aid and, as the ERIC case study notes, this created an ethical dilemma related to informed consent: Participants could consent to take part in research based on thinking that they would receive substantial material compensation. In this circumstance it can be argued that informed consent was not obtained by researchers.

Another consideration which is prominent in the research is that participants might use the compensation that they obtained from participating in research to engage in harmful or illegal activity. Runnels et al.’s (2009) research with homeless populations outlines several ethical challenges related to compensation. As the authors note, homeless populations are
generally quite poor and so receiving compensation may be the prime motivation for participating in a research study. Given this, the ability of participants to give genuine consent can be called into question. This is a similar issue to that encountered by the Young Lives project in Ethiopia, described above. For Runnels et al. (2009) the incentive created by providing compensation for participation in research is cause for concern. Providing such an incentive in low-resource areas can encourage multiple participation. Depending on the research design, this could degrade the data collected.

A related issue is whether money given for participation in research will be used to engage in illegal or harmful activities. While some researchers are concerned about the use of money gained through research participation to buy drugs or alcohol, Runnels et al. (2009) assert that the ethical responsibility of interviewers does not extend to policing how participants spend their money. Facing a similar dilemma, Richter et al. (2007) opted for a different resolution. Conducting research with street children in Brazil, the researchers considered it to be unethical to provide money or gifts which might be used to buy drugs. Instead of this, they offered youth participants a meal following participation in research (UNICEF, 2012; Richter et al., 2007).

IV. Privacy and confidentiality

Ethical issues related to privacy and confidentiality have received significant attention in the literature. In some contexts, the literature suggests that maintaining the privacy of research participants is of upmost importance (Thomson, 2008; Powell et al., 2012). However, as an increasing number of examples illustrate, a dogmatic adherence to the principle of
confidentiality without regard to the context in which research takes places does not necessarily lead to more ethical research, and in some cases can make research less ethical. As will be examined below, transformative approaches to research involving youth which strive to engage youth in research have produced particularly strong criticisms of mandating privacy.

Following Hill (2005), Powell et al. (2012) identify three ways of thinking about confidentiality that are relevant to research with youth in challenging contexts:

1. Public confidentiality – not identifying research participants in publications that will be circulated to the general public;

2. Social network confidentiality – not passing on information to family members, friends or others known to the child;

3. Third party breach of privacy – where a group or household member reveals something personal about another.

(Hill, 2005, p. 75, cited in Powell et al., 2012).

In addition to being a pragmatic consider for social research, issues related to confidentiality play a prominent role within most national research ethics guidelines that impact upon university based research. An example of this is provided by the Canadian Tri-Council Policy Statement which reads:

“There is widespread agreement about the interests of participants in protection of privacy, and the corresponding duties of researchers to treat personal information in a confidential manner. Indeed, the respect for privacy in research is an internationally recognised norm and ethical standard.... This Policy is based on a proportionate approach to the assessment of the ethical acceptability of research. Researchers and
research ethics boards (REBs) are expected to identify and minimize privacy risks, keeping in mind that a matter that is not sensitive or embarrassing for the researcher may be so for the participant.”

(Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada, 1998, p. 55)

The ESRC Framework For Research Ethics, a UK document equivalent to the Canadian Tri-Council Policy Statement, states that researchers based in UK institutions should maintain “The confidentiality of information supplied by research participants and the anonymity of respondents must be respected.” (ESRC, 2010 Guidelines, p. 3) Certainly, the phrasing of this policy provides room for interpretation. As Liebenberg notes (personal communication, June 26, 2014), there is a significant difference between dogmatically adhering to the idea that privacy is essential and respecting the privacy of research participants, which could include respecting their right not to be anonymous.

a. The importance of privacy depends on context

Certainly, protecting the identities of research participants as well as the information that they provide is imperative in some contexts. In some contexts failing to maintain a high standard of confidentiality has the potential to increase the risks participants are exposed to. However, in other contexts requiring research participants to be anonymous has the potential of diminishing a sense of ownership that they might feel in the research (Bray & Gooskins, 2005).

One example about protecting the identities of research participants is provided by Pittaway et al. (2010). These authors argue that researchers working in refugee and IDP settings
have “often forgotten the capacity that their work might have to cause unintended harm to participants through inappropriate disclosure of identities or other personal information that to the researchers may have appeared innocuous” (2010, p.6). Despite being published in other countries and languages, stories and photographs can be used to identify research participants (Beauchamp and Childress, 2001; Mackenzie, McDowell & Pittaway, 2007). Pittaway et al. argue that such breaches of confidentiality calls both the values which guide this research and the ‘ethics of consent’ into question (Pittaway et al., 2009).

The review of the literature also produced several examples of research projects in which mandating the privacy of research participants could be argued to make the research less ethical. As Honkatukia, Nyqvist and Pösö (2003) point out, implementing ethical principles related to privacy and confidentiality is much more complicated than an abstract account would suggest. Drawing on ethical dilemmas encountered in a research project which investigated the experiences of violence of youth living in a Finnish reformatory, Honkatukia et al. (2003) argue that it is important to give youth an opportunity to speak out, and for them to speak freely about their experiences. While allowing youth to share their experiences is a good thing, the process through which sharing occurs can also produce ethical issues which much be managed. As Honkatukia et al. (2003) note, being exposed to the stories of others has the possibility of re-traumatising youth. This observation speaks to the need to ensure that the manner in which youth share their stories is monitored to ensure that ill effects do not result (Honkatukia et al., 2003, p. 323).
b. On Requiring Confidentiality

Requirements of confidentiality and anonymity are underwritten by positivist assumptions which are rooted in the adaptation of biomedical model of research ethics to social research (Tilley & Gormley, 2007 p.379). While an ethical framework based on the model provided by bioethics my aspire to the principles of respect, beneficence, justice and dignity, in research contexts involving vulnerable youth such a model can lack the nuance necessary to deal with privacy and confidentiality condensations in a way which produces ethical research (Pittaway et al., 2010).

Anonymity is extremely difficult to achieve (and arguably a questionable goal) for research based on participatory or interpretive methods (Tilley & Gormley, 2007; Liebenberg & Ungar, 2011; Walford, 2005). Interpretive methodologies - particularly ethnographic research which relies on thick description - frequently require a familiarity between researcher participant and researcher which complicates the possibility of ensuring anonymity and confidentiality (Tilley & Gormley, 2007). Within participatory action research developing a sense of partnership between researchers and participants may be essential, and allowing youth the opportunity to claim public ownership over the data that they have collected can be essential to the formation of this relationship.

In a report which analyzes the impact of the Canadian Tri-Council Policy Statement on research in the social sciences and humanities, it is advised that REBs adopt a participant-centred perspective in relation to confidentiality, recognising that in some circumstances it is neither in the interests of participants or researchers to attempt to enforce confidentiality.
without regard to context (Tilley & Gormley, 2007; SSHRC, 2004; Ungar & Liebenberg, 2011).

For the committee writing this review, this recommendation is rooted in recognition that:

“Considerations of “voice” are crucial within several methodological traditions, and many researchers noted that attention to “respect for the dignity of persons” should normally recognise participants’ right to ask to be identified and to have their views correctly attributed to them. In some research traditions and research sites, imposition of a rigid requirement that participants not be identified can reflect disrespect for the participant because of the manner in which it features the researcher’s voice instead of the participant’s”


The literature search revealed several cases in which participatory research projects challenged REBs as pertains to ensuring the anonymity of youth participants. As a part of their work on the International Resilience Project, Liebenberg and Ungar (2011) worked with a group of youth who used both video and photography, along with narrative interviews and observations, to document their experiences within their communities.

Youth involved in this research were engaged in telling their own stories, and as a result objected to having the data that they created anonymized. Youth felt that they should be recognized as experts on their own lives and that they should be able to take ownership over the video and photographic data produced in the project (Liebenberg & Ungar, 2011). The authors made an application to the relevant REB which argued that the participatory nature of this project offered an opportunity for youth and researchers to engage with each other in a mutually beneficial manner, and that great benefit could be derived from allowing youth to
have their names attached to the content they created. In the end youth’s faces were blurred in photographs, but their names were retained in publication.

Tilley and Gormley (2007) provide another example in which participants wanted their names to be attached to research. Conducting research within a school in a low socio-economic region of Northern Mexico, the authors found that both parents and teachers reacted negatively to the idea of having the data they produced anonymized. Youth and gatekeepers wanted their names to be included in published research, and also that the conception of anonymity offered by the Canadian REB was not shared by Mexican researchers or authorities. One participant, a teacher, shared an email with the authors which stated:

“I like the idea that up in Canada, some people are going to read about me and that my name will be in a book. I think it’s great that somebody who lives as far away as Canada is going to know that in the little town of Garcia, Nuevo Leon, Mexico, there is this Grade 6 teacher by the name of Maestro Luis Pulido who tries his hardest to teach his students and who plans science experiments for them to do.”

(Tilley & Gormley, 2008, p. 380)

While this message was provided by a teacher, the authors also state that similar opinions were communicated by mothers in the study. One mother stated that “If I were to use a pseudonym, it would be like denying the paternity of my own child” (2008, p. 381). Most parents felt that the concept of confidentiality was odd, one going so far as to state that only a coward would decide to hide their identity.
V. Harms and benefits

Considering the relationship between the potential risks and potential benefits of research is at the heart of most discussions of research ethics. A portion of any ethical guidelines are usually concerned with minimising the risks of research while maximising possible benefits. According to Oakes (2002), “ethical guidelines and principles help advance knowledge while protecting participants.” Undergirding this position is a conception of research which sees it as a way of creating knowledge to inform policy or service provision which can have a positive impact on the lives of vulnerable individuals (Daley, 2013, p. 1). While the desire to weigh the harms and benefits of youth participation in research may be rooted in a desire to produce the best possible outcomes while protecting research participants, there is some danger that overly protective attitudes toward vulnerable youth may lead to exclusion from research which itself can be framed as a harm (Spriggs, 2007, p. 1).

Weighing the potential risks of participating in research against the potential benefits is a difficult task which often includes judgements of valuation. As Lincoln and Tierney (2004) note, the process of weighing potential benefits alone often consists of several calculations:

1. Calculations of the possibility of direct benefit to research participants;
2. Calculations of the possibility of benefits which can be created through pursuing the research questions a given project seeks to answer.

Calculating the risks and benefits of a given research project does, of course, not occur within a vacuum. These calculations are themselves made within a context which has its own influences and pressures. As Nyambatha (2008) notes, researchers have come under criticism
for the fact that pieces of research may provide benefits to their careers while providing little benefit to the individuals and populations involved as participants. In addition to this failing to conduct research has also been framed as a potential source of harm in that not conducting research can have the effect of depriving “disadvantaged populations of the benefits of imminent incremental improvements to their health” (Buchanan & Miller 2006, p. 781, cited in Spriggs, 2007, p. 19). The benefits that can be enjoyed as a result of research of course depend upon the proper dissemination of research; research which remains available only to an academic audience is likely to have little benefit to those involved as participants.

**a. REBs and Harms and Benefits**

As discussed, the ethical directives given by REBs have their origins in a framework designed to guide biomedical research involving humans. Relying on this framework to provide guidance for arbitrating between the harms and benefits is often unhelpful. For example, the assumption that “research involves risk” is embedded in ethics frameworks based on the medical model. In many medical studies there is both the realistic possibility of experiencing both tangible benefits and of experiencing serious harms from participating in a study. For example, if a research participant opts to undergo an experimental surgical treatment, they stand to benefit directly from the success of this treatment, while the run the risk of encountering complications that may be associated with an unproven procedure (SSHRC Ethics Special Working Committee, 2004, p. 56).

When carried over to social sciences or humanities research however, this model for understanding risk has the potential to create unreasonable expectations of both risks and potential benefits as, in many research projects the potential harms that participants are
exposed to are often negligible (and sometimes indistinguishable from those they might encounter in everyday life) (SSHRC, 2004, p. 23). The limitations of a conception of risks and benefits which is based on a biomedical model has given rise to calls for reform to research ethics frameworks. In the Canadian context, concerns are a factor which has led to a call for “a separate section of the TCPS (Tri-Council Policy Statement) devoted to non-experimental forms of research, particularly focusing on the social sciences and humanities” (SSHRC, 2004, p. 56).

b. Discourse of protectionism

Dixon-Woods, Shaw, Agarwal and Smith (2004) argue that an assumption of children as vulnerable, incompetent and needing of protection plays a role in debate about the inclusion of young people in research. According to this account a discourse of protectionism pervades much of ethical thinking on research with children. While it is reasonable to recognize that children and adults have differing abilities which, in some contexts, could render children more vulnerable to abuse in the research process, perceptions of the vulnerability of children are often rooted in culturally based notions of authority or power between children and adults (Bray & Gooskins, 2005; Alderson and Goodey, 1996; Mayall, 2000; Alanen & Mayall, 2003). Basing research upon an assumption of children as weak and needing of protection can further frustrate the conduct of research which attempts to engage children and youth in the production of knowledge.

Research on children and youth contributes to publically held understandings of children and youth. Certainly, researchers cannot be held solely responsible for this; researchers do not have complete control over how their findings are interpreted by policy makers and journalists. Morrow and Boyden (2013) provide an example in which a UNICEF
research report which commented upon the status of children in the UK was poorly interpreted by the media and thus came to reinforce “dominant ideas reflecting the problematic status of children and young people in the UK” (2013, p. 2908). Particularly, the report was interpreted in a way that emphasized the deficits in the behaviour of children in relation to engaging in risky health behaviours. This example serves to illustrate the necessity of considering harms and benefits of participating in research broadly, and not limiting evaluation to the moment of data collection. As Morrow and Boyden state, “research on a broad topic like well-being requires careful handling at the dissemination stage… with questions about the clarity of the term and the claims that can be made for it” (2013, p. 2914).

c. The role of context

The context in which research takes place must play a significant role in valuations of the risks and benefits of participating in research. Morrow and Boyden (2013) provide a useful discussion which helps to frame considerations of possible harm in contexts of violence or political unrest.

In a comprehensive discussion about ethical issues in research with children, Morrow and Boyden (2013) confirm that, depending upon contextual factors, children can be more vulnerable to abuse than adults when involved in research. However, this discussion makes a significant addition: Recognising that differentials in power between adults and children have the potential to create ethical breaches, Morrow and Boyden hold that this power differentials can be influential not only at the point of data collection, but also at the points of study and methodology design, data interpretation and presentation of research findings (Morrow and Boyden, 2013, p. 2896, p. 2903).
Contexts in which there is armed conflict or political tension provide an illustration of the need to consider contextual factors in calculations of potential harms and benefits. In these contexts it can be important that care be taken to ensure that children do not, and are not perceived to, divulge information that may compromise their security or that of their families, friends, communities or the researchers themselves (Morrow & Boyden, 2013, p. 2905; Boyden 2004). Politically contentious contexts are often accompanied by shifting and complex systems of political affiliations that may not completely be understood by researchers. As Morrow & Boyden (2013) note, speaking with researchers who seem to be politically neutral can embolden children who might share information that they had not previously felt able to share within their communities. For example, in a research with Tamil adults and children in Sri Lanka, participants shared information related to their experiences of violence although this information was not solicited by researchers. The authors choose not to publish their findings as it was thought that putting such information into circulation could constitute a risk for both individual children and their communities (Armstrong, Boyden, Galappatti & Hart, 2004). As Morrow and Boyden outline, this particular situation forced the authors to make a valuation of potential risks and benefits: on one hand the research project gave a platform for people to share their stories with a wider audience. On the other hand sharing these stories had the potential of putting research participants or their communities in danger (Morrow and Boyden, 2013, p. 2905).
d. Managing expectations

The way in which researchers communicate potential benefits for participating in research to research participants also has ethical implications. Drawing on the experiences of researchers working with the Young Lives project, Morrow notes that in resource poor communities it is often the case that outsiders are perceived as representing the government or aid organizations and as such, they are expected to provide material goods. In the eyes of many research participants there was not a clear distinction between research and intervention (Morrow, 2009, p. 14). This example illustrates clear concerns related to consent; if participants consented to be involved in research on the basis of expecting a material reward their consent may be regarded as invalid.

The cultural context within which research takes place may also have an impact on the arbitration of the harms and benefits of participating in research. Drawing upon a research project conducted in Pakistan, the ERIC project examined the interaction between research and a culture of hospitality (ERIC, Case Study: Harms and Benefits). According to researchers working in Pakistan, the expectation that community members provide food and refreshments to visitors, whether or not they have the extra resources to do this, is high. While the cost of providing refreshments brings this issue into focus, as the authors note, the ethic of hospitality may have other implications related to issues of consent. If it is imperative to welcome and help a guest, how is it possible to know if consent is truly voluntary, and to be certain that research participants are not putting themselves at risk of harm as a result of cultural pressure?
Section 5: Discussion and Conclusions

This report details the findings from a scoping and systematic review of the literature. The findings suggest that the ethical and methodological considerations involved in research with youth are complex and vary tremendously according to the social, economic and political context within which research takes place. Relatedly, it was also found that in some cases institutional research ethics boards fail to respond to the complexity involved in social research and have the potential to direct research practice in a way that is unethical. There is some evidence to suggest that this is a product of the frequent mismatch between the ways in which REBs and qualitative researchers understand knowledge (Wyn, 2011; Bray & Gooskins, 2006).

As the transition towards understanding the value of incorporating the voices of youth in research illustrates, the nature of behaviour that is considered to be ethical changes. While it was once acceptable to conduct research on the bodies of subjects who did not consent in the name of accumulating knowledge, changes in ethical standards have rendered these practices unacceptable. A less dramatic, although still important transition has occurred in ethical thinking related to research with youth. As discussed earlier, research which delegates responsibility for youth to gatekeepers in the name of protecting youth from the dangers of participation in research was once considered unproblematic. Relatively recent developments in ethical thinking and research practice serve to challenge this notion, with the recognition given by the UNCRC serving to underline the imperative of the genuine inclusion of youth in research.
Ethics and methodology are closely related (Abebe, 2009; Morrow, 2009). Certainly, this idea formed part of the basis for the historical development of research ethics. While changes with regard to the way in which youth are conceptualized within research have taken place at both theoretical and practical levels – as indicated by the latest iteration of the UNCRC and by the development of participatory research practices by researchers working with youth – the evidence suggests that changes at the organizational (REB) level have been slower to occur. Institutional ethics requirements which hamper the ability of researchers and participants from realizing the goals outlined by youth, feminist, critical race, queer, and cultural studies (Swauger, 2009) can be argued to promote research practices which are not ethical.

Through synthesizing the available evidence from researchers and practitioners the report aims to synthesize work and provide a resource that can be used to work toward conducting ethical research, and increasing the extent to which the work of ethics governing bodies ensures the production of ethical research with children and youth in challenging contexts.
I. **Key Findings**

**General:**
- There are frequently differences between the expectations of REBs and those of researchers working with children and youth in challenging contexts with regard to appropriate research strategies for working with vulnerable youth.
- The application of some REB-mandated practices has the potential to decrease youth engagement in research and exclude marginalized populations from research.
- Some researchers have worked with REBs to create research strategies that are capable of meaningfully involving youth and meeting institutional ethical requirements.
- Ethical issues in research with children in challenging contexts are often directly related to the context in which research takes place.

**Informed Consent:**
- Consent can involve group/community dynamics, not only individual considerations.
- Ensuring informed consent depends on social/economic context.
- To be consistent with the goals of emancipatory research a model of informed consent must be flexible according to social and economic context.

**Payment and compensation:**
- Most literature supports that some form of compensation for participation in research should be given, although there is no consensus on the form this compensation should take.
- The social and economic context of research participants plays a role in determining what sort of compensation is appropriate.
- Debates about compensation for participation in research can be closely related to issues of consent, particularly in resource-poor contexts.

**Privacy and confidentiality:**
- Mandating privacy is inappropriate for some types of research and in some contexts.
- Participatory research is sometimes incompatible with the conceptions of privacy and confidentiality mandated by REBs.

**Harms and benefits:**
- The model for understanding risk employed by many REBs is rooted in a medical model of risk evaluation.
- Evaluating risks and benefits should always be considered in relation to the research context, and neither researchers nor participants should be regarded as objective decision makers in this regard
- A discourse of protectionism can serve to diminish youth engagement in research, further marginalising youth in challenging contexts.
- Research participants and researchers may not have shared expectations of the benefits of participating in research.
Section 6: Recommendations

**For Researchers**

**General:** Researchers should negotiate appropriate ethics procedures with representatives of youth involved in research. This could involve including organizations in developing Ethics applications.

**General:** Researchers should work with organizations/advocates to advocate for youth-specific needs to Research Ethics Boards.

**Informed Consent:** Researchers should develop procedures for ensuring informed consent with advocates of youth. These procedures should be sensitive to social and economic context.

**Payment and Compensation:** Researchers should engage with advocates to develop compensation that is appropriate to social and economic context.

**Privacy and Confidentiality:** Procedures related to privacy and confidentiality must be based on: 1) negotiations with representatives of youth involved in research and 2) a realistic assessment of the potential harms or benefits of maintaining confidentiality.

**Harms and Benefits:** Researchers should: 1) include organizations/advocates in early stages of research design to maximize mutual benefits related to research and 2) work with organizations/advocates to develop reasonable expectations amongst research participants.

**For Organizations/Advocates**

**General:** Representatives of youth should advocate for ethical standards of research which work for the youth they represent.

**General:** Work with researchers to advocate for youth-specific needs to Research Ethics Boards.

**Informed Consent:** Organizations that represent youth should develop understanding of situations of youth advocate for context appropriate informed consent.

**Payment and Compensation:** Representatives of youth should work with youth to consensus of appropriate compensation, advocate for this consensus to researchers.

**Privacy and Confidentiality:** Representatives of youth should develop understanding of particularities of situations of youth involved in research as they relate to confidentiality and advocate for best solution for them.

**Harms and Benefits:** Organizations should: 1) develop complex understanding of potential harms/benefits of a given piece of research to the populations they represent and 2) advocate for populations they represent to researchers.
### Researchers and Organizations should work together:

* Researchers who work with youth should seek places on Research Ethics Boards.
* Researchers and organizations should share their experiences of conducting ethical research with each other.
* Researchers and organizations/advocates should develop arguments for research practices that can be presented to Research Ethics Boards.

### Recommendations for Research Ethics Boards:

* REBs should require board members to undergo training which prepares them to think critically about research with children and youth.
* Researchers should collaborate with organizations/advocates to develop possible training materials.
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# Appendix A: Glossary of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tr>
<td>Aboriginal</td>
<td>The descendants of the original inhabitants of North America. The Canadian Constitution of 1982 recognizes three groups of Aboriginal people – Indians, Métis and Inuit. These are three separate peoples with unique heritages, languages, cultural practices and spiritual beliefs [PHAC-FNCIS]. However, all shared the common history of colonialism and attempted assimilation.</td>
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<tr>
<td>Adolescence</td>
<td>“Adolescence begins with the onset of physiologically normal puberty, and ends when an adult identity and behaviour are accepted. This period of development corresponds roughly to the period between the ages of 10 and 19 years.” (‘WHO</td>
</tr>
<tr>
<td>Alternative Care</td>
<td>“Alternative care is defined as care for orphans and other vulnerable children who are not under the custody of their biological parents. It includes adoption, foster families, guardianship, kinship care, residential care and other community-based arrangements to care for children in need of special protection, particularly children without primary caregivers.” (UNICEF, 2006, p. 15)</td>
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<tr>
<td>Best Practice</td>
<td>“Best Practices are interventions that incorporate evidence-informed practice, identify and employ the right combination of program elements to ensure targeted outcomes, and match these interventions to the local needs and assets of communities. This definition of best practices thus prioritizes the evidence garnered from researchers, practitioners, and indigenous knowledge, depending on the question being asked” (CYCC-Violence, p. 70)</td>
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<td>Bullying</td>
<td>“A form of aggression (physical, verbal, or psychological attack or intimidation) by one or more children that is intended to cause fear, distress, or harm to another child who is perceived as being unable to defend himself or herself. A power imbalance typically exists between the bully and the victim, with the bully being either physically or psychologically more powerful, resulting in repeated incidents between the same children over a prolonged period.” (Farrington, Baldry, Kyvsgaard, &amp; Ttofi, 2010, p. 9; Smokowski &amp; Kopasz, 2005, p. 101)</td>
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<tr>
<td>Child/ Children</td>
<td>“Every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier” (United Nations General Assembly, 1989, art. 1)</td>
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<tr>
<td>Child Maltreatment</td>
<td>There are five classifications of maltreatment: physical abuse, sexual abuse, neglect, emotional maltreatment, exposure to intimate partner violence (PHAC-CIS 2008).</td>
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<tr>
<td><strong>Children and Youth in Organized Armed Violence</strong></td>
<td>“Children and youth employed or otherwise participating in Organized Armed Violence where there are elements of a command structure and power over territory, local population or resources” (Dowdney, 2006, p. 13)</td>
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<tr>
<td><strong>Child Soldier</strong></td>
<td>“A Child soldier is any person under age 18 who is part if any kind of regular or irregular armed force or group in any capacity, including but not limited to cooks, porters, messengers and those accompanying such groups, other than purely as family members. This definition includes girls recruited for sexual purposes and for forced marriage. It does not, therefore, only refer to a child who is carrying or has carried arms.” (“UNICEF - UNICEF in emergencies - Children and armed conflict,” 1997)</td>
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<tr>
<td><strong>Child trafficking</strong></td>
<td>“The recruitment, transportation, transfer, harbouring or receipt of a child for the purpose of exploitation ... even if this does not involve any of the means set forth in [the definition of Trafficking in persons] (“the recruitment, transportation, transfer, harbouring or receipt of persons, by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability or of the giving or receiving of payments or benefits to achieve the consent of a person having control over another person, for the purpose of exploitation. Exploitation shall include, at a minimum, the exploitation of the prostitution of others or other forms of sexual exploitation, forced labour or services, slavery or practices similar to slavery, servitude or the removal of organs”) [United Nations, 2004]</td>
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| **Community of Practice** | The translation of best practices and the mastery of knowledge and skill through participation in the sociocultural practices and relations of a community (Lave & Wenger, 1991, p. 29). A community of practice defines itself along three dimensions:  
  - What it is about – its *joint enterprise* as understood and continually renegotiated by its members  
  - How it functions mutual engagement that bind members together into a social entity  
  - What capability it has produced – the *shared repertoire* of communal resources (routines, sensibilities, artifacts, vocabulary, styles, etc.) that members have developed over time. (Wenger, 1998) |
| **CYCCs (Children and Youth in Challenging Contexts)** | By CYCCs, this report refers to children and youth who face particular challenges and risks that increase their vulnerability and threaten their safety and development. This definition is not place or culture-specific and refers to CYCCs world-wide. CYCC populations specific to the knowledge syntheses will be defined in the reports. |
| **Chronic Illness/Disease** | “The word ‘chronic’ is typically used for conditions, illnesses, and diseases lasting three months or more. Often, chronic conditions are characterized by lasting symptoms and/or pain that persists, sometimes even despite treatment.” (‘What Is Chronic Illness?’ http://carly- |
| Civic Engagement | “Individual and collective actions designed to identify and address issues of public concern. Civic engagement can take many forms, from individual voluntarism to organizational involvement to electoral participation. It can include efforts to directly address an issue, work with others in a community to solve a problem or interact with the institutions of representative democracy” (American Psychological Association, 2012). |
| Community Youth Development | “Community Youth Development is an approach that espouses the principle that when youth are enlisted as active agents of community building, it contributes positively to both youth development and community development. Community Youth Development assumes the involvement of young people in their own development and that of the community - in partnership with adults - to make use of their talents and increase their investment in the community.” (‘Heartwood Centre for Community Youth Development’) |
| Engagement | “The meaningful and sustained involvement of a young person in an activity focusing outside the self. Full engagement consists of a cognitive component, an affective component, and a behavioural component- Heart, Head, and Feet.” (‘Centres of Excellence for Children’s Well-Being- Youth Engagement’) |
| Environmental Scan | A surveying approach that was used to capture resources and programs that exist outside of the academic, peer-reviewed literature (Chrusciel 2011) |
| Evidence-based practice (EBP) | “Interventions based on empirical, research-based support which are used to inform the judgements of practitioners in accordance with the particular priorities, needs, contexts and other factors of both service users and service providers (ie. What research shows is effective).” |
| Evidence-informed practice (EIP) | Interventions based on empirical, research-based support, which are employed in accordance with the particular priorities, needs, contexts and other factors of both service users and service providers (Chalmers, 2003; Proctor & Rosen, 2006) |
| External validity / generalizability | “The extent to which the claims/arguments are generalizable to, or applicable in, contexts different from the specific context in which they were generated (ie. transferability).” |
| Family | “The fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children, should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community” (United Nations General Assembly, 1989) |
| Generalizability | The ability to for general principles or conclusions from detailed fact, information, or experiences (http://www.thefreedictionary.com/generalizability) |
| Grey literature | “Information produced on all levels of government, academia, business and industry in electronic and print formats not controlled by commercial |

89  CYCC Network · 2014 · http://cyccnetwork.org/ethics
| **High quality information** | “Authoritative, high quality information is any peer-reviewed source that is reliable, objective, and internally and externally valid.” |
| **Homeless Youth** | “Definitions of the term ‘homeless’ of ‘street youth’ are numerous and varied, as are the social realities of different countries. However, one constant found among all street youth is their precarious living conditions, which include poverty, residential instability and emotional and psychological vulnerability. These conditions may lead to behaviour that exposes street youth to physical, mental, emotional and psychological risks.” (‘Street Youth in Canada: Findings from Enhanced Surveillance of Canadian Street Youth, 1999-2003’, 2006) |
| **Indigenous knowledge** | “The local knowledge generated within a community, which is contextually dependent on the cultural beliefs and practices of the community and undergoing constant modification in response to its changing needs.” (Agrawal, 1995; Smylie et al., 2004; Warren, 1991) |
| **Institutional Review Board (IRB)** | See Research Ethics Board |
| **Internal validity** | “The extent to which the evidence put forward actually relates to the claims / arguments being put forward (ie. truth value).” |
| **Intervention** | In this report, an intervention refers to the program, project, strategy, etc, employed by a government agency or organization that aims to introduce new ideas, activities and information intended to improve their target audience’s quality of life. |
| **Knowledge Mobilization** | In our context- it is mobilizing knowledge about best practices for NGOs |
| **Maltreatment** | “Physical abuse, sexual abuse, emotional maltreatment, neglect, and exposure to intimate partner violence, all of which pose significant risk of harm to a child’s physical or emotional development. Accordingly, situations classified as maltreatment may range from those in which a caregiver intentionally inflicts severe physical or emotional harm on a child, to situations in which a child is placed at risk of harm as a result of a caregiver’s clear failure to supervise or care for a child, to situations in which living conditions would make it extremely difficult for any caregiver to ensure a child’s safety.” (Trocmé et al., 2008, p. ix) |
| **Neglect** | “The failure of parents or carers to meet a child’s physical and emotional needs when they have the means, knowledge and access to services to do so; or failure to protect her or him from exposure to danger. In many settings the line between what is caused deliberately and what is caused by ignorance or lack of care possibilities may be difficult to draw.” (Pinheiro, 2006, p. 54) |
| **Non-physical** | “Degrading and potentially damaging forms of psychological violence,
<p>| <strong>violence</strong> | including persistent threats, insults, name-calling or other forms of verbal abuse, belittling, isolation or rejection. In violent settings, there is constant fear and anxiety caused by the anticipation of violence; pain, humiliation and fear during its enactment; and loneliness, rejection, distrust, and self-disgust. In addition to direct violence, witnessing violence between family members or in the community can itself pose serious consequences.” (Pinheiro, 2006, pp. 47, 61) |
| <strong>Objectivity</strong> | “The extent to which the evidence is unbiased (ie. neutrality).” |
| <strong>Peer-reviewed information</strong> | “Books, journals, and conference proceedings published by scholarly publishers or professional organizations, and thus subject to independent review by experts. The credibility and authority of the information is determined by extrinsic criteria (ie. based on the reputation of the author, publisher, etc)” |
| <strong>Physical violence</strong> | “The intentional use of physical force against a child that either results in or has a high likelihood of resulting in harm to the child’s health, survival, development or dignity. In extreme cases, this violence can result in a child’s death, in disability, or in severe physical injury. In all instances, however, physical violence has a negative impact on a child’s psychological health and development. Includes homicide, sexual violence, corporal punishment beating, kicking, biting, choking, burning, scalding, or forced ingestion” (Pinheiro, 2006, pp. 51–52). |
| <strong>Positive Youth Development</strong> | “Youth development views youth both as partners and central figures in interventions. These interventions systematically seek to identify and utilize youth capacities and meet youth’s needs. They actively seek to involve youth as decision makers and tap their creativity, energy, and drive; and they also acknowledge that youth are not superhuman – that they therefore have needs that require a marshalling of resources targeted at youth and at changing environmental circumstances (family and community)” (Mafle’o &amp; Api, 2009). |
| <strong>Practice-based evidence (PBE)</strong> | “The practice employed by practitioners that has proven to be effective, arising from the contingent conditions and characteristics that facilitate program success.” (Barkham &amp; Mellor-Clark, 2003; Fox, 2003) |
| <strong>Receptor Communities (RC)</strong> | These are community organizations within the CYCC Network |
| <strong>Refugee</strong> | “any person, who owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his/her nationality and is unable or, owing to such fear, is unwilling to avail himself/ herself of the protection of that country; or who, not having a nationality and being outside the country of his/her former habitual residence as a result of such events, is unable, or owing to such fear, is unwilling to return to it” (United Nations, 1951) |</p>
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<th><strong>Reliability</strong></th>
<th>“The extent to which the evidence is stable (i.e. would be the same if measured at different times and / or by different observers; consistency of analysis).”</th>
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<td><strong>Research Ethics Board (REB)</strong></td>
<td>An REB is a committee, usually within a university or other research institution, that is meant to ensure that research with humans is conducted in an ethical manner.</td>
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<td><strong>Resilience</strong></td>
<td>“In the context of exposure to significant adversity, resilience is both the capacity of individuals to navigate their way to the psychological, social, cultural, and physical resources that sustain their well-being, and their capacity individually and collectively to negotiate for these resources to be provided in culturally meaningful ways.” (Ungar, 2005, p. 225)</td>
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<tr>
<td><strong>Scoping Review</strong></td>
<td>A review intended to “map’ or identify the extent and nature of the literature that currently exists in the field of interest” (Arksey 2003; p336; Mays et al 2001).</td>
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<td><strong>Service User</strong></td>
<td>For the purpose of this report, we will use the term ‘service user’ to refer to any group or individual who can affect or is affected by the achievement of the organization’s objectives (Freeman 1984; 46). Synonyms include ‘Stakeholder’, ‘Beneficiary’, ‘Consumer’, &amp; ‘Participant’.</td>
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<td><strong>Sexual Violence</strong></td>
<td>“Includes sexual touching, abuse or rape, forced sex within forced and early marriage, spousal abuse (physical and psychological), honour killings and intimidation within the family, or harmful traditional practices (e.g. female genital mutilation / cutting, uvulectomy). The shame, secrecy and denial associated with sexual violence against children foster a pervasive culture of silence, where children cannot speak about sexual abuse they have suffered, adults do not speak about the risk of sexual violence or do not know what to do or say if they suspect someone they know is sexually abusing a child.” (Pinheiro, 2006, pp. 54–55)</td>
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<tr>
<td><strong>Technology</strong></td>
<td>“How different innovations in technology (i.e. mobile phones, the internet, social networking) are used to help children and youth in the most challenging of contexts. Emphasis will be placed on those innovations which have been used with these young people to prevent violence and promote well-being.”</td>
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<td><strong>Unaccompanied Refugee Children</strong></td>
<td>“Unaccompanied children are those who are separated from both parents and are not being cared for by an adult who, by law or custom, is responsible to do so.” (United Nations High Commissioner for Refugees, 1994, p. 121)</td>
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<tr>
<td><strong>Validity</strong></td>
<td>The extent to which a concept, conclusion or measurement is well-founded and corresponds accurately to the real world. (<a href="http://encyclopedia.thefreedictionary.com/Validity+%5Bstatistics">http://encyclopedia.thefreedictionary.com/Validity+[statistics</a>] )</td>
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<td><strong>Violence (Direct)</strong></td>
<td>“The intentional or threatened use of physical force or power, involving both a perpetrator and a victim and occurring within the home, school, workplace, community or other settings, which either results in or has a high likelihood of resulting in physical or psychological harm,”</td>
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<td>Definition</td>
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<td>Violence (Indirect)</td>
<td>“The intentional or unintentional physical or psychological harm derived from structural inequalities and power imbalances inherent in social, economic, and political institutions, which may not involve a direct perpetrator yet nonetheless prevent victims from meeting their basic needs.” (Farmer, 1996; Galtung, 1969)</td>
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<td>Young People</td>
<td>This is a broad term used to refer to children, adolescents and youth as one, general group.</td>
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<tr>
<td>Youth</td>
<td>“Youth are defined as persons between the age of 15 and 24.” (‘Youth</td>
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<tr>
<td>Youth Community</td>
<td>“A youth community can be defined as a population of youth who share backgrounds, situations, or lifestyles with common concerns, i.e. ethnic background, socioeconomic background, geographical area (rural, for example), lesbian or gay youth, etc.” (Halifax Regional Municipality)</td>
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## Appendix B: Evaluation Grid for Scoping Review

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<td><strong>Relevance</strong></td>
<td>The article was not directly relevant, addressing only one of the key concepts related to the research question</td>
<td>The article was somewhat relevant, addressing some of the key concepts related to the research question</td>
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<td><strong>Peer Reviewed</strong></td>
<td>The article was not evaluated by one or more people of similar competence to the producers of the work.</td>
<td>The article was evaluated by one person of similar competence to the producers of the work.</td>
<td>The article was evaluated by more than one person of similar competence to the producers of the work (e.g., through a journal).</td>
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<td><strong>Rigorous Methodology</strong></td>
<td>There was not sufficient evidence to show that a rigorous methodology was followed. Methods were not clearly presented, lacking context and coherence.</td>
<td>There was some evidence provided that the methodology used was thorough but with room for more rigour. Methods were coherent and relevant to context.</td>
<td>Methods were coherent and relevant to context. Evidence presented illustrates that rigorous methodology followed.</td>
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<td><strong>Appropriate Sample Size</strong></td>
<td>The number of participants in this research is not adequate for answering the research question (either too large or too small)</td>
<td>The number of participants in this research are marginally acceptable to answer the research question</td>
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<td><strong>Internal Validity</strong></td>
<td>A causal relationship between intervention and outcome was not established.</td>
<td>A causal relationship was somewhat established. There was some evidence that the intervention caused the intended and unintended results</td>
<td>A causal relationship was established. There was evidence that what was done in this study caused the intended and unintended results</td>
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<td>External Validity</td>
<td>The quantitative results are not generalizable (i.e. not applicable to other cases, contexts, people); qualitative results are not transferable.</td>
<td>It was not clear if results are widely generalizable or transferable.</td>
<td>The results are generalizable (i.e. applicable to other cases, contexts, people) and transferable.</td>
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**Final Score:**
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