MASTER-THESIS

Titel der Master-Thesis

„The Need For An Obligatory Ethical Framework When Researching Children in Nepal"

Verfasser

Manu Krishan

angestrebter akademischer Grad

Master of Arts (MA)

Wien, 2014

Universitätslehrgang:	Master of Arts in Human Rights
Studienkennzahl lt. Studienblatt:	A 992 884
Betreuerin:	Ass.-Prof. Dr. Brigitte Lueger-Schuster

Table of Contents

Acknowledgements

1   <u>Chapter 1: Introduction and Background</u>

This paper includes four main chapters acquiescent to the understanding of ethical concerns when conducting research with children, specifically social research conducted by key-stakeholders when it comes to children's protections and rights in the context of Nepal. When we speak of obligatory ethical framework it is imperative to comprehend the meaning of 'ethical framework'. In this context, this constitutes an ethical review board and an ethical code of conduct or child protection policy, which are regulatory mechanisms that have ethical guidelines inherently placed to consult and provide researchers with ethical standards and advices. It constitutes the ethical mechanisms in place that provide necessary protection for the research and for the rights of the child. Therein, Ethical approaches determine inherent philosophical understandings and explanations of ethical guidelines and codes and therefore need to consequently be understood. The following chapter will introduce Ethics and Ethical Research, the underlying ethical approaches, key components and ethical challenges that have arisen in the international literature reviewed and in guidelines. This chapter is dedicated to outline the theoretical aspects of ethical research involving children to get a grasp of the underlying issues and conceptions that have influenced child research ethics. These will be fundamental in the comprehension of ethics and ethical research with children and consequently give reasons and groundwork for the further interpretation and understanding in the context of Nepal. Following this chapter, we will present the research that commenced in Kathmandu, Nepal on the current ethical understanding, practices, and challenges in research that involves children. Henceforth, chapter three will provide the main findings that have emanated from the research on the ground and these will be discussed and interpreted according to the research questions, issues discussed by the key-stakeholders and the literature reviewed. Finally, in chapter four, after having completed the discussion and interpretation of the findings, conclusions and recommendations will enable a set of responses that could be implemented for the betterment of research with children in the context of Nepal.

1.1   Introduction to Ethics and Ethical Research

Ethics represents, "well-founded standards of right and wrong that prescribe what humans ought to do, usually in terms of rights, obligations, and benefits to society, fairness, or specific virtues[1]". Research ethics and methodologies are intertwined, with ethically sound research protocols and tools adding to the value of the research and ethical standards as formulated in guidelines help to minimize any risk of potential harm resulting from the data collection process, to participants, researchers and others, and assist in ensuring that any risks are balanced by potential benefits and promote the aims of research, such as knowledge, truth, and prevention and avoidance of error. What is meant by prevention and avoidance of error is prohibitions against constructing, falsifying, or misrepresenting research data, which promote the truth and avoid inaccuracies[2]. Many of the ethical customs help to ensure that researchers can be held accountable to the public and that the researched can be adequately protected and build public support for research and people are more likely to fund research projects if they can trust the quality and integrity of research[3].

Furthermore, since research often involves a great deal of cooperation and coordination among many different people in different disciplines and institutions, ethical standards promote the values that are essential to collaborative work, such as trust, mutual respect, accountability, and fairness and given the significance of ethics for the conduct of research, and it should come as no revelation that many different professional associations and organisations, government agencies, and universities have approved and adopted specific codes, rules, mechanisms, and policies relating to research ethics[4]. Finally, many of the standards of research endorse a range of other important moral and social values, such as human rights, social responsibility, compliance with the law, and health and safety[5]. Therefore, following ethical standards is essential for good research practice and ethical failures in research can significantly

---

[1] CP MERG (2012), p. 1,
[2] See: "What is Ethics in Research & Why is it Important?" available at:
'http://www.niehs.nih.gov/research/resources/bioethics/whatis' retrieved on June 20, 2014
[3] Ibidem.
[4] Ibidem.
[5] Ibidem.

harm human subjects, researchers, public and key stakeholders. Furthermore, we will signify the importance of ethics when research involves children.

1.1.1 Ethical Research involving Children and the New Sociology of Childhood

Research with, and for, children is indispensable because knowing about children and their lives and comprehending the child's perspective is key to protecting, promoting, and supporting their well-being and to improve the lives of children and adolescents it is necessary to find out about their circumstances, their needs, and the services they require to meet their needs[6]. Suggestively, individuals, organisations and institutions caring for children may regard them as a ready source of research data with little regard to the ethical considerations as children's contribution and influences have been rarely heard and their ability to contribute to its research development ignored[7]. Hence, the record of research application comprises many unethical practices involving children, from intrusive and invasive procedures, to the over-investigation of some populations[8]. It is incumbent for researchers to maintain good research ethics and exercise due caution and consider how it would be advisable to act when encountering difficulties in research practices and consequently, ethical research needs to be respectful of children's human dignity, rights and wellbeing and all who participate in any activity, commissioning, funding and reviewing research, are responsible for ensuring that the highest possible ethical standards are met in all research involving children, regardless of research approach, focus or context[9].When dealing with children, it has been suggested that various protective mechanisms need to exist to protect the child as well as the researcher as ethical challenges and dilemmas may arise anytime, especially when considering sensitive topics involving vulnerable children[10]. The vulnerability of children is in large part due to their inability to protect their own interests, have less power than adults, know less about consequences, and may feel

---

[6] Schenk and Williamson, 2005, p. iv.
[7] See: "What is Ethics in Research & Why is it Important?" available at:
http://www.niehs.nih.gov/research/resources/bioethics/whatis, retrieved on June 20, 2014.
[8] Ibidem.
[9] Powel et al., 2012, p. 45.
[10] Ennew & Plateau, 2004, p. 34.

unable to object[11]. The age difference and the difference in the social standings create power inequalities, which means that they are susceptible to exploitation and harm and therefore need to be farther protected[12]. Numerous researchers have identified that Nonetheless, the new shift in social studies in childhood views children as co-participants in the research process and stresses their competency and agency rather than seeing them as objects of research[13]. Hence, we will look at this in the latter sections of chapter one when speaking of participatory methods of research.

1.1.2   Medical/Health Vs. Social Research

It is imperative to comprehend how ethics in research has transformed. Hence, we will shortly introduce the history of ethical guidelines and protocols from the initiation of medical research towards the application of ethical standards in social research. From the time immediately after the second world war, until the early 1990s, there was a gradually developing consensus about the key ethical principles that should inspire the research endeavor[14]. The importance of ethical principles and guidance in research was acknowledged formally for the first time with the development of the nuremberg code, 1947 in response to wartime experimental atrocities where extreme harm was caused to human subjects by wartime medical experimentation[15]. The nuremberg code was based on Anglo-American law, and focused on respect for personal integrity in experimental research and consequently provides ten points which are guidelines to follow in experimental research[16]. The code has given rise to many normative principles in research, including informed and voluntary consent, properly formulated scientific experimentation, and the research being of benefit to participants in it[17]. The Nuremberg Code, drafted by a tribunal after harmful research experiments

---

[11] Ibidem. p. 34.
[12] Schenk and Williamson, 2005, p. 52.
[13] Sime, 2008, p. 63-64.
[14] See: "Nuremberg Code" available at:
https://www.princeton.edu/~achaney/tmve/wiki100k/docs/Nuremberg_Code.html, retrieved on May 20 2014.
[15] Ibidem.
[16] Alderson & Morrow, 2011, p. 20.
[17] See: "the ten points of the Nuremberg Code" available at:
http://en.wikipedia.org/wiki/Nuremberg_Code#The_ten_points_of_the_Nuremberg_Code, retrieved on June 22 2014.

during the second world War, altered the ways in which research was being conducted in many places. With the Code, the research community saw the rise of ethical principles and protocols that had to be followed to for the protection of research participants[18]. Since then, health and medical researchers have continued to develop ethical codes and regulatory systems of healthcare ethics and are now well established in many countries[19]. Hence, ethical research has been governed by medical and health related research ethics and ethical guidelines, as frameworks and mechanisms have been put in place due to them because of experimentations in the past[20]. Consequently, it has been suggested that organisations and institutions that are conducting social research fall in the 'umbrella' of the health related ethics systems and mechanisms[21]. The literature suggests that regulations and mechanisms embedded in the medical culture, have a different approach and comprehension and may find it hard to understand the very different world of social work and that regulations that are present at the moment, are primarily based on health based ethical considerations e.g. informed consent[22]. Social research, relying heavily on qualitative data collection, interviews and questionnaires, is unlikely to have a direct impact on physical health, in the same approach as medical research[23]. Characteristically, the requirement to bring social research into a medical arena represents a struggle between disciplines and, "there is uncertainty about where healthcare or social work begins and ends[24]". Henceforth, we will look at the ethical approaches, which will provide an understanding of underlying principles embedded in different ethical stand points, either in social or medical research. We will determine which approaches have governed ethical mechanisms and regulations and determine which is relevant in the context of this research. Numerous ethical approaches and guidelines and code of conducts have been contributed to the guiding literature to ethical research with children and provide the necessary

---

[18] Abebe 2012, p. 79.
[19] Melville 2005, p. 374.
[20] See: "History of ethics", available at http://www.cgu.edu/pages/1722.asp, retrieved on 19 June 2014.
[21] Lambert & Glacken, 2011, p. 782.
[22] Sanders, 2003, p. 113.
[23] Ibidem. p. 113.
[24] Butler, 2002, cited in Alderson and Morrow, 2006, p. 406.

groundwork[25]. Therefore, to understand the nature of ethical research with children one must comprehend the underlying premises that formulate them. Hence, in the following section we will look at ethical approaches and move towards ethical components and issues that are significant in the child research ethics literature reviewed.

1.2   Ethical approaches

Ethical guidelines and codes incorporate ethical principles and frameworks that are based on centuries of philosophical debate about duty, harm-benefit and rights, as well as wisdom drawn from sound research practice [26]. Ethical guidelines have underlying ethical frameworks and philosophies that formulate them and most ethical guidelines take a range of perspectives, and tend to incorporate principles and dimensions from "across a range of ethical approaches, rather than exclusively drawing on one[27]." Guidelines form, "a link between abstract ethical principles and sound ethical practice, and are informed by both [28]". The ethical approaches described below contribute to the development of sound ethical approaches to research involving children and will initiate a philosophical and historical introduction to ethical research. Each ethical approach or framework has its advantages and limitations and, "there is often disagreement within and between the frameworks, and debate about which framework is the best[29]", and are underlying in interpreting ethical practices, regulations and obligations in different fields. One very influential child ethics researcher depicts three main ethical approaches that reflect ethical philosophies and that help determine the action to be taken and conduct ethical research; duties, best outcomes, and rights[30]. Furthermore, another researcher directs to the inclusion of the virtue-based framework, which is to be included here to grasp added principles in ethical research[31].

---

[25] CP MERG, 2012, p. 2.
[26] Alderson & Morrow, 2011, p. 20.
[27] Ibidem. p. 20.
[28] CP MERG 2012, p. 13.
[29] Alderson & Morrow, 2011, p. 19.
[30] Alderson and Morrow, cited in CP MERG 2012, p. 13.
[31] Gallaghar, cited in CP MERG 2012, p. 13.

1.2.1 Best Outcomes Approach

The best outcomes approach is a form of consequentialist ethics [32]. Consequentialism is the class of normative ethical theories holding that the consequences of one's conduct are the fundamental basis for any decision about the rightness or wrongness of that conduct[33]. Suggestively, this has been widely attributed in medical research guidelines in the past[34]. Thus, from a consequentialist standpoint, a morally right act, or inadvertence of acting, is one that will produce a good outcome, or consequence and involves strategies to reduce harm and costs, and promote benefits[35]. Suggestively, the researcher or individual focuses on the future effects of the possible courses of action, considering the people who will be directly or indirectly affected and the outcomes are considered in given situations, and this person considers ethical conduct to be whatever will achieve the best consequences or outcomes. The person using the consequences framework desires to produce the most good, and has a utilitarian approach, as actions that are 'right' are those that result in the greatest overall good for the greatest number of people[36].

One limitation of the harm and benefit approach in research with children is that the focus on 'the greatest good for the greatest number' outcome can be less beneficial for individual children, which could compromise the individual child's rights as a consequence[37]. One researcher pointed out that, "harm is often invisible and elusive, complicated by different estimations, different viewpoints -researchers', children's or carers' - and differences between short - and longer-term outcomes[38]". Suggestively, different kinds of benefits and maleficence cannot be directly compared against each other, with regards to the individual child or a specific characteristic of the group of children.

---

[32] See: Ethics, available at http://www.iep.utm.edu/ethics/, retrieved on 19 June 2014.
[33] Ibidem.
[34] CP MERG, 2012, p.14.
[35] See: Ethics, available at http://www.iep.utm.edu/ethics/, retrieved on 19 June 2014.
[36] Lorenzetti, (2010), 'Ethical Frameworks for academic decision-making', available at: http://www.facultyfocus.com/articles/faculty-development/ethical-frameworks-for-academic-decision-making/ retrieved on 19 May 2014.
[37] Gallagher 2009, Cited in CP MERG 2012, p. 14.
[38] Alderson and Morrow, 2011 p. 23, cited in CP MERG 2012, p. 14.

1.2.2 Duty Based Approach

Ethical conduct is described by doing one's duties and doing the right thing, and the goal is performing the correct is sometimes described as "duty", or "obligation", or "rule"-based ethics, because rules, "bind you to your duty[39]". It takes the underlying ethical position that "right actions are those that treat people as ends, never as means to an end[40]", and is grounded on the idea that there are undeniable universal duties that should be carried out that combine the principles of autonomy, beneficence and non-maleficence, and justice[41]. It has been argued that these principles, "determine the structure and content of most current theoretical discussions, empirical studies and professional guidelines on research ethics[42]"

Autonomy is the capacity of a rational individual to make informed, un-coerced and reasoned decisions about things that affect themselves[43]. This gives potential research participants the freedom to choose whether they want to participate in the research process and act without the constraints of others. It has been argued that autonomy lies on five components: disclosure, understanding, competence, voluntariness and consent[44]. Disclosure meaning the provision of accurate comprehensive information to potential participants, understanding being the need of participants to understand the relevant information given to them, competence as the participants must have sufficient cognitive abilities to understand the information, voluntariness, hence to act freely, without coercion, and without the influence of power dynamics, and consent, which entails freely given consent to participation with the right to withdraw without any consequence[45].

Beneficence and malevolence entails, 'to do good' and 'to do no harm' and means that researchers have an obligation to assess the potential harms from research and work attentively to minimize or eliminate them while trying to maximize benefits and this principle gives rise to norms requiring that the risks of research be reasonable

---

[39] See: Ethics, available at 'http://www.iep.utm.edu/ethics/', retrieved on 19 June 2014.
[40] Gallagher, 2009, cited in, CP MERG, 2012, p.12.
[41] CP MERG, 2012, p. 13
[42] Corlyon et al., 2006, p.12.
[43] Holland, 2010 p. 362
[44] Richter et al., 2007, cited in, CP MERG, 2012, p. 12.
[45] CP MERG, 2012, p. 13.

in the light of the expected benefits, that the research design be sound, and that the investigators be competent both to conduct the research and to safeguard the welfare of the research subjects.[46].

Justice entails that all research participants are treated fair and equally and refers to the ethical obligation to treat each person in accordance with what is morally right and proper[47]. Hence, fair inclusion of participants and to avoid discriminatory selection of participants and treating participants fairly during the research process and in relation to the consequences of the research. Researchers divide it to distributive justice and procedural justice. The former refers to the just distribution of the benefits and goods from research, while maintaining that no harm occurs to participants. In the field of research, the principle refers primarily to distributive justice, which requires the equitable distribution of both the burdens and the benefits of participation in research[48].

The duty based framework has the advantage of creating a system of rules that has consistent expectations of all people avoiding intuitive and ad hoc procedures and if an action is ethically correct or a duty is required, it would apply to every person in a given situation. Suggestively, They provide a clear way to justify decisions and avoid narrow or biased approach[49]. Nevertheless, it has been argued that these principles often leave only abstract conceptions and requirements for researchers, and, "typically fail to offer more than vague or largely theoretical insights into the implementation of these principles in a variety of research settings[50]". An issue arises when duties conflict each other, or conflict with other rights, for example when the child's autonomy may decide whether they want to participate in a research done on parental alcohol or drug abuse. In this case it's argued that parents right to privacy conflicts with the child's rights to express her/his views[51]. Another issue is that current ethical frameworks are based on non-maleficence rather than beneficence, as children's autonomy is still compromised for the 'greater good' and personal benefits are not the primary aim of research

---

[46] Ibidem. p. 13.
[47] CP MERG, 2012, p. 13.
[48] Richter et al., cited in CP MERG, 2012, p. 13.
[49] Ibidem. p. 13.
[50] Corylon et al 2006, p. 12.
[51] Gallagher 2009, cited in CP MERG 2012, p. 14.

processes for the children.[52]

1.2.3 Rights Based Approach

Since the adoption of the Universal Declaration of Human Rights in 1948, a great number of international instruments have been adopted to ensure the unconditional respect for the human person in very diverse contexts[53]. Significantly, children's rights, reflected in plenteous international and domestic legal instruments, are rights that afford distinctive consideration to children on the basis of their unique and vulnerable status, and these rights, deemed necessary by the international community because children are often overlooked as 'rights bearers' and social actors[54], As children's rights exist in the moment when research interests and children's everyday lives intersect, continuing throughout the research process and beyond, to treat children as 'moral agents in their own right' requires researchers to recognise that children as research participants and as persons affected by research arrive with rights and retain their rights at all times[55].

Children's participation and involvement in research is highlighted by increasing acknowledgement of the status of children and citizenship, which has been recognized universally by the UNCRC. For example, non-discrimination requires the application of all the rights in the convention to all children at all times and identification of children who may require special measures for the full implementation of their rights[56]. The provision on the best interests of the child states that the best interests of the child must be a primary consideration in all actions concerning children[57]. The literature explicates a clear relationship between human rights and major principles of underlying research ethics e.g. autonomy and respect, beneficence and non- maleficence, and justice can be communicated as a set of rights: the right to self determination, participation, freedom of expression, access to information, privacy, anonymity, dignity, fair treatment and protection from harm[58]. The right of the child to participate in matters affecting him or

---

[52] King and Churchill 2000, cited in CP MERG 2012, p.13.
[53] Bell, 2008, p. 9
[54] Ibidem, p. 10
[55] Powel et al, 2012, p. 11.
[56] Ghandhi, 2012, p. 96.
[57] Ghandhi, 2012, p. 96.
[58] CP MERG, 2012, p. 12.

her is made explicit in Article 12 of the UNCRC[59]. Hence, Article 12, together with the child's right to freedom of expression[60]; freedom of thought, conscience and religion[61]; and freedom of association[62], powerfully assert the status of children as individuals with fundamental rights, opinions, and feelings of their own. Additionally, the right to information, requires duty bearers to provide child-friendly information to support children in claiming their rights[63].

Researchers have promoted a child rights orientated perspective into child research ethics and pointed out that four types of rights in the UNCRC are essential for child research ethics: Welfare, as research should contribute to children's well being; protection, as research should use methods designed to avoid harms and increase benefits; provision, as children should feel good about their contribution; choice and participation, as children should be informed about the research agenda and make informed choices about all aspects of participation[64]. Some researchers have been advocating the 'the right to be properly researched[65]', by combining a set of provisions from the convention which are article 3.3, which states that, "States Parties shall ensure that the institutions, services and facilities responsible for the care of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, the numbers and suitability of their staff, as well as competent supervision[66]", article 12.1 which claims that, "States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the children, the views of the child being given due weight in accordance with the age and maturity of the child.[67]", article 13.1 which further iterates 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

---

[59] Ghandhi, 2012, p. 98
[60] Ghandhi, 2012, p.98
[61] Ghandhi, 2012, p. 98.
[62] Ghandhi, 2012, p. 98.
[63] Ghandhi, 2012, p. 99.
[64] Bell et al., 2008, p. 10-11.
[65] Ennew & Plateau, 2004, p. 29.
[66] Ghandhi, 2012, p. 96.
[67] Ghandhi, 2012, p. 98

media of the child's choice[68]." And lastly, article 36, which promulgates the states responsibility to "Protects children against all ... forms of exploitation prejudicial to any aspects of the child's welfare.[69]"

The UNCRC has suggestions and implications for researchers, which could act as both a framework for interpretation and applications of the rights of child into research context and as an international charter of children's rights[70]. Consequently, numerous guidelines and codes have provisions that incorporate the rights based framework[71]. Furthermore, the existing human rights system, with its extensive body of international standards and wide range of follow-up mechanisms, represents one of the achievements of our time and offers children an ethical, moral and legal mandate for protection, provision and participation rights.[72]. Explicitly accepting the correlation between human rights and research ethics by embedding human rights principles in research ethics guidelines is one way to foster a rights-based approach to child research. It has been suggested by a number of researchers that the UNCRC can provide a useful framework and approach for deliberations and therefore has an influence in creating more ethical research practices as this document has opened up a multiplicity of possibilities for examining issues that concern children and in which they hold an opinion[73]. One key benefit in the use of a children's rights-based approach to research ethics is that the UNCRC is an international human rights instrument that provides a framework of common, universally agreed-upon standards[74].

On the contrary, some researchers have maintained that it is not always apparent how children's rights are recognized in child research ethics and that the rights of the child, as enshrined in the UNCRC need to be translated into workable research ethics[75]. Consequently, Some researchers have pointed out that one should be careful to assume

---

[68] Ghandhi, 2012, p. 98
[69] Ghandhi, 2012, p. 103
[70] Powel et al., 2012, p. 11.
[71] Ennew & Plateau, 2004, p. 1; Laws & Mann, 2004, p. 2; Lundy & McEvoy, 2011, p. 131.
[72] Bell, 2008, p. 9, Bae, 2009, p. 395.
[73] Bell, 2008, p. 9; Ennew & Plateau, 2004, p. 29
[74] CP MERG, 2012, p. 16.
[75] Bell et al., 2008, p.11; Bell, 2008, p. 11.

that their ethical positions will coincide with the law[76], as there is "a close relationship between law and ethics, but not everything that is legal is ethical[77]", for example a state may not have a legal requirement for children's informed consent, but their ethical standards and institutions may have their own ethical guidelines that prescribe following such considerations[78]. However, the relationship between human rights principles, as reflected in international human rights instruments such as the UNCRC, and research ethics guidelines is not always apparent or clearly stated within social science research ethics guidelines[79].

1.2.4 A Virtue-based Approach

This approach emphasizes the role of one's character and the virtues that one's character embodies for determining or evaluating ethical behavior. Virtue ethics is one of the three major approaches to normative ethics, often contrasted to deontological approach i.e. duty based, which emphasizes duty to rules and consequentialism i.e best outcomes, which derives rightness or wrongness from the outcome of the act itself. The virtue approach to ethics assumes that there are certain ideals toward which we should strive, which provide for the full development of our humanity[80]. It is claimed that These ideals are discovered through thoughtful reflection on what kind of people we have the potential to become and are attitudes or character traits that enable us to be and to act in ways that develop our highest potential[81]. They enable us to pursue the ideals we have adopted. Virtues include characteristics such as justice, honesty and truthfulness, kindness, as opposed to vices such as deceit, cowardice and injustice[82]. Suggestively ethical guidelines are not framed based on virtues and vices they play a significant role as to how individuals and researchers in a specific social or cultural context behave and reflect in research processes where "some would argue that a good researcher is someone who strives to be objective and unbiased; others would claim that

---

[76] Bell, 2008. P. 13.
[77] Masson 2004, cited in Powel et al., 2012, p. 12
[78] Ibidem, p. 12.
[79] Bell 2008, p. 13; Lundy & McEvoy, 2011, p. 131.
[80] See: Ethics, available at: http://www.iep.utm.edu/ethics/, retrieved on 19 June 2014.
[81] CP MERG, 2012, p. 16.
[82] Ibidem. p. 16.

a good researcher is someone compassionate, caring and empathic[83]".

The limitations of the virtue-based approach include the lack of universal understanding on what constitutes virtues as definitions of virtues quarrel between and even within societies[84]. On the hindsight it allows for reflection on ethical dilemmas, without reducing ethical discussion or research practice to a set of rules based on codified principles making it a reflexive approach to dealing with ethical issues which will be discussed. What is meant here is that, although the virtue based framework has its limitations it gives leeway for ethical discussion and reflection on ethical dilemmas dependent on the context, researchers are able to recognize characteristics in their personal lives and experiences they have had, and understand and reflect on the issues, assisting in thinking through ethical dilemmas, challenges and solutions.[85].

Concluding remarks on Ethical Frameworks

Hence, which approach is best suited for research with children? Is it right to choose one exclusively or should the approaches be intertwined? These approaches are fundamental and inherent in ethical codes of conducts, guidelines, as well as child protection policies and establish an underlying comprehension of the ethical considerations and issues that researchers face when conducting research. As we have seen all of them have their advantages, disadvantages, and limitations and are overlapping in their respective aspects. Nevertheless, they are noteworthy and essential in the conceptualization of ethical understanding and provide meanings to comprehend the notions of universality of ethical principles vs. the argument for situated ethics. Although guidelines cannot be categorized primarily on ethical approaches it is a starting point to understand the understanding through different ethical understandings. The duty based approach and the best outcomes approach have been suggestively utilized in many medical guidelines which are primarily therapeutic researches, whereas the rights-based and virtue based approaches are at forefront in the ethics of social research literature and understanding as their underlying principles are formulated in

---

[83] Gallagher 2009, p. 12.
[84] Ibidem, p. 12.
[85] CP MERG, 2012, p. 16.

numerous organisations guidelines who conduct research on children which will be pointed out in the latter sections.

1.3   Key Ethical Components and Issues

The key ethical components of guidelines emerging from the review of published literature include consent, protection from harm, privacy and confidentiality, and payment of research participants [86]. It must be noted that these principles are overlapping, influence each other and are dynamic. The following sections are divided into the main ethical components of guidelines and concurrent concerns related to the experiences in different world contexts that are attributed concurrently. Nevertheless, the focus lies in the majority world context, as the following research undertaken was based in Nepal.

1.3.1   Consent and Voluntary Participation

Attaining informed and voluntary consent from children is fundamental to the research relationship which mirrors underlying important ethical considerations and signals respect for the research participant's dignity, their ability to express their views, and their right to have these heard in matters that affect them[87]. The literature suggests that informed consent lies on four notions, that consent includes an explicit act, for instance, a verbal or written agreement, consent can only be given if the participants are informed and have an understanding and conception of the research, consent must be given voluntarily without coercion or force, and consent must be renegotiable so that respondents may withdraw at any stage of the research process.[88]. Furthermore, it has been suggested that it entails three interactions, which are "a two way exchange of information, with the central feature present in all decision making of digesting information, weighing it up in light of personal values, and making and standing by a decision [89] ". The three relations constitute the provision of information by the researcher, the potential participant understanding the information, and then making a

---

[86] Powel et al, 2012, p. 1; Ennew & Plateau, 2004. P. 2.
[87] Ibidem, p. 11.
[88] Gallagher, 2009, cited in Powel et al 2012 p. 13.
[89] Alderson 2002, cited in Powel et al 2012, p. 13.

response to it[90].

Consent involves an explicit act, for instance a verbal or written agreement with the participants that necessarily needs to be confirmed by any participant as they get informed about the research[91]. The written signature of the research participant usually signifies consent, but it has been suggested that in certain situations research staff may carry out the informed consent process verbally[92]. It has been suggested that children must be made aware who else consent is being sought from and in group settings, individual consent must still be obtained.[93] . There have been three ways to including children in research, as unknowing objects of research, aware subjects, and as active participants[94]. In addition to seeking consent from the individual child, "it will be important to seek the support of the broader community, and institutions which care for children[95]".

Researchers are often compelled to seek consent from a range of adult gatekeepers before children are allowed to be approached for researchers[96]. Adult or Ethical gatekeepers are not only caregivers or parents but are institutional gatekeepers for instance ethical review boards, schools, legal guardians, care- homes or orphanages[97]. It has been claimed that there are three levels of gatekeeping, research ethics committees, professionals asked to assist in recruitment, and parents [98]. Its suggested that ethical gatekeepers may guide the researcher on ethical matter, whereas it may also hinder and block research activity as it constructs a, 'Hierarchy of gatekeeping', which may include numerous individuals in the process[99]. Therefore, adult gatekeeping plays a significant role as to how to reach the children and has a positive function, however it has been suggested that this can be controversial when

---

[90] Cocks, 2006, cited in Powel et al, 2012, p. 13.
[91] Shaw et al. 2011, p. 27; Ennew & Plateau, 2004, p. 37; Laws and Mann, 2004, p. 33
[92] Ennew & Plateau, 2004. P. 38.
[93] Shaw et al 2011, p. 3.
[94] Alderson, 2004, p. 100.
[95] Laws & Mann, 2004, p. 33.
[96] Ibidem. p. 33
[97] Hood et al 1996, cited in Powel et al 2012, p.23.
[98] Cashmore, 2006, p. 972.
[99] Powel et al 2012, p. 23.

gatekeepers may end up censuring children and their participation[100]. From one side its been suggested that its important to protect children from harm, however, a strong protectionist discourse denies children the space to express their views and may selectively choose children who are not marginalized or vulnerable for their protection[101]. Furthermore, it is important to note that in some cultural contexts the focus on the individuals, in this case the child is at odds with societal or cultural customs, in which the right to consent is a collective one, involving the wider community or the family and henceforth it is recommended that local consultation is necessary to determine who, other than the child should be approached when the child is to be involved in research[102].

When researching with children, parental consent has been attained in several different ways and constitutes a number of issues. Researches involving children normally require that 'active consent' be obtained from parents, who sign and return a consent form, specifically stating that they give permission for their child to participate[103]. If the consent form is not returned for any reason, the researcher should be unable to include the child in the study. This form of consent is widely accepted by researchers and Ethical review boards (ERB) as it shows that children and parents have intentionally chosen to participate in the research process[104]. Nevertheless, it is argued that there are occasions when parents fail to or forget to return the form although having no intention or objection towards the research, blocking the children's wish to participate or not[105]. One issue regarding parental consent is when research involves sensitive issues where the parents may be directly involved, when research is on child abuse or family violence where the parents or legal guardians may exercise their right to refuse consent in what they see as "best interests" of the child or to protect the privacy of the family and prevent the child to reveal problems within the family[106]. Hence, parents and other adults have an important, positive function in protecting children, but

---

[100] Ibidem. p. 23.
[101] Powel et al 2012, p. 24.
[102] Ennew & Plateau, 2004. P. 47.
[103] CP MERG, 2012, p. 37.
[104] Powel et al., 2012, p. 16.
[105] Carroll-lind et al., 2006, p. 982.
[106] Cashmore, 2006, p. 970.

some may use their power to censor children and young people and may not always have their best interests in mind[107].

Passive consent procedures are when parents are informed of the research and required to respond only if they do not want their child to participate, thus, active dissent and tt is taken to be an affirmative response[108]. Passive consent is viewed as an appropriate approach for studying children's perceptions, especially in sensitive subjects and is in line with participatory rights, as the children's right to express themselves is priority over parents right to privacy[109]. However, it has been suggested that an issue in passive consent procedures is ensuring that parents are actually informed[110]. This type of consent can be compromised when parents don't receive the information, are not able to read or understand the information, or when children don't inform the researcher that the parents denied participation in the research[111]. However, the literature suggests that researcher prefer this consent process because it means that research sample can be dependent on the child's active agreement, and passive agreement of the caregivers[112]. Hence, a non-response from parents lets researchers by-pass adult gatekeeping and increases sample size and privileges children's decision-making and participation rights[113]. Some guidelines advocate the use of 'assent' instead of 'consent'[114]. Assent recognizes that while children might be unable to give legally valid consent for themselves and It removes the reliance on the child demonstrating adult-centric attributes such as maturity, competence and completeness; rather, it accepts the child's state of being[115]", it is important to involve them as much as possible in the decision about whether they would like to participate, or not, in the research and asserting children's assent addresses the principles of autonomy and beneficence.[116]. the advantages of this is that assent carries less weight than informed consent, where

---

[107] CP MERG, 2012, p. 36-37
[108] Carroll-lind et al., 2006, p. 982.
[109] Powel et al., 2012, p. 16.
[110] Cashmore 2006, p. 971.
[111] Ibidem. p. 971.
[112] Carroll-lind et al., 2006 p. 983.
[113] Ibidem, p. 982.
[114] Laws & Mann, 2004, p. 34; Schenk & Wiliamson, 2005, p. 42;
[115] Cocks, 2006, p. 257.
[116] Lambert and Glacken, 2011, p. 787.

children are not seen vulnerable in all aspects[117]. Furthermore, it entails a forum through which the children's willingness to participate can be acknowledged and respected and where, "the researcher to remain constantly vigilant to the responses of the child at all times: it is not something gained at the beginning of the research then put aside[118]", and the researcher needs to attune to the child's communication, consequently moving from the adult centric consent procedures. With respect to assent, a child may refuse to be part of a research even though the parent may have given consent[119].

The discussions in minority world literature about who should be required to give consent, and whether parental consent should be passive or active are subdued to a large degree in countries where accessing parents is a major challenge[120]. The literature suggests that In some contexts there are valid reasons for not gaining parental consent e.g. in the absence of parental support, for instance one researcher claims that In African contexts children may be living separately from parents as a consequence of HIV/AIDS or parents living elsewhere in order to have work[121]. it may not be appropriate to seek parental consent when children are emancipated minors, runaways or living in the street [122]. Furthermore, Practical challenges, including difficulties identifying and locating parents or guardians, skepticism of signing documents, low rates of literacy in which case parents are unable to read the information and make informed consent have also been addressed in the literature several times[123]. In this case it has been argued that research should be guided by the 'best interests' of the child and the involvement of child advocate or who have the same responsibility and power as parents.[124].

Participants in the research need to have adequate Information and understanding of the research as it's a vital element of seeking children's participation in research and there should be an emphasis of 'transparent discussion[125]' with the aim to facilitate a genuine negotiation. Initial information to be shared should indicate that

---

[117] Powel et al., 2012, p. 17
[118] Cocks, 2006, p. 257.
[119] Powel et al, 2012, p. 17.
[120] Ibidem, p. 16.
[121] Abebe, 2009, p.455.
[122] CP MERG 2012, p. 36
[123] Powel et al., 2012, p. 14
[124] Abebe, 2009. p. 455.
[125] Alderson and morrow 2004, p. 100.

the children "are already, or have the potential to be subjects of the research and are able to engage in the process [126]". Therefore, children must be provided that is appropriate for their age and competencies, bearing in mind the differing experiences, evolving capacities and environmental context for each child[127]. Researchers have suggested using information sheets that are viable in the specific context and children's comprehension, including the verbal equivalent of research to the participants stating 'participants rights[128]'. It is proposed that researchers spend time verbally explaining the research to potential participants, to help ensure that there are not mismatches in understanding[129]. Steps should be taken to ensure that children understand the research process and what they have consented to do, for example, by asking children questions one-to-one or asking them to summarise what they have been told[130].

A key topic emphasised in the existing ethics literature is that there may be an expectation of short and long term benefits and advantages to participation that influence parents' and children's consent and participation[131]. To avoid this, parents and children should be provided with information about the research and that researchers should make efforts to ensure that children and participants understand what is involved and what the expectations are, from the participants as well as the researchers[132]. This may involve using strategies to encourage and/or ensure understanding, including providing appropriate information, allowing the child time to consider participation and being "clear about what the research will and will not provide.[133]". One researcher suggested that at the beginning of a research project, many student researchers focus on the gaining and documentation of record of consent, rather than the actual informing process[134].

Furthermore, consent should always be voluntary without coercion[135]. Children

---

[126] Alderson & Morrow, 2011, p. 19.
[127] Laws & Mann, 2004, p. 33.
[128] Ibidem. p. 33; Powel et al, 2012, p. 18
[129] Shaw et al., 2011, p. 2.
[130] Laws & Mann, 2004 p. 31; Ennew & Plateau, 2004. P. 38.
[131] Wendler et al., 2012, p.
[132] Ennew & Plateau, 2004. P. 38.
[133] Shaw et al., 2011, p. 3.
[134] Conroy and Harcourt, 2009, p. 161.
[135] Powel et al, 2012, p. 18.

should not be coerced in anyway to acquire information from researchers or any others involved in the research including caretakers and parents[136]. Moreover, Children should not be coerced in carrying on if they wish to stop, "and do not need to explain why they want to stop - this is their right[137]". It is valid for researchers to refer to potential benefits from research and they may make available payment or a gift but "neither of these should be done in a pressurizing way and it not acceptable to coerce or offer inducements for participation[138]". Furthermore, coercion can exist in different settings e.g. schools, homes, and community, where it has been suggested that compliance with adults and authorities can affect children's participation due to power relations[139]. Researchers have argued that there is a possibility that participants in the research feel they will benefit directly, Researchers must make sure that compensation is not incentive for the participation of the children, and that if compensation of any sort is utilized, that parents and children are informed that their participation or answers to questions will not affect this by any means[140]. Children should have sufficient time to consider the information, reflect on their decision, talk to people about it and have any questions answered before giving their consent[141]. In majority world contexts power disparities are such that children are most often subordinate to adults and there is an emphasis on obedience to and respect for adults children may consent to participate because they want to show respect to adult caretakers or are constrained by power relations in the community[142].

Finally, consent must be renegotiable for participants at all times of the research process as once provisional or initial consent is established, ongoing consent cannot be assumed but should be negotiated in situated contexts[143]. Hence, it has been claimed that the most ethical course of action is to use 'process consent', where consent is

---

[136] Carroll et al, 2006, p. 984.
[137] Laws & Mann, 2004 p. 33; Shaw et al., 2011, p.3.
[138] Bell et al 2008, p. 98.
[139] Powel et al 2012, p. 20.
[140] Ibidem, p. 21.
[141] Shaw et al., 2011, p. 3.
[142] Ahsan, 2009, p. 395; Powel et al., 2012, p. 19.
[143] Powel et al 2012, p. 20; Spriggs, 2010, p. 26.

obtained at every step of the research process, rather than an initial agreement[144]. Suggestively, Research shouldn't continue with children if they are reluctant to go on with their research involvement and behavioural and verbal signs of dissent need to be sensitively observed and attended to by researchers.[145]. Furthermore, Children who are able to verbally dissent may not make an explicit spoken request to withdraw out of situations in which they are uncomfortable[146]. The literature suggests that whenever possible, researchers must engage in ongoing practice of reaffirming the willingness of the children to continue their participation as different research paradigms produce different time periods over which participation may be required[147]. Studies that are placed over many years may significantly change over time. It is argued that if there is any type of change in the research process, this should be discussed with the involved participants and responsible committees and stakeholders[148].

1.3.2 Privacy, Confidentiality and Anonymity

Valuing the privacy and confidentiality of children participating in research engages close reflection of several aspects: privacy with regard to how much information the child wants to reveal or share, and with whom; privacy in the processes of information gathering/data collection and storage that allows the exchange of information to be confidential to those involved; and privacy of the research participants so that they are not identifiable in the publication and dissemination of findings[149]. Privacy considerations in research include both the need to have a safe, private physical location in which the research can take place, and ensuring participants' privacy through confidentiality and anonymity[150]. Suggested in numerous guidelines, confidentiality in research with children can be assured by using anonymity, for example, ensuring that children's survey responses are not linked to their consent forms and thus children are

---

[144] Sime, 2008, p. 21.
[145] Ibidem. p. 21.
[146] Bell et al., 2008, p. 97.
[147] Ibidem, p. 98.
[148] Powel et al., 2012, p. 30.
[149] See: Child-ethics charter, available at http://childethics.com/wp-content/uploads/2013/10/ERIC-compendium-Charter-section-only.pdf retrieved on June 23 2014.
[150] Ennew & Plateau, 2004. P. 47.

not identifiable[151]. Most often, the setting in which research with children takes place is at school or at home, and confidentiality can be compromised in both of these locations through difficulties in finding a private space due to various reasons[152]. Furthermore, guidelines suggest researchers should avoid preventable intrusion into the private lives of the prospective participants and all children and adults should have the right to confidentiality and privacy except if the protection of life and safety is required or legal considerations arise[153].

The location and context of the interview and data gathering make significant implications on ethical issues. Privacy considerations in research include both the need to have a private and safe physical location in which the research can take place and privacy concerning how the participant's identities will be kept protected[154]. It has been suggested that one may not be able to control the environment or offer an appropriate alternative, but the researcher should be aware of the effect the environment can have on the child[155]. For the researcher's own protection, as well as that of the child, it is asserted never to be alone in a house or building with the child[156]. However, If it is a child's wish that a parent or friend be present during research interviews the researcher should agree to this[157]. There are a number of issues when interviewing children in schools where finding a private space may not be possible and where anonymity may be compromised[158].

Interviewing children at home also has its pro's and con's as iterated in the literature in various guidelines and publications[159]. Children may be used to having a voice at home, more so than in school or vice versa, conversely, confidentiality may be difficult to ensure[160]. It has been suggested that interviewing at home can be costly and time consuming and the challenges of interviewing at home include the nature of the

---

[151] Schenk & Wiliamson, 2005, p. 33
[152] Valentine, 1999, p.120; Sime, 2008, p. 67; Yee, 2006, p. 404.
[153] Shaw et al., 2011, p. 33
[154] Powel et al., 2012, p. 25.
[155] Ibidem, p. 15.
[156] Shaw et al., 2011, p. 33
[157] Ibidem, p.3.
[158] Powel et al., 2012, p. 25.
[159] Yee, 2006, p. 404-405.
[160] Powel et al., 2012, p. 25; Abebe, 2009, p. 454. Yee, 2006, p. 405.

environment and interruptions, for example by parent's curiosity and concern for the child[161]. Researchers find that parents, relatives and other children just come and join in the interview, with adults commonly believing that they should participate in children's interviews in order to provide 'correct' answers and they may insist on being present at the interviews which may affect the child's ability to answer certain questions and there can be issues on finding a quiet private setting, without parents or siblings, especially when families living in poverty sleep and live in the same room[162]. Interviewing at home entails that every setting is different and that they cannot be all managed the same way, consequently, "homes need to be considered as complex, unpredictable settings that are likely to configure the nature of the research relationships and of the data collected in every single encounter[163]". However, one researcher managed the difficulty with confidentiality and other people joining interviews by converting them into less private events and conducting them in public spaces, for example, the community market space and tea houses in which children worked. The public setting drew less interest and involvement from others than an attempt at privacy[164].

Information and data gathered through data collection should be securely stored and protected, especially when it is sensitive and that data should be kept separate from identifying information[165]. Suggest by the literature, personal data should be accessible only by those who need to use it, and sensitive data must be kept in a locked room with controlled access, or kept in a locked filing cabinet or a locked drawer, or in password protected computer files and Consideration needs to be given to the transporting and storage of audio or videotapes[166]. Direct identifiers of research participants should be removed or destroyed at the earliest possible opportunity[167]. It has been pointed out that having pictures taken of the children and filming the research has its implications and can compromise confidentiality, privacy and anonymity and researchers should share findings with participants before making them public and seek their consent to plans for

---

[161] Powel et al., 2012, p. 26.
[162] Abebe, 2009, p. 457; Powel et al., 2012, p.26.
[163] Sime, 2008, p. 76.
[164] Abebe, 2009 p. 456.
[165] Bell et al., 2008, p.97; Ennew & Plateau, 2004. p.167; Laws & Mann, 2004 p. 37.
[166] Laws & Mann, 2004 p. 37.
[167] Ennew & Plateau, 2004. p.41; Shaw et al., 2011, p. 3.

distributing publications or communication information, especially photos and video recordings[168]. It is suggested that Researchers are to discuss issues with children about maintaining confidentiality, especially in assessing the risk in using potentially identifying material in reports[169].

One key issue in the literature is the dilemma around the limits of confidentiality in the light of disclosure of abuse and harm or in cases of public safety, for example when a participant discloses having committed a crime or being about to commit a crime[170]. Furthermore, It is suggested that there are divergent opinions and practice about breaching confidentiality to report suspected child abuse[171]. It is proposed that researchers may often feel a moral duty to disclose information when the child or participant is perceived as being at risk of harm. Here, the literature notes that researchers should think though the circumstances in which they feel they need to break confidentiality and alert participants as part of the consent process[172]. Researchers are advised to inform potential participants of this during the consent procedure, and have a planned strategy in place if needed[173]. Hence, they need to make it clear that if someone's health or life is at stake, they should report it. For example, privacy is particularly important when the research study is exploring children's issues related to HIV/AIDS because of the social stigmatization and secrecy attached to it[174]. Suggestively, Identifiable information in the publication and dissemination of findings should be avoided, and the use of anonymity or pseudonyms should be used, especially when it comes down to sensitive studies[175]. It has been suggested that it is common practice for researchers to encourage the child to talk to appropriate adults, if they disclose abuse, or agree to the researcher doing so[176]. Hence, the literature suggests that some researchers would breach confidentiality even if the child did not agree to further

---

[168] Ennew & Plateau, 2004. P. 212-213; Schenk & Williamson, 2005, p. 55.
[169] Laws & Mann, 2004, p. 37; Schenk & Williamson, 2005, p. 33.
[170] CP MERG, 2012, p. 45.
[171] Wiles et al, 2014 p. 419; Cashmore, 2006, p. 973.
[172] Alderson and Morrow 2011 p.20.
[173] Schenk & Williamson, 2005, p. 12.
[174] Abebe, 2009, p. 455.
[175] Ennew & Plateau, 2004. P.41; Schenk &Williamson, 2005 p. 32; Shaw et al., 2011, p. 33
[176] Ennew & Plateau, 2004. P. 248; Schenk &Williamson, 2005 p. 36; Laws & Mann, 2004, p. 9-10.

disclosure, and specify this clearly before the interview and others believe that disclosure of abuse should not occur until the child consents, following a discussion[177]. Nevertheless, one researcher claims that reporting suspected abuse and neglect is the just thing to do[178]".

It has been argued that it is at the stage of dissemination that some researchers see the greatest potential for harm in research with vulnerable populations such as children who live or work on the streets[179]. Issues and breaches of confidentiality may occur after participating in the research to the families, communities, and the children when reporting the findings and dissemination of the findings as dissemination may result in misrepresentation[180]. Suggestively, ways of minimizing this potential harm is through maintaining privacy regarding the identities of the individuals, families and communities[181].

1.3.3   Protection of Children: Harms and Benefits

Researchers are responsible for protecting children from any "physical, social or emotional harm that might arise from the research[182]". Risks in social research are more likely to include "distress and anxiety, embarrassment and loss of self esteem[183]". Therefore, it has been suggested that researchers should do everything necessary to predict any adverse consequences and guarantee that participation will lead to no harm and that there are measures taken to minimize any potential harm through the use of benefit and harm analysis[184]. Furthermore, it has been established that, "Children should be protected from both over-research and under-research[185]". Hence, suggestively researchers should make sure the intended research has necessary outcomes as harm can occur in researches both qualitative or quantitative in nature, and take several forms, arising from different sources and shaped by the specific research

---

[177] CP MERG, 2012, p. 45.
[178] Fisher, 2009, p. 25.
[179] Young and Barret, 2001, p. 132.
[180] Ennew & Plateau, 2004, p. 165.
[181] Schenk and Williamson, 2005, p. 13.
[182] Laws & Mann, 2004, p. 29.
[183] Alderson & Morrow, 2011, p. 27, Ennew & Plateau, 2004. p. 38.
[184] Bell et al., 2008, p. 95.
[185] Alderson & Morrow, 2011 p.19.

topic, participants, methods and methodology used, and local setting[186]. Guidelines on harms and benefits in research involving children include significant emphasis on the researchers responsibilities to protect children from harm, during, and after the research processes, and puts significant emphasis on vulnerable children [187]. The literature highlights that harm can occur at any given time in the research, up to after the research when the findings are disseminated as children may reveal harm or safety issues while participating in the research, during the research, and after the research [188]. The researchers need to balance the desire to protect the respondents from the potential harms of the research, while allowing them to benefit from the results.[189].

Participation in research should have positive benefits for children in addition to not harming them where benefits can be hard to define and assess, and causality difficult to determine, with some benefits not being known until long after the research has happened [190]. The benefits can be to individual participants or to the wider community. These however, normally tend to be future orientated and comply with the best-outcomes framework where children do not personally benefit from the outcomes of their participation although there are significant other gains for other children[191]. A benefit for children may be learning the findings of the study, which requires the researchers to follow up and provide the information and findings in a language and style they understand[192]. Benefits can take several forms, for example, the children knowing that their views and experiences are taken into consideration, the experience of the research process itself, when the "activities are joyful, educational and educational services, direct political or economic betterment, referral to therapeutic services and opportunity to access resources[193]".

It is argued that the right recruitment methods and selection criteria's enforce

---

[186] See Section: Harms and Benefits in "Child Ethics Charter", available at http://childethics.com/wp-content/uploads/2013/10/ERIC-compendium-Charter-section-only.pdf, retrieved on June 20 2014
[187] Shaw et al., 2011, p. 34
[188] ERIC Compendium, 2013, p. 37.
[189] Powel et al, 2012, p. 23.
[190] ERIC Compendium, 2013, p. 34.
[191] Ibidem, p. 34.
[192] Ennew & Plateau, 2004, p. 38; Powel et al, 2012, p. 33.
[193] Powel et al., 2012, p. 23.

beneficence for all children and reduce harms for marginalized ones[194]. Consequently, It is suggested that research involving children should be equitable and non-discriminatory. The principle of justice entails that research should be inclusive of children without discrimination on the basis of gender, ethnicity, disability, age, language, geographic location or any other individual or social characteristics[195]. Certain children like street children, children with disabilities, children in child labour, gay and transgender children are typically left out from participation as these children are normally more difficult to find and reach and perceived as more difficult to engage in certain researches[196]. Researchers have pointed out that excluding children vulnerable children from researches are aimed at protecting them from abuse and avoiding complexities, but this leads to the opposite where their voices are unheard and exclusion is not defensive in terms of equity, justice and beneficence.[197]. However, in addition to not excluding children from researches, the literature suggests that there is a need for more researching involving specific vulnerable or marginalized groups, which need to be handled sensitively and further iterates that the principle of inclusivity is advocated[198].

The most fundamental initial consideration in undertaking research involving children is deciding whether the research actually needs to be created and children need to be included as there should be clear and justifiable reasons why children are being included in the research, with researchers able to substantiate that the information is not readily available elsewhere.[199]. Deciding whether children should be part of the research and their involvement entails reflection on the part of researchers, institutions, funding agencies and other key stakeholders in the initial phases of data planning and accordingly, at the very beginning of the research process researchers need to engage with critical issues regarding the purpose of the research and the impact that participating in the research may have on children in terms of potential harm and possible benefits and researchers must make sure that they have understood the

---

[194] Shaw et al., 2011, p. 37
[195] Bell et al., 2008, p.96.
[196] ERIC Compendium, 2013, p. 38.
[197] Bell et al., 2008, p.96.
[198] Ibidem. p. 96.
[199] ERIC Compendium, 2013, p. 30.

secondary sources and knowledge gained from the literature and should have clear reasons for including children in the research.[200].

Children may reveal harm and safety issues while participating in the research, especially when dealing with sensitive issues, including neglect or child abuse, or researchers may suspect that children or others are at risk and need protection. A key concern is that children may be re-traumatized due to the research process, where it is suggested to refer participants to appropriate services and resources[201] and the use of debriefing between researchers[202]. It is the researcher's responsibility to protect children from putting themselves at risk and to intervene when a child is at risk[203]. It is claimed that the duty of researchers to protect the safety of children overrides their responsibility to guarantee confidentiality[204]. Furthermore, it is suggested that researchers have a responsibility to ensure that children are not in jeopardy when members of the community or any key-stakeholders are consulted[205]. Concerns about children's safety can be raised in many research, but are most often an issue in sensitive researches which involve vulnerable children[206], this may include research with street children, on violence against children, commercial sexual exploitation of children or in sensitive environments such as humanitarian emergencies and conflict situations[207]". This needs sensitive and immediate response and follow ups in which support or referral is mediated to appropriate services as research should be conducted in settings in which the child and parent can obtain adequate medical and psychological support[208]. However, it is argued that in many contexts there is a lack of these kinds of support, and services to report safety concerns to.[209].

The skill of researchers is paramount in dealing with situations that involve balancing risks and benefits of actions and the need for risk assessments has been

---

[200] Ibidem. p. 31;
[201] Powel et al., 2012, p. 23.
[202] ERIC Compendium, 2013, p. 35.
[203] Ennew & Plateau, 2004, p. 38; Einarsdóttir, 2007, p. 206; Flewit, 2005, p. 539.
[204] ERIC Compendium, 2013, p. 35.
[205] Ibidem, p. 36
[206] Powel et al 2011, p. 22.
[207] Ibidem. p. 23.
[208] Laws & Mann, 2004 p.29; Ennew & Plateau, 2004, p. 38; Shaw et al., 2011, p. 34
[209] ERIC Compendium, 2013, p. 35.

highlighted in the literature as, "researchers must always consider how the research is affecting participants and continually monitor any unforeseen or anticipated consequences of the process.[210]". However it is important to note that there have been cases where children were harmed through abusive and incompetent researchers, and other individuals in the research setting e.g. interpreters, drivers and support staff[211]. The ethical guidance literature also addresses the matter of protecting children from the abusive actions or poor practice of research staff and other professionals. Some ethical guidelines recommend adopting, or do adopt, a child protection policy and/or an ethical code of conduct for researchers[212] which state that research staff should avoid actions or behaviour that may be construed as poor practice or potentially abusive[213]. Child protection policies, provide clear guidelines for managing concerns about child protection, and conduct codes incorporate guidelines for recruitment, training and ongoing conduct of staff[214].

Harms can occur after disseminating the findings. There is possibility that misperceptions may be perpetuated by the media in reporting research findings and it is argued that researchers should maintain and strive to ensure the research is reported accurately, and not misrepresentative or discriminatory to children's voices, experiences or circumstances[215]. Stigma and stereotypes may occur through research that is poorly designed, biased and politically driven researches, which reveal stigmatizing information[216]. Exploitation of children's views and experiences may be driven for headline grabbing researches. Although research methods cannot be objective or apolitical, researchers should strive to maintain professional standards and integrity on behalf of the children. Another harm that can be caused to communities and groups are policies, which are recommended by researchers or the findings that may be used to support policies that may be damaging or ineffective[217]. Although researchers do not

---

[210] Bell et al., 2008, p. 97.
[211] ERIC Compendium, 2013, p. 35.
[212] Laws & Mann, 2004 p. 40.
[213] Ibidem. p. 41; Ennew & Plateau, 2004, p. 39.
[214] Ennew & Plateau, 2004, p. 40.
[215] Ibidem. p. 164.
[216] ERIC Compendium, 2013, p. 32.
[217] Ibidem, p. 33.

normally have the position to affect policies after the dissemination of their findings, the ways in which the information may be used to implement policies may be damaging for the child, the communities and groups through the policies adopted due to the research[218].

1.3.4   Compensation and Payment

Four types of payments have been identified in research: reimbursement, compensation, appreciation and incentive[219]. Nevertheless, there is no clear consensus in the literature whether children should be paid for participation and what kinds of rewards are appropriate[220]. Furthermore, when children are involved in research "The recipient of the incentive may be the child, the parent, guardian, or others who control access to the child, such as teachers, nurses, physicians, schools or clinics [221]". Incentives are influenced by many factors, for example the development level of the child, type of research, duration of the study, the socio-economical status of the participants, and as suggested, the gatekeepers and mechanisms in place[222].

Reimbursement payments compensate children and parents for their direct expenses related to participation for example transportation, accommodation and meals[223]. Compensation provides recompense to children and/or to parents for their time, work and effort and for any inconvenience when participating in the research. Here, children or parents may be recompensed for the loss of income while participating in the research as the principle of non-maleficence gives researchers the obligation to ensure that potential harms like lost income are minimized or eliminated [224]. Appreciation payments are tokens or bonuses given to children after the completion of their participation to acknowledge their contribution to the research and to thank them. This may take form monetarily, or with gifts, vouchers, books etc[225]. However, it has been suggested that this way of compensation may put hopes in the future projects and

---

[218] Ibidem. p. 33.
[219] Wendler et al, 2002 p. 167; Spriggs, 2010, p. 12.
[220] Powel et al., 2012, p. 29.
[221] Rice and Broome, 2004, p. 168.
[222] Ibidem. 169-170.
[223] Wendler et al, 2002, p. 167.
[224] Spellecy et al., 2008, p. 202.
[225] Wendler et al, 2002, p. 167.

work and does create an incentive, on the grounds that children will attempt to be interviewed several times by different researchers to gain benefits each time, and in the context of drug use or hunger, this can be a form of inducement or coercion[226]. It has been suggested that offering incentives is best avoided, as it may influence participation and constitute persuasion or pressure on participants potentially create a sense of obligation, raise expectations or become a form of control[227]. The literature explicates that payment or compensation to participants should be linked to their attendance and involvement in the research study and independent of their responses and behaviour during the process, including the decision to stop participation or not answer certain questions[228]. Any financial dealings in the research context change relationships and impact on the power disparities already at concern[229]. Incentive payments deliberately encourage the participation of children in research, which varies from cash payments to other alternatives such as vouchers and travel and reimbursement costs[230]. Some organizations' guidelines generally advise against financial payment for research participation, mostly due to concerns regarding incentives[231].

Other forms of compensation may be more appropriate or appreciated, including non material forms of compensation that benefit the child and which we outlined previously, for example having an enjoyable social experience and networking, children knowing that their views and opinions are listened to, gaining education and educational resources and learning transferable skills[232]. Suggestively, a number of guidelines state that researchers are advised to be transparent about payment or remuneration to avoid stimulating tensions as the timing of disclosing is vital for the recruitment of individuals in the research and should be made as part of the research plan[233]. However, some researchers may not choose to let the participants know about

---

[226] Powel et al., 2012, p. 35.
[227] Ennew & Plateau, 2004, p. 40; Laws & Mann, 2004 p. 38;
[228] Schenk & Williamson, 2005, p. 51.
[229] Wendler et al, 2002 p. 167.
[230] Ibidem. p. 167.
[231] Edmonds, 2005, p. 13; Ennew & Plateau, 2004, p. 40; Schenk and Williamson, 2005, p. 51.
[232] Ennew & Plateau, 2004, p. 40; Laws & Mann, 2004 p. 39; Shaw et al., 2011, p. 5-6.
[233] Ennew & Plateau, 2004, p. 40.

the compensation and give it after the data collection has been completed[234]. They argue that delaying disclosure can help to reduce the event of children trying to please the researcher by telling them what they want to hear. However, it is argued that any payment or compensation should be decided in advance, prior to recruiting participants and discussed during the consent process[235].

Researchers have mentioned that compensation is seen as necessary compensation for the time in which participants would otherwise have been earning money and are income-generating children[236]. In countries where children are income-generating individuals, taking part in a research may find a loss and the child is taken away to participate in the wellbeing of the family and the research takes them away from work[237]. In this case it has been suggested that participants are required to be compensated accordingly to minimum wage rates[238]. On the contrary, some researchers identified that it is more ethical when faced with participant's poverty to help out with small amounts of cash for basic necessities[239]. Nevertheless, it has been further suggested, that in decision making regarding compensations to participants, that researchers look into the importance of local context and consult with local and national stakeholders, whether payments should benefit communities, rather than payment to individual research participants and consideration of people's livelihoods and local living standards in determining the payment, with a particular awareness of situations of poverty and disadvantage[240].

Some guidelines outline the pros and cons of providing incentives for participation in research. Arguments in favour of incentives for respondents include that it can increase participation levels, especially in poor communities, accelerate recruitment and hence save time and resources, recognise the value of respondents' time and contribution; and prevent bias by helping to ensure poor people are not prevented from participating. Arguments against providing incentives to respondents include the

---

[234] Sime, 2008, p. 69.
[235] Ennew & Plateau, 2004 p. 40.
[236] CP MERG, 2012, p. 47.
[237] Powel et al., 2012, p. 30.
[238] Rice and Broome, 204, p. 168.
[239] Abebe, 2009, p. 455.
[240] Edmonds, 2005 p. 13.

cost involved, the possibility of compromising voluntary consent by creating a sense of obligation, the possibility of sample bias through encouraging those who want recompense to participate and possibly say what they think the researcher wants to hear, and it can create expectations of recompense for participation in research in the future. Furthermore, in the contexts of extreme poverty there may be resentment against children who participate in research, which may cause harm to the child.[241]

Addressing compensation in locally specific ways requires researchers to reflect on cultural contexts and understand the nature and value of people and children's time in their willingness to undertake research activities[242]. Children's participation should be recognised and recompensed, in line with local living standards, cultural and socio-cultural factors, and their contribution and the livelihoods of research participants should not be adversely affected by their participation in research [243]. Therefore it is necessary for researchers to consult with local communities through 'avenues of consultation' which consequently opens dialogue between researchers and their counterparts, opens a transparent environment, and facilitates and improves interpretation and disseminations of findings. Hence, suggestively, the nature of payment and compensation should be determined by local consultation or national-level consideration with selected stakeholders as local context influences perceptions of research payment and incentives[244]. It may be appropriate to give payment to the community as a whole for the benefit of the children involved in the research[245]. If so, this should be discussed with broad representation of community members and stakeholders to ensure fair distribution[246]. Furthermore, Other issues highlighted in the literature is that offers of payment also raise ethical concerns then, when they have the potential to distort parents' decision-making; the opportunity for financial gain may lead parents to agree to research enrollment they otherwise would have opposed as contrary to their children's interests[247]. Research enrollment decisions are inherently complex,

---

[241] CP MERG, 2012, p. 47; Laws & Mann, 2004 p. 39, Shaw et al., 2011, p. 20.
[242] CP MERG, 2012, p. 28.
[243] Laws & Mann, 2004 p. 40.
[244] Edmonds, 2005 p. 13.
[245] CP MERG, 2012, p. 13.
[246] Schenk and Williamson, 2005, p. 51
[247] Rice and Broome, 2004, p. 170

and the offer of payment may lead parents to unconsciously inflate the benefits and/or minimize the risks of their children's research participation. This possibility seems especially worrisome in the context of pediatric research because the primary decision makers, typically the child's parents, may benefit financially without having to face the risks. Another argument against offering inducements and rewards was that children might attempt to be interviewed several times for the benefits of research[248].

1.3.5   Childrens Participation, Methodologies and Methods

Ethically sound techniques are argued as adding to the value of research and contrariwise, methodological soundness can improve research ethics, hence methodology and ethics are integrally linked[249]. Methodologies provide the philosophy, theory and traditions that frame the research and evolve over time and determine methods used in practice[250]. Consequently, the method is the technique or tool, a component of research, for example a qualitative methods such as interviews, focus group discussion, drawings, play, photography, and other activities[251]. Evidently, the literature suggests that numerous guidelines and researchers have suggested that participatory methods improve gathering of information[252]. Nonetheless, research with children has been governed by observational methodologies, usually in the context of psychological and medical research and researchers researched 'on' children rather than 'with' them[253]. Until recently, researchers working with children often did not view them as capable, competent, responsible people who are able to contribute ideas and knowledge to researchers where children were largely understood as incompetent and developing 'becoming-adults[254]'. Where traditional social research has marginalized and silenced children's perspectives participatory techniques are offered as an emancipatory alternative to passive, observer orientated researches[255]. Social

---

[248] Powel et al., 2012, p. 35.
[249] Ibidem, p. 37.
[250] Ibidem, p. 37
[251] Einarsdóttir, 2007, p. 199.
[252] Schenk & Williamson, 2005, p. 5; Ennew & Plateau, 2004, p. 30-31; Einarsdóttir, 2007, p. 207.
[253] Conroy and Harcourt, 2009, p. 160.
[254] Ibidem. p. 161.
[255] Hutz and Koller, cited in Powel et al., 2012, p. 37.

researchers are increasingly acknowledging the importance of understanding children's perspectives as these may differ from, and be more sophisticated than, accounts based on what adults think children think[256]. Children are seen as social actors and agents as it is recognised that young people are agentic in making their own socio-spatial worlds, as well as being impacted upon by them. Children's agency and autonomy is vital in defining the theoretical framework and methodology, where children are regarded as competent social actors who are experts in their own lives. Suggestively, participation has become both an aim and a tool in an ethical quest towards 'empowering' children[257].

The participatory researcher becomes a facilitator whose responsibility is not to produce knowledge, but rather to help participants to produce knowledge about themselves and in participatory research, both researchers and those researched are recognised as active participants in the research process. This approach to research also seeks to address some of the power imbalances between the researcher and the researched, which can be compounded for children by the adult–child dynamic[258]. Researchers argue that the use of participatory methods, with children playing a more active role, can enhance the ethical acceptability of research with children and young people and its validity[259]. The strength of using participatory approaches lies in the fact that researchers will be able to gain access to children and bring their problems to public notice and childhood researchers have experimented with a range of 'child-friendly' methods, designed to make research 'fun' and 'relevant' to children to do this[260]. Childhood and conceptions of it is constantly evolving and changing as they adapt to various contexts and constraints as there are multiple childhoods that are different in different cultures, contexts, time and space[261].

There are many ways in which children can be more actively involved in research, both as respondents and as co-researchers[262]. The literature suggests that

---

[256] Gallacher and Gallagher, 2008, p. 500.
[257] Ibidem, p. 501.
[258] Powel et al., 2012, p. 41-42.
[259] Einarsdóttir, 2007, p. 206.
[260] Einarsdóttir, 2007, p. 200.
[261] Ibidem. p. 200.
[262] Powel et al., 2012, p. 40.

children's participation in research appears to be fairly broadly conceptualized, and four central forms can be recognized. First, some research appears to be described as participatory simply because children or young people are invited to be participants, but where all other aspects of the research have been designed and directed by the researcher. This has been categorized as 'passive' participation where children are considered to be objects acted on by others whereby knowledge is generated largely from parents, teachers and other adult caretakers. [263] . Second, others aim to enable children's views to be expressed through 'child-centred' forms of communication such as play, art, drama, games and photography and this form of participation has taken the form of 'active participation[264]'. Third, researchers involve children in research about aspects of their own lives and encourage participants to have some impact on aspects of the research process, such as research design, analysis or dissemination[265]. Fourth, some researchers or organisations train children in formal social research methods, in order for them to carry out research into other people's lives, concerning topics that they have identified as of interest to them.[266]. Furthermore, we will look at the specific ways children have participated in researches and what the guidelines suggest about participation of children by initially looking at the methods utilized.

Interviews and questionnaires in one form or another, together with observations, have been the most common method used in research with children and are considered to passively engage children's participation[267]. Two common ways of interviewing children is through focus group discussions or group interviews, and individual interviews or questionnaires[268]. A focus group discussion is a form of qualitative research in which groups of participants are asked about their perceptions, beliefs, opinions and attitudes towards the research topic[269]. Questions are asked in an interactive group setting where participants are free to discuss and talk with other group members where children are initially asked questions in a group and if they wish they

---

[263] Hampshire et al., 2012, p. 220.
[264] Conroy and Harcourt, 2009, p. 160.
[265] Thomas, 2007, p. 204.
[266] Hampshire et al., 2012, p. 222.
[267] Gallacher and Gallagher 2008, p. 505; Einarsdóttir, 2007, p. 199.
[268] Einarsdóttir, 2007, p. 200.
[269] Ibidem. p. 200.

can speak individually to a researcher about their experiences. Guidelines suggest that when conducting Individual qualitative interviews and addressing very sensitive or traumatic issues in interviews with children, it has been suggested to de-personalize questions or postulate scenarios as a prompt for discussion and consequently props can be useful, for example, asking the child to give advice to a doll or a puppet[270]. Suggestively, posing demands in the third person can also avoid the risk of children looking for a 'right' answer or feeling inclined by direct questioning[271]. Its suggested that paired or triad interviews may alleviate some of the power imbalance when adults are interviewing children, it can be beneficial to conduct these forms of interviews with children who already know each other well[272], it is important to consider the focus of the research as it may not be suitable if you need to collect detailed or sensitive information at an individual level and for some studies it may be necessary to ask children directly about their own experiences, in which case this needs to be approached sensitively[273].

Active' participatory methods are those through which children 'become actively involved rather than passively responding'. It implies "both an intentionality (a conscious will) and a performativity (doing something)[274]". As well as being intentional, it involves action. In recent years, many exciting and innovative methods have been used to engage with children in research. The literature emphasizes the value of methods in which children produce data through practical activities, rather than simply talking or filling in surveys[275]. These methods focus on child participation and are developed in such a way that they include a wide range of methods to facilitate the incorporation of children's perspectives for example the use of drawing, photography, video, conversations, tours, plays and construction play as means for children to actively engage in research processes[276]. In working with preschool children, some researchers have argued that researchers should attempt to engage the myriad symbolic

---

[270] Shaw et al., 2011, p. 21.
[271] Einarsdóttir, 2007, p. 201; Shaw et al., 2011, p. 21
[272] Laws and Mann, 2004, p. 30; Shaw et al., 2011, p. 21.
[273] Schenk & Williamson, 2005 p. 6.
[274] Gallacher and Gallagher 2008, p. 504.
[275] Einarsdóttir, 2007, p. 206.
[276] Ibidem, p. 200.

languages through which children represent and communicate their experiences[277]. They advocate a 'mosaic' of techniques combining the visual with the verbal which encourages the use of a diverse range of data collection techniques such as mapping exercises, child-led tours, and role play exercises[278]. Others have sought to engage more senses, engaging with children in various embodied and performative ways such as using children's drawings that added children's interpretations[279]. Other researchers have advocated the use of "activities such as collage, model-making, story-telling, print journalism and electronic publishing, radio production, drama, puppetry, music and dance[280]". Furthermore, child-led photography has been used in a number of studies[281]. Furthermore, it was claimed that with older children, active participatory methods are often designed to capitalize upon their emerging writing skills, involving worksheets, diaries, story-writing or spider diagrams [282]. One researcher used child-directed photography to discover what the preschool children in her class respected in their outdoor play area. However, the data she used in her paper came not from the photographs alone, but from the discussions she had with the children and it is claimed that, "The success of research with young children lies in the watching, listening, reflecting and engaging in conversation; seeking to enter the child's world in just a small way[283]". Hence, here we can see how even participatory methods are not an ends in themselves for children's empowerment, but need further reflection between the researcher and the researched[284].

It has been suggested that there are number of benefits children as well as researchers and society can gain when children are involved in research processes through participatory methods[285]. Research that makes the most of children's abilities, and treats them with respect, can provide children with opportunities that bring

---

[277] Clark and Moss, 2001, cited in Gallacher and Gallagher 2008, p. 506.
[278] Gallacher and Gallagher 2008p. 506.
[279] Einarsdóttir, 2007, p. 201, Gallacher and Gallagher 2008, p. 506.
[280] Gallacher and Gallagher 2008, p. 501.
[281] Einarsdóttir, 2007, p. 201.
[282] Ibidem, p. 200-203.
[283] Greenfield (2004), cited in Gallacher and Gallagher 2008, p. 506.
[284] Laws and Mann, 2004, p.10.
[285] Shaw et al, 2011, p. 5-6.

significant improvements in their own wellbeing[286]. Perhaps the most important one is that it is their right to participate in researches and their voices can be heard[287]. Furthermore, active participation in particular, help to challenge the silence surrounding much violence against children, and the stigma that can attach to those who have experienced it. It has been suggested a participative approach helps overcome fear and builds skills to resist exploitation, improves their critical thinking skills, and teaches them how to access information, increasing their self confidence[288]. Equally, In relation to traumatic events, the process of involvement, if undertaken in a supportive and understanding environment, can help children to explore past experiences and regain confidence for the future[289]. Providing choices can set up 'opportunities for children to express themselves in a way that makes them feel empowered and capable[290]'. Furthermore, providing choices acknowledges diverse interests the children have by providing different ways to participate in the activities, and due to this diverse use of methods, new methods are developed to promote children's participation, avoiding uninteresting, tedious repetitions for children and for researchers. It is argued that participatory methods are more ethically acceptable than traditional methods and that "participatory methods generate 'better' knowledge than other techniques and that these methods are seen as producing more 'authentic' knowledge about children's subjective realities.[291]" as it helps focus the research, and clarify the analysis and the interpretation of data[292]. Obtaining data from children themselves increases the possibility of presenting a picture that is freer of adult interpretations. Furthermore it is beneficial to society, as it involves learning the skills of co-operation e.g. how to negotiate with your peers, collective problem-solving and respecting other people's points of view and contributes to intergenerational communication[293].

Some researchers argue that, "participatory methods are no less problematic, or

---

[286] Shaw et al, 2011, p. 4-5.; Ennew & Plateau, 2004 p.30; Laws and Mann, 2004, p.10; Schenk & Williamson, 2005, p. 5.
[287] Ennew & Plateau, 2004, p.30.
[288] Shaw et al, 2011, p. 5-6; Laws & Mann, 2004 p. 11.
[289] Laws & Mann, 2004 p. 11.
[290] Ibidem. p. 11.
[291] Cahill, 2000, cited in Gallacher and Gallagher 2008, p. 501.
[292] Laws and Mann, 2004, p.13.
[293] Ibidem, p. 14.

ethically ambiguous, than any other research method[294]", and that critical examination and reflection of participation and participatory methods is necessary. Whilst participatory approaches are increasingly commonplace in data collection, children's involvement in the planning, analysis and dissemination of research is usually more limited to passive methods of participation. For example, even when considering active participatory methods it must be noted that they do not necessarily actively encourage children's participation. Even when acknowledging participatory research a number of researchers present a challenge to the perhaps too convenient assumptions in childhood and social work research that imply, at times, that participatory research is indisputably the right way, even better than other methods of research and they put to question and debate that researchers in fact still manage and construct participatory methods such as active participatory methods, for example, when conducting the active participatory method of taking photographs or drawing pictures, researchers instruct the children what and how to take the research[295]. Hence, without aid and encouragement from adult-designed 'participatory methods', children cannot fully exercise their 'agency' in research encounters. Therefore, claiming that participatory methods are empowering is contradictive in this way, and advocates of 'participatory methods' risk spreading the very model that they purport to oppose[296]. Hence the use of reflexivity and training is signified in the literature as a means to overcome the power relations and issues that arise in research practices and will be discussed in the following section.

1.3.6   Power disparities, Research Training, and Reflexivity

Power disparities and issues have been widely recognized as one of the biggest ethical obstacles and challenges to researchers including children in research as power is considered as something that adults have more than children[297]. Power differentials between the adult researcher and the children may come forth at all levels of planning the project or research, from initial planning of which tools and methods to use, through data collection, as well as in data analysis and interpretation, when the researcher has

---

[294] Young and Barret, 2001, p. 513.
[295] Gallacher and Gallagher, 2008, p.507.
[296] Ibidem, p. 507
[297] CP MERG, 2012, p. 49; Powel et al., 2012, p. 41-42; Gallagher, 2008, p. 142-144; Holland et al, 2010, p. 363.

actually left the field and where often specialised theoretical knowledge is required[298]. It is argued; the researchers are powerful, since they determine the aims, methods, the data collected and the knowledge produced[299]. Furthermore, the cultural context impact on children's autonomy and their expressions of willingness to participate, or to decline participation. Suggestively, The participants being studied, who are often already marginal by their race, class, ability, age, socio-economic status and so on, find themselves further marginalized by their exclusion from the process of knowledge-production[300]. For researchers, the power to interpret the empirical material and represent children's lives in abstract terms is something that is generally unavailable to them, indicating how knowledge becomes a source of inequality, difference and power and hence, it has been suggested that researchers use different techniques to minimize unequal power relations by using participatory techniques[301].

It has been suggested that this discussion on power relations and disparities must be extended beyond the actual fieldwork experience. Issues of representation and power imbalances are particularly apparent in relation to interpreting and disseminating research findings[302]. Some researchers attempt to include children and young people in the data analysis and interpretation phase as a means of addressing this issue, whereas, others suggest sending the data interpretation to young people for their input[303]. Researchers and guidelines also emphasise the importance of ensuring that research participants are provided with a research report, specifically designed for children and young people, at the completion of the project[304]. Power relations between adults and children means that it can be difficult to ascertain that children's consent is given freely and voluntary. Hence, "children's consent must be seen in the context of constraints, obligations and expectations over which researchers have little control[305]" strong expectations regarding obedience of children to adults impact on the child's decision

---

[298] Schäfer & Yarwood, 2008, p. 132.
[299] Gallagher, 2008, p. 142; CP MERG, 2012, p. 49.
[300] Schäfer & Yarwood, 2008, p. 132.
[301] Lambert et al, 2013, p. 609.
[302] Powel et al., 2012, p. 42.
[303] Schäfer & Yarwood, 2008, p. 122.
[304] Ennew & Plateau, 2004 p. 38.
[305] Gallagher et al, 2010, p.479.

making, where it may be due to power relations in the community or when consent can be affected by wanting to show respect for the elders or adult care takers. Traditions and strong cultural standards may exist which the researcher is not aware of, for example hospitality in some cultures may affect research relationships, where people may feel obliged to participate and fail to decline.[306] Researchers suggest that using methods which are non-invasive, non-confrontational and participatory, and which encourage children to interpret their own data might be one step towards diminishing the ethical problems of imbalanced power relationships between researcher and researched[307], Researchers have suggested and debated various researcher roles such as non-authoritarian adult, friend, least adult, and observer, in facilitating children's authentic participation[308]. Furthermore, it is argued that to minimize these power disparities, participatory methods of research should be advocated, which will be discussed in the following sections.

Children may be harmed during research by abusive or incompetent and there researchers need to be aware that adults with abusive intentions may use research as a means to gain access to the children[309]. On the contrary to intentional harm, unintentional harm or abuse through researchers incompetence or poor practice may lead to various problems. What we mean by incompetency is the lack of sufficient knowledge or not applying principles and knowledge adequately. Furthermore, lack of skills in research design and methodology, lack of integrity and dignity, cultural awareness, perception and insight, sensitivity, understanding of language, all can compromise beneficence and contribute to harm and issues in research[310]. This may not directly be the researcher, but could be their support staff, for example, people hired in the community as interpreters, drivers, and others who have not received any training on research procedures, especially research ethics[311]. Consequently, It has been recommended to implement a staff code of conduct specifying appropriate behavior, creating procedures for reporting suspected abuse by research staff, and providing

---

[306] Abebe, 2009, p. 458; Nyambedha, 2008, p. 776.
[307] Schäfer & Yarwood, 2008, p. 122.
[308] Einarsdóttir, 2007, p. 199.
[309] ERIC Compendium, 2013, p. 35.
[310] Ibidem. p. 35.
[311] Ibidem. p. 35.

ongoing training on ethical issues to staff. A number of ethical guidelines address researcher safety with reference to strategies, protocols and researcher training and that safety for research staff is essential and should be placed above completion of the research tasks at all times[312]. Researcher safety can be attended to with security plans, back up communication systems, secure transportation and team strategies and training programs should establish professional boundaries and self-care for researchers[313]. Nevertheless, there is a gap in the literature regarding ethics related training of researchers, perhaps reflecting the gap in practice. Researchers argue that training in the area of ethical issues in non-medical research is usually minimal as the training in research ethics does not, and perhaps cannot, fully prescribe or legislate for the peculiarities of research practice[314]. However, the emphasis in the literature on the need for critical, reflexive practice and the increase in publications discussing problematic ethical issues indicate a keen interest in discussing and extending knowledge in these areas[315].

Reflexivity is considered to occur when the observations or actions of observers in the social system affect the very situations they are observing, or theory being formulated is disseminated to and affects the behaviour of the individuals or systems the theory is meant to be objectively modeling[316]. Hence, for example an anthropologist living in an isolated village may affect the village and the behaviour of its citizens. It is a means of handling the gap between adult researchers and child participants by advocating self-awareness on the part of the researcher regarding assumptions and beliefs about childhood and how this may influence the research and is tool to bridge the gap of power issues[317]. Reflexivity is the capacity of researchers to reflect critically about the impact of their research on participants and their communities, on researchers themselves, and on the body of knowledge under investigation[318], and has been argued to be a significant and necessary characteristic when conducting research as it "is an

---

[312] Ennew & Plateau, 2004 p. 39; Shaw et al., 2011, p. 13.
[313] Shaw et al., 2011, p. 42.
[314] Horton, 2008, p. 370.
[315] Abebe, 2009, p. 461; Cocks, 2006, p. 261.
[316] Cocks, 2006, p. 262.
[317] Powel et al., 2012, p. 42-43.
[318] Cocks, 2006, p. 262.

approach researchers can apply to bridge the gap between themselves and the researched.[319]" It refers to circular relationships between cause and effect. The ethical literature suggests that researchers advocate the use of critical reflexivity, based on their experiences in the field[320]. Reflexivity in the researcher role provides opportunities for building rapport and establishing the participants as the experts regarding the research focus[321]. The issue of reflexivity and ethics starts in the conceptualization of a research project. When doing research with children, the way in which childhood is perceived and understood by the adult researchers will inevitably frame the focus of the research and the tools used within.[322].

Some researchers have noted that although some regulation and institutionalisation of ethical research and adherence to ethical guidelines improves research processes, it is believed that applying such guidelines must be complemented with a "reflexive appreciation of the social structure in which the research is being conducted[323]". Hence, an integral part of researcher training should be reflection on what researchers themselves bring to the researcher relationship, alongside ethical issues and methods, in how to do ethical research and processes and potential socio-ethical implications should be discussed and explored in a dialogue between the researcher and the researched[324]. Dialogue can therefore become a tool to assist ethical research and to support a move towards the goal of emancipatory understanding as not only does this create a potential space in which to discuss and explore how the research can be conducted ethically, it can also create a space in which socio-ethical issues could be renegotiated during the research process[325].

The researcher should be aware of childhood experiences and engagement with children as an adult, personal biases and how these impact on the study, and experiences the researcher has encountered, both academic and life based experiences[326]. However,

---

[319] Ibidem. p. 262.
[320] Powel et al., 2012, p. 42.
[321] Sime, 2008, p. 75.
[322] Abebe, 2012, p. 81; Flanagan, 2012; p. 537.
[323] Abebe, 2012 p. 80.
[324] Powel et al., 2012. p, 43.
[325] Abebe, 2012, p. 80.
[326] Powel et al., 2012, p. 43.

the space for such dialogue cannot be created without an awareness of and reflection on the tensions for example, power inequalities that are likely to emanate between the researcher and the researched in the research process[327]. These tensions are likely to be significantly affected by the socio-cultural context of the research. In retrospect, reflexivity fall under the auspices of the virtue based approach, in which researchers need to balance ethics in specific contextual ways respectively[328]. Reflexivity in the research process can enable reflection on assumptions and roles and also on the choice of research methods.

1.3.7 Ethical Review Boards, Community Advisory Boards and Code of Conducts

Although numerous guidelines and authors have suggested following ones own conscience and reflexive reponses, many have advocated for better ethical guidance and ethical review. Therefore, Ethics mechanisms, including ethical guidelines, codes, research ethics boards and advisory groups have been ways of trying to ensure that ethical standards are maintained and met in research[329]. Numerous publications and guidelines highlight the importance of ethical review boards[330]. Most national legal regulations require research institutions, such as non-governmental organisations and universities to establish an independent ethical review board to thoroughly review all research plans and provide ethical supervision[331]. They have the capacity to approve, modify researches prior to approval and reject proposals and are responsible for critical oversight over researches conducted on human participants which are scientific, ethical and regulatory in their conduct and the purpose of an ERB review is to assure, both in advance and by periodic review, that appropriate steps are taken to protect the rights and welfare of humans participating as subjects in a research study[332]. Research ethics committees play a vital role in raising awareness of ethical issues and monitoring

---

[327] Cocks, 2006, p. 262, Holland et al, 2010, p. 363.
[328] See: section (1.2.4)
[329] Powel et al., 2012, p. 44
[330] Schenk and Williamson, 2005, p. 8-9
[331] Ibidem, 2005, p. 9.
[332] Melville, 2005, p. 381.; Schenk and Williamson, 2005, p. 10.

research standards and scientific conduct[333]. As suggested, "They play a pivotal role in scrutinising research proposals and evaluating the adequacy of the research. [334]". Additionally, they "can help prevent poor research, safeguard research participants and be a protective barrier between potential participants and researchers[335]" The suggested composition of an ERB is to include members with expertise in child development, experts of various backgrounds with knowledge from working in relevant activities and members representing minorities and gender balance[336].

Furthermore, community advisory boards, also known as local stakeholder groups, community review boards, or advisory committees provide an opportunity for investigators to consult with communities and are another form of supervisory and review mechanism that can give feedback to researchers[337]. Combining independent agencies to review proposals and engaging the local community to advise and monitor activities is further essential to have a better understanding and transparency between local community and researchers[338]. These groups provide a mechanism to address community perceptions of the proposed activities, assessing risks and benefits and ensuring children's protection throughout the activity[339]. Suggestively, they ensure that the proposed activities are in accordance to children's age and culture and provide culturally specific input into assessment of research protocols. The members are required to update themselves regarding current understanding of children and their levels of competence and agency[340]. The ethical guidelines and publications highlight the need to consult the community in various aspects[341]. On top of that, the literature and guidelines suggested that the organization providing funding for an activity bears the major responsibility to ensure that its funds are used ethically and have responsibility of supervision of activities[342]. Suggestively, They must establish

---

[333]Schenk and Williamson, 2005, p. 10; Sanders, 2003, p. 13.
[334] Balen et al., 2006, cited in Powel et al., 2012, p. 46.
[335] Alderson and Morrow, 2011, p. 74.
[336] Shaw et al, 2011, p. 45.
[337] Ibidem, p. 44.
[338] Shaw et al, 2011, p. 45; Schenk and Williamson, 2005, p. 9.
[339] Schenk and Williamson, 2005, p. 10.
[340] Ibidem, p. 9.
[341] CP MERG, 2012, p. 28; Schenk and Williamson, 2005, p. 10;
[342] Schenk and Williamson, 2005, p. 8

regulations for ethical supervision by requiring plans for the activity to be reviewed by an in-country ethical review board where possible, or by establishing in-house ethical review mechanisms.[343]

It has been argued that children's participation in researches has been blocked due to overly protective ethical review processes and is considered as one of the greatest ethical issues in the research process[344]. It has been considered one of the forms of gatekeeping, which may censor the children's right to expression[345]. Gaining ethics approval can be a lengthy process, with ERB's taking months to decide about approval, which unintentionally blocks or delays the research project[346]. Nonetheless, they play a critical role and can help prevent poor research, safeguard research participants and be a protective gatekeeper for participants and researchers[347]. However, There is a danger that after gaining approval from an ERB a project may be regarded as ethical in its entirety[348]. It is suggested that research "committee guidelines and requirements do not exonerate researchers from considering the full extent of research ethics arising within their research[349]". Furthermore, ethical requirements that need to be fulfilled alter researchers willingness to address certain issues because of the protectionist gatekeeping and extensive preliminary work that is required[350]. However, it has been argued that "The ethical review process should not be viewed simply as a hurdle to overcome[351]".

There are a number of suggestions and recommendations in the literature that suggest improving the capacity of ERB's. First, it has been pointed out that until recently, ERB's have only specifically dealt with research that is medically related or health related[352]. As suggested in the initial phase of the literature review, ethical committees are still in the auspices of health or medical related research protocols and

---

[343] Shaw et al, 2011, p. 45.
[344] Powel et al., 2012, p. 45.
[345] Ibidem, p. 46.
[346] Ibidem, p. 46.
[347] Alderson and Morrow 2011, p. 74.
[348] Powel et al., 2012, p. 46.
[349] Bell, (2008) p. 8.
[350] Bessant, 2006, cited in Powel et al., 2012, p. 47.
[351] Melville, 2005, p. 381.
[352] Alderson and Morrow, 2006, p. 407.

standards. Numerous researchers argue that this mandate should extend to all forms of researches, to forming multidisciplinary ethics committees [353]. Furthermore, it is suggested that that reviewers acknowledge and develop awareness of beliefs that exist about children and childhood and be "reflexive about their own positioning[354]". Hence, what is suggested here is that they, "should expect gatekeepers to test their motives, and must be able to explain why participation is so important[355]". Furthermore it has been identified that existing ethical review committees are the basis of codes and protocols in social researches and therefore one informs the other. As a consequence, it has been suggested that research ethics committees who are responsible for health related protocol reviews could be informed by social researches and researchers[356].

It has been pointed out that to improve the role of ethics review boards, children, young people and parents should be included in the board and be involved in the screening of research projects[357]. Furthermore, It is recognized that there may be occasions when researchers feel they need to break confidentiality or where a researcher lets "something slip[358]". This may be due to emotionally challenging research e.g. fieldwork on sensitive issues working with vulnerable children. Here, it is argued that discussion between research team and debriefing should be carried out as a mechanism to avoid information to come out. In this respect, legal and regulatory frameworks influence how these issues are dealt with and it is argued can improve the process of confidentiality[359]. Although this may be a useful way for organizational research it is problematic for student researchers who are mainly left alone in the research process. Consequently, some researchers argue that current guidelines and protocols within universities and institutions are problematic, as they evolved from medical, rather than social sciences standpoints, and tend not to be child-centric and that in the case of academic research, existing university ethics committees should be actively redesigning

---

[353] Ibidem, p. 408
[354] Lambert & Glacken, 2011, p. 782.
[355] Ibidem, p. 782.
[356] Alderson and Morrow, 2006, p. 411-413.
[357] Alderson and Morrow, 2006, p. 408.
[358] Wiles et al., 2014 p. 421.
[359] Ibidem, p. 421.

their systems of approval to ensure that the supervisor monitors their students work more efficiently and understands the risks involved[360].

The conduct of staff that gathers information from children and adolescents is governed by either legal or ethical requirements through code of conducts[361]. Adults working with children may be subject to multiple legal codes governing their behavior e.g. professional groups have established codes of ethical standards that govern their work with young people, even when the adults working with children are not formally bound by such codes[362]. Hence, ethical codes of conduct and regulations are adopted by organisations and professionals to assist members in understanding the difference between 'right' and 'wrong' and in applying that understanding to their decisions and will discuss challenging issues, tough decisions that will often need to be made, and provide a clear account of what behavior is considered ethical, correct or right in their specific circumstances and fields[363]. In the context when professionals are bound by such regulations, failure to comply with a code of practice can result in expulsion from the professional organisation[364]. Suggestively, Codes of conduct offer an invaluable opportunity for responsible organizations to create a positive public identity for themselves, which can lead to a more supportive political and regulatory environment[365]. A code is also a tool to encourage discussions of ethics and to improve how researchers deal with the ethical dilemmas, prejudices and areas that are encountered in everyday work and is meant to complement relevant standards, policies and rules, not to substitute for them but it has been suggested that they can never be more than a starting point because of the multifaceted issues and complexities that arise in research practices[366]. Hence, the obeying and applying of universal ethical protocols within the social sciences has implications for how childhood research is being

---

[360] Ryan et al., 2012, p. 173; Powel et al., 2012, p. 48.

[361] CP MERG, 2012, p. 27

[362] Schenk and Williamson, 2005, p. 7.

[363] See: Ethical Code: available at http://en.wikipedia.org/wiki/Ethical_code retrieved on 20 June 2014.

[364] Ennew & Plateau, 2004 p. 40.

[365] Ibidem. p. 40.

[366] Cree et al., 2002 cited in Powel et al., 2012, p. 45

conducted[367]. Furthermore, this codified approach to ethics provides a framework for the important work undertaken by human research ethics committees who are charged with monitoring the research proposals and outputs of their specific institutions[368].

One researcher looked at the implications of moral judgments and argued that ethical protocols and guidelines play an essential role in the phenomenon of risk management, acting as a tool of surveillance and protecting children from perceived harm and danger. She believes, however, that rigid ethical measures can act to inhibit the participation of children in research[369]. It has also been suggested that ethical codes and guidelines stem from medical research, and as a consequence, social research ethical guidelines have used them as a basis[370]. The literature highlights the practicality of ethical codes and regulations, but also highlights that 'the map is not the territory[371]', as it is not possible to identify in advance what will happen in the research process, or to be prepared for every outcome as formal ethical guidelines, "can prove useful checklists[372]", but they have gaps, and encouragingly are more valuable if they are used dynamically in practical situations and are "iterative and responsive, which does not fit the standard format of knowing in advance what will happen and how it will be managed[373]". An interesting debate in the literature is about the viability of universal ethical codes and the different resonances in different world contexts. Research planned and undertaken in majority world countries challenges assumptions underlying Minority world ethical guidelines[374]. Hence, one researcher questions whether ethical frameworks developed in western universities can be valid for research in other cultures and world contexts, and notes, "ethical research guidelines could be yet another western construct that create a global discourse of 'our way' is the 'right way' to do things[375]". Furthermore, researchers argue that ethical codes can never be more than a starting

---

[367] Ennew & Plateau, 2004 p. 40.
[368] Mortari and Harcourt, 2012, p. 235
[369] Farrell, 2005 cited in Powel et al., 2012, p. 44.
[370] Powel et al., 2012, p. 44
[371] Horton, 2008, p. 375.
[372] Alderson 2004, p. 102.
[373] Powel et al., 2012. p. 43
[374] Ibidem. p. 102.
[375] Skelton, 2008, p. 29.

point because there will always be ambiguities and complexities in research[376] and that "research on ethical dilemmas has indicated that practice cannot be made to fit written codes, however well they are devised[377]". Often codes of conducts are formulated based on international standards and guidelines and are made universal. However, One researcher points out and supports the idea of ethics as situational and responsive, which is "specific to the sociocultural setting and the context of the moment[378]", and consequently should be considered at accordingly.

2 Chapter 2: Context in Nepal and Research

2.1 Introduction and Background of Research

Recent research, scholarly journals and articles on children and the sociology of children has reached a lot of debate as to what the best ways are to protect children and how to actively involve children. As suggested by the documentation and review of the international standards and literature on ethical research with children in the first chapter, ethical issues are inherent in all aspects of research with children, from planning and recruiting individuals, to after the dissemination of the findings. It is apparent that ethical soundness of researches contributes to more reliable forms of data and data collection procedures, empowers children through participatory methods, and protects them from exploitation. The literature suggests that an ethical framework, that is an ethical 'environment' consistent of an ERB, advisory committee, an ethical code of conduct and child protection policy can improve research involving children and protect them, as well as the research staff by monitoring research activity and further provide training to researchers on the issue of power disparities between researcher and participants and with these measures in place, and when researchers have understood and adopted a reflexive stance, child research ethics and children's participation can improve the rights of the child. In the context of nepal; due to the various researches undertaken by different institutions and international community specifically on the rights of the child, there is a need to investigate and understand the nature, scope and

---

[376] Cree et al., 2002, p. 54.
[377] Lindsay, 2000, cited in Powel et al., 2012, p. 45.
[378] Ahsan, 2009, p. 396.

understanding of research being ethical as ethical research enhances research credibility and consequently protects the rights of the child. The stance here is that, if ethical obligatory regulatory mechanisms are in place they may have the capacity to guide researchers, discredit flawed research, and move towards children's empowerment through the use of rights based research practices. Hence what we want to look at is; what are the gaps and issues in researches involving children? And how can they be overcome? By looking at the experiences of researchers and the problems they have faced, we will investigate and find out what is necessary for research to be as ethical as possible in Nepal, to protect the child, and to protect the researcher from misconduct. Therefore, There is a need to identify the existing protocols and guidelines followed by external as well as local organisations and whether they seek ethical approval and from whom. Hence, it is essential to understand what researchers experiences are with these agencies, and how much influence they have with regards to ethical matters i.e. ethical review, monitoring, and involvement. Hereafter, we will commence the presentation of the research undertaken in Kathmandu, Nepal, on the need for an obligatory ethical framework, consistent of an ethical review board and a code of conduct between key stakeholders to improve research that involves children, to protect the children, as well as the researcher from misconducts.

2.2   Context of Nepal

The Federal Democratic Republic of Nepal is a landlocked country in the Himalayas surrounded by India on three sides (south, east and west) and Tibet, a region of China, to the north. With a population of approximately 30 million and children younger than 15 years old making up more than 40% of the population[379]. It includes ethnic and caste groups with distinct cultures and languages, giving this small land locked country a cultural and linguistic diversity that is remarkably complex, Nepal is the world's 93rd largest country by land mass and the 41st most populous country[380]. Nepal was closed to foreign visitors until 1951, a situation which contributed greatly to its mystique in the west. Kathmandu is the capital of the country visited by tourists from around the world, as well as volunteers and researchers. Deep-rooted poverty and a

---

[379] Nepal, http://en.wikipedia.org/wiki/Nepal, retrieved on 14 June 2014.
[380] Ibidem.

decade of violent political instability have taken a toll on the Nepalese people as it experienced a violent civil conflict that destabilized much of the country and worsened the situation for many vulnerable groups, with the heaviest impact on women and children[381]. Much of the population lives in remote rural areas on the plains and others living in scattered settlements in the hills and mountains. More than one in three people in Nepal live in extreme poverty, subsisting on less than $1 per day[382].

Nepal has suggestively developed a supportive legal and policy framework. As the UNCRC was ratified in 1990, and various International Labour Organisation conventions aimed at preventing child labour and other child abuses are in force[383]. These instruments have guided the protection of child rights in the Interim Constitution and the forthcoming new Constitution. Protecting children is a universal obligation and While the UNCRC and other human rights instruments and national laws create legal obligations for the government to protect children, all adults share a responsibility to do so.[384]

Furthermore with regards to current ethical mechanisms, "The Nepal Health Research Council (NHRC) was developed as an example of commitment of the Government of Nepal to promote scientific study and quality research in health in Nepal[385]". It started as Nepal Health Research Committee under the Ministry of Health, chaired by the Secretary of Health in 1982. The committee was further developed into the Nepal Health Research Council, a statutory and autonomous body as promulgated by the Nepal Health Research Council Act No. 29 in 1991[386]. Since its inception, NHRC has suggestively focused its attention on strengthening research capability through training of individuals in research methods in order to develop a corpus of people who can develop good quality research proposals[387]. NHRC also serves as the main national institution responsible for technical and ethical review of all proposals

---

[381] 'Nepal" available at:
http://www.savethechildren.org/site/c.8rKLIXMGIpI4E/b.6150545/k.B8DE/Nepal.htm,
Retrieved on 25 June 2014.
[382] Ibidem.
[383] Ibidem.
[384] NHRC, 2005.
[385] NHRC, 2006, p. 5.
[386] Ibidem.
[387] NHRC, 2006, p. 3.

submitted by individual health scientists, national authorities, NGO, INGO's and universities but is primarily responsible on health related researches [388]. After appropriate review, these proposals are to be cleared by the NHRC and is responsible for the establishment of Ethical Review Boards (ERB) and issuing guidelines for health research in Nepal[389]. Hence, All other ethical review committees in Nepal are under the supervision of the NHRC ERB[390]. Although the ethical review boards of the NHRC have the responsibility to review all researches and the NHRC has established ethical review boards on specific populations or issues, there is none specifically attributed to research that is undertaken with children. Yet, it is officially compulsory as pointed out in its policy document and guidelines, which prohibit the initiation of research if ethical approval has not been granted and which states that research involving human participants includes, "Studies of responses to physical, chemical, genetic, psychological, or social interventions [391]". Although there are the guidelines and policies by the NHRC they are based on research on children in health related studies and do not cover social research strongly enough which consequently give way for researches to be taken on which may not consider ethical considerations.[392]

As formally there is no ethical review of proposals when social research is conducted on children, there is a need to investigate into the experiences of researchers practices and understanding of ethical research and the establishment of an ethical review board who specifically watches over children and research involving children including social research. Hence, approval may not always be sought out by researchers, researching organizations, funding agencies as there is no compulsory mechanism to penalize research that goes on without ethical approval and monitoring. Therefore the following research questions will provide an overview of what we are trying to comprehend, and additionally we will look at how the research was approached.

---

[388] Nepal, Health Research Council (NHRC) National Health research Policy in Nepal. Kathmandu Nepal. Available at: http://nhrc.org.np/policy, retrieved on May 22 2014

[389] Ibidem.

[390] -'Global Research Ethics Map: Nepal', available at: https://webapps.sph.harvard.edu/live/gremap/view.cfm, retrieved on June 18 2014.

[391] NHRC, 2005, p. 34.

[392] Ibidem.

2.3 Research Questions

1. What are the current policies and practices regarding ethical matters in working with children in Nepal and are they in line with international ethical guidelines as currently approved by the international community?

2. What are the differences between non-academic and academic researchers in terms of the gaps, learning's and issues related to research ethics for children among key stakeholders such as child rights NGO's, Government agencies, academia and research institutions?

3. In what way can an institutional review board (IRB) combined with an ethical code of conduct focused on research involving children create an ethical framework where child research ethics can develop and empower, protect and respect the rights of the child?

4. Who can take responsibility to become the IRB and who could create the code of conduct, what measures could the IRB take to improve ethical research involving children and what measures and consequences can be attributed to researches that don't seek ethical approval?

2.4 Methodology and Design

Initially, The research methodology required gathering relevant data from the specified literature on ethical research with children. Journal articles and international literature on ethical research with children were reviewed. International code of conducts and standards were comprehended to form adequate research questions and interview questions consequently. A Purposive sampling procedure was used and a qualitative evaluation was employed for this research project leveraging methods such as interviews to collect substantive and relevant data. The research data collection entailed interviews with 12 key stakeholders whose work is based on the protection of children and their rights in Nepal. The research is qualitative empirical research, which involves consulting and interviewing key stakeholders e.g., Research Institutions(2), Academia(2), International Non-Governmental Organisations(3), Non-Governmental organisations(3) and Governmental Organisations(2) to gather their experience on ethical research with children. This was undertaken by an assistant researcher from a

relevant NGO that advocates children's rights in Nepal and had prior experience of data collection in Nepal. This was primarily due to the fact that some researchers prefer to speak in Nepalese or switch from English to Nepalese and that researchers are more comfortable to speak to someone who is in the same field, from the same place and culture. This further attempted to close the gap and issue of cross cultural research, and the biasness that comes from it. A pilot interview was prepared and completed prior to going into the field. Furthermore, communication and dialogue between lead researcher and research assistant were vital in the procedure, and were encouraged. Particular individuals were chosen with characteristics relevant to the study who are alleged will be most informative. These interviews were conducted with practicing researchers and key stakeholders. Upon collecting the qualitative data derived from said interviews an analysis (interview coding) of the interviews was completed.

Timeline:

Jan-Feb	Literature review and analysis of current ethical documents/ comparison of international literature and national ethical guidelines to find gaps in current ethical research with children. (On-going)
Feb	Construction of data gathering tools and open ended structured interview questions
March-April	Data collection/ interview with 12 key stakeholders
April	Data collection, data analysis, coding and interpretation
May/June	Thesis writing
June/July	Finalization of thesis

2.4.1 Process of Qualitative Data analysis

1. Data collection and management on the ground;
2. Organising and preparing data to be analyzed;
3. Coding and describing data;
4. Conceptualisation, Categorising, Identifying themes;
5. Connecting and interrelating data vs. conflicting statements and issues
6. Interpretation, creating explanatory accounts, providing meaning(discussion)

2.4.2 Aims and Objectives

- To Explore the International literature and guidelines on ethical research with children. To investigate the existing ethical protocols, ethical review board and a code of conduct involved in research with children that enhance the protection of the child's and researchers rights and foster other ethical developments in research involving children.

- To explore the current situation and comprehension of ethical research with children in the context of Nepal. The study entails looking into the experiences, learning's and issues faced by key stakeholders who are currently involved in the research involving children.

- To give added value and recommendations as to what further measures can be taken, and in what direction, to improve ethical research with children in the context of Nepal.

2.4.3 Limitations

Communication:

Although constant communication was held between the prime investigators of the research it is still necessary to point out that this communication was sometimes problematic due to various reasons such as time differences, working hours, and disconnection of communication due to power cuts in Nepal. Distance contributes to lack of communication and understanding of the practical issues on ground. Furthermore, there was a loss of communication due to not physically taking the interviews, as non-verbal communication entails a vast amount of information.

Subjectivity:

As the interviewees are all dedicated to children's protection and the rights of the child it is important to note that their point of view and self reflection may be prejudiced by subjectivism. It is important to note that at numerous times it seemed like a checklist questioning and answering, which may make results sound very optimistic. it is important to note that sometimes participants gave unclear accounts of their guidelines and the ethical considerations they follow in research with children. This may be due to the nature of the study and 'checklist' answering. What is meant here is

that many contributors answered questions in a way that it seemed that they were being cross-examined about their conduct and practices. Furthermore, coming from a minority world context and doing research in a majority world context raises a number of issues as to bias and cultural misunderstanding which comes from cross cultural research. Subjectivity is also apparent in the data analysis and evaluation by the lead researcher. this was best avoided by engaging in dialogue with the research assistant who is from Nepal and conducted the interview on the ground but one needs to take note. However, the research assistants participation and involvement in child rights orientated programs and researches also entails subjectivity as the interest is on the protection of the child.

Time:

Although the timeline suggests that there was enough time for all the processes, there were issues with regards to data collection, which stretched out for months due to holidays and availability of interviewees. Nevertheless on the positive side this gave leeway for literature review and further understanding of ethical issues in publications.

Children's perspectives:

Furthermore, if more time had been present, then children's experiences would have been possible to incorporate. It is unfortunate not to have children's views and experiences of research and researchers on the ground incorporated. Children's right to express about matters that are of concern to them is vital in the literature, and it is necessary to further look into what children's experiences are with regards to researches and researchers with regards to ethical matters.

Problems with data analysis:

There was a failure to analyze earlier from day one, which would have improved further data collection. This would have suggested new questions to ask in the interviews, suggest what to focus on during the interviews and given an indication of relevant and non relevant constructs.

Lack of correspondents

Some of the major key-stakeholder with regards to ethical considerations in research were not approachable which hindered the research process and data collection and also swelled the timeline. Although this may be described as a impeding factor, it must be noted that refusal of participation is still information as per se and should be

considered respectively.

3 Chapter 3: Results and Discussion

3.1 Major Findings and Results from Interviews

The following chapter will look at the results obtained from the codified interviews. Initially we will generally look at each group of key stakeholders and identify their concern and experiences categorically, to get a general understanding of the current issues and conceptions of ethical research involving children between key-stakeholders. we will look at what was said with regards to child protection policies and code of conducts; ethical approval and ethical review; the key ethical components and in every section the challenges that were identified by the researchers will be highlighted in the end. This will give leeway and understanding for what follows, that is, the discussion of findings.

3.1.1 Non-governmental Organisations

A non-governmental organisation (NGO) is an organisation that is neither a part of a government nor a conventional for-profit business. Usually set up by ordinary citizens, NGOs may be funded by governments, foundations or businesses. For this research three local NGOs were interviewed who primarily or secondarily work in child rights advocacy and issues. The NGO's work with various children, from school children to vulnerable children i.e. children who have been sexually abused, confronted forms of commercial sexual exploitation, street children and children in child labour.

When initially questioned about ethical considerations, The NGO's interviewed stated that they follow their own ethical guidelines and protocols which are formulated in their own organizational child protection policies and code of conducts. One child orientated NGO claimed that they have a code of conduct and furthermore a child protection committee that approves researches in the organizational level[393]. In this organisation every researcher had to sign the child protection policy and the code of conduct and prior to research "before conducting the research we used to make a code

---

[393] Interview with Raju Ghimire, Voices of Children (VOC), Kathmandu, 21 April 2014.

of conduct for example in our organisation there is a code of conduct[394]". Furthermore, another NGO claimed that their child protection policy had an ethical guideline inherent in one of its clauses, but did not iterate any further[395]. Although individual organisations and institutions have formulated child protection policies and have one way or the other some form of ethical guidance, they claim there is a lack of a unified policy or guideline as in Nepal is no "national guidelines for researchers or organisation's like us so no one knows who follows what[396]". Another researcher pointed out that when they had to do research they did not have to follow any universal ethical guidelines in terms of "government side or any other institution but organization level we follow but institution level that guides the whole organization that is lacking[397]". Furthermore, it is iterated that "if the government has that kind of mandate or that kind of policy, every organization has to follow the same way[398]". Nevertheless, it was questioned, "whose going to make sure that the researchers are dealing with this children in a dignified way? Whether they are following the ethical codes of conduct or not so there's a huge gap in how these guidelines will be made and who will be the entity which will provide this guideline and how will the researchers follow these guidelines[399]".

   With regards to ethical approval and guidance, the Participants have pointed out that, "There's no authority, or institute, or agency in Nepal which will monitor how the researchers are performing on the ground[400]" and, "there is a need, because many researches are repeated and it's the same topic and many researches should be done, and they are not done because of lack of money and people do not know if there is a research or not and whether there is duplication also[401]". It is disputed by the two of the

---

[394] Interview with Raju Ghimire, Voices of Children, Kathmandu, 21 April 2014.
[395] Interview with Bimala Gyanwali, Chairwoman, Children-Women in Social Service and Human Rights (CWISH)/ AATWIN, Kathmandu, 20 April, 2014.
[396] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.
[397] Interview with Bimala Gyanwali, Chairwoman, Children-Women in Social Service and Human Rights (CWISH)/ AATWIN, Kathmandu, 20 April, 2014.
[398] Interview with Raju Ghimire, Voices of Children, Kathmandu, 21 April 2014.
[399] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.
[400] Ibidem.
[401] Interview with Bimala Gyanwali, Chairwoman, Children-Women in Social Service and Human Rights (CWISH)/ AATWIN, Kathmandu, 20 April, 2014.

three interviewees, that if formulated nationally and when an ethical review board is placed that monitors research activity, and undertaken by all organisations working on children's rights, this could protect the child, as well as the researcher. However, on the contrary one participant claimed that, "for the researcher that body will not do anything, I don't think they will have the capacity about that but just to ensure that child rights perspectives are brought in and ethical considerations are put in place properly and code of conducts are followed up[402]". Moreover, this contributor pointed out that up till now, "ethical considerations are just spelled out on the research paper[403]". This participant suggested that independent organisations have established ethical considerations but this goes beyond organisational outreach, when researches are, "being done for academic purposes, for project purposes, so the issue is to mainstream the ethical considerations in Nepal[404]", towards all institutions and organisations dealing with children.

When asked about the ethical review board, it was suggested that, " as of now there is no, but it should be owned by a governmental institution, maybe in collaboration with academic institutions, or there should be an independent board[405]". It has been suggested that there is the ministry of children women and social welfare and the Central child welfare board that have the capacity to take on such a proposition as they have the network and connections to establish such a body[406]. Furthermore, another participant approved and claimed that, "definitely it should be a government body and maybe it would be nice to have such a body under the central child welfare board, I think because the CCWB is a government institution that monitors organisation's working for children's rights[407]". Another participant claimed that the CCWB has established connections with key-stakeholders and can formulate a child protection policy and a code of conduct that should be followed by all researchers, giving it leeway to become the ethical review board. Furthermore, another researcher addressed this issue and claimed that, "definitely it should be a government body and maybe it would

---

[402] Ibidem,
[403] Ibidem.
[404] Ibidem.
[405] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.
[406] Interview with Raju Ghimire, Voices of Children, Kathmandu, 21 April 2014.
[407] Ibidem.

be nice to have such a body under the central child welfare board I think because the CCWB is a government institution that monitors and organization working for the child rights.[408]". Moreover, it has been suggested that the composition of such a body should be clearly thought through. It has been proposed that such a body should be compromised of "comprised of academia, researchers, civil society organisations and activists, child psychologists and representatives of young people as well[409]".

When speaking of accountability and measures that could be taken on organisations and researchers one participant claimed that, "after the research if the children felt something like uneasy or something then definitely they should have some kind of body who should listen to the voice of the children and definitely there should be something to punish the researcher who did a mistake with the children…[410]". Suggestively, there have been no occasions where researchers have been penalized or held accountable for misconduct in research because, "that will only be possible when we have some guidelines or national policy or something like that…[411]". However, one participant claimed that if these national policies were put in place, "the research could be nullified, and they should not allow such research to be published, that should be the penalty[412]". On the contrary, another contributor stated that, "Ethical guidelines and considerations are moral bindings, we cannot bind anybody making laws or punishments. This is their inner quality and how much the researcher is sensitive[413]".

All of the participants agreed that training of researchers in ethical considerations and issues is vital and is provided by their respective NGO prior to the initiation of research. One contributor claimed that their researchers, "go through a very depth orientation about using child friendly language and how to do focus groups, how to work with young people and how to use creative tools so that you get authentic and

---

[408] Ibidem.
[409] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.
[410] Interview with Raju Ghimire, Voices of Children, Kathmandu, 21 April 2014.
[411] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.
[412] Ibidem.
[413] Interview with Bimala Gyanwali, Chairwoman, Children-Women in Social Service and Human Rights (CWISH)/ AATWIN, Kathmandu, 20 April, 2014.

proper information from children[414]". Another approving this statement; "yes, before going to research during the preparation phase or the expert within the organization, the experience of the human resource they used to present and they used to talk, they used to train the researchers[415]".

Researchers also advocated the fact that the ethical institutional review board could provide universal training for researchers, for example one researcher claimed that "there should be training if the organization don't have, without training there will be no good or qualitative research[416]", and further stated that the CCWB should provide such workshops for researchers. Another participant claimed, "we are actually conceiving these kinds of ethical considerations committee we will be advocating for that so that a plan for us as well, so its already there and we will be working towards that goal, what we perceive is that if such a high level committee or commission is made then they can outsource some organisations to do such training[417]", reinstating the need for unified training and highlighting the need for a body.

When asked about the influence funding agencies have on their particular organisations with respect to ethical considerations and whether they enforce to seek ethical approval one participant claimed that "some organisations do, some organisations don't, nothing like approval here, they should provide you with a guideline, which you follow, and you sign[418]". Some donor agencies provide their own ethical guidelines which are modified accordingly and, "especially child protection, code of conduct and to communicate with the children they have their own guidelines and under this we also have our guidelines[419]". Another participant claimed that donor agencies, "say follow your own organizations guidelines because situation is different we have international organizations and in local level there are different circumstances.. so that you follow your one country level guideline or your organization guideline but

---

[414] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.
[415] Interview with Raju Ghimire, Voices of Children, Kathmandu, 21 April 2014.
[416] Ibidem.
[417] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.
[418] Ibidem.
[419] Interview with Raju Ghimire, Voices of Children, Kathmandu, 21 April 2014.

you follow their guideline [420] ". Nevertheless, it has been asserted that funding involvement in considering ethical issues is varying, and dependent on the donor agency. One contributor stated that some external funding agencies, they, "follow the timeline and everything, much more than how the conduct is carried out, but there are some other organisations who are very particular about it and very concerned about it[421]".

It is suggested that Informed Consent has been attained by researchers verbally and through written consent, "with children sometimes they say yes, sometimes they sign sometimes they don't, they don't need to sign, but when they say yes they come to the next session, because we do not do it in one session and finish that thing, we have to build a relationship[422]". Additionally one NGO stated that, "most of the time it's verbally but some cases can be sensitive for example the sexual abuse case we take the written consent.[423]". Another claimed that, "basically in the government level and the organization level we take verbal consent. In the case of survivor we take the consent verbally, we tell them our objectives and from this we are doing research[424]". Adequate information has been suggestively provided through constant rapport building and providing the necessary information to the children through meetings as "the best way is the researcher to arrange a meeting with them and make a plan about the research to fix the date, to know their interest[425]". Hence, the participant claimed, "we always have to provide information to the children of the research is about, why are we conducting and what's the benefit of it for them and why should they speak about it and why they should be part of this research[426]". Furthermore, approved by another contributor that, "at all times we raise awareness among the children about availability of emergency support system called the child helpline so if anything happens they can call helpline, if

---

[420] Interview with Bimala Gyanwali, Chairwoman, Children-Women in Social Service and Human Rights (CWISH)/ AATWIN, Kathmandu, 20 April, 2014.
[421] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.
[422] Ibidem.
[423] Interview with Raju Ghimire, Voices of Children, Kathmandu, 21 April 2014.
[424] Interview with Bimala Gyanwali, Chairwoman, Children-Women in Social Service and Human Rights (CWISH)/ AATWIN, Kathmandu, 20 April, 2014.
[425] Interview with Raju Ghimire, Voices of Children, Kathmandu, 21 April 2014.
[426] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.

a researcher not behaving well with them they can call the helpline. So we have a reporting mechanism for the children, so that kind of also monitoring through children for us.[427]", indicating that children are provided with services to where they can get information and support. One contributor suggested that when having done a research with children, they had the space to come back and renegotiate their involvement in the research. This has been highlighted as, "sometimes for example we take the verbal consent from the children and we take the video and after 2-3 months or a year the children come back and say they felt really bad and we used to give them their photo and video[428]". Moreover, one participant asserted that children always have the space to renegotiate consent through their child helplines, which are provided in the consent procedure[429]. The other participants did not exclusively speak about negotiability but maintained that services were put in place where children could get feedback and consultation.

When asked about the selection of the children for research purposes one participant responded that, "depending on the nature of the research we select the children[430]". Another contributor maintained that, " the selection criteria for us is very process oriented, we organize various activities before we know who our respondents will be so we interact with them and our field workers build contact and rapport and only then who are willing to speak to you, who are not very vulnerable, then we will choose them [431]". Furthermore, one participant asserted that, "we go through our member organizations. They run the rehabilitation center and they provide us with the connection with the children and in that we say these are our ethical considerations... [432]". When asked about vulnerable children and how they are selected one participant stated the use of, "mobilizing peer educators who are former street children who can build rapport and only then we do that so we take a very very long process to get back

---

[427] Ibidem.

[428] Interview with Raju Ghimire, Voices of Children, Kathmandu, 21 April 2014

[429] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.

[430] Interview with Raju Ghimire, Voices of Children, Kathmandu, 21 April 2014.

[431] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.

[432] Interview with Bimala Gyanwali, Chairwoman, Children-Women in Social Service and Human Rights (CWISH)/ AATWIN, Kathmandu, 20 April, 2014.

to the respondents[433]". The NGO's emphasized the need to look into harms and benefits and suggested that this depends, "for the target group, you have to know the background of the target group and what will be their feelings, for example if for the children we are going to talk about the sexual abuse issue and for that particular issue we have to prepare[434]", and claimed, "its very important because we are working in the advocacy so we believe the advocacy should be in fact, we work in policy level and policy changing[435]". Another participant maintained this claim an addressed the issue that, "we are child protection organisations but I don't know if an academician, a pure academician comes and he or she might not have a broader knowledge on child protection.[436]".

Furthermore, with regards to harms and benefits, its was iterated that, "during the preparation period we have discussed a lot about this[437]". Building rapport through peer educators was one measure to reduce harm and maximize benefit, claimed by one of the three respective NGOs. Nonetheless, the participants stated that services, prevention programs and crisis management procedures are the measures put in place to reduce harm and maximize benefit, "for example if you are interviewing a survivor of rape, I mean that's a very sensitive area where you might require a counselor with you, and talk in a manor that will not re-victimize the child and not passed on its interface so that child will suffer again,[438]". Subsequently, another NGO contributor confirmed that, "The children are also brought into communication with the counselors, its an ethical thing for us and we directly work with children, we run a service center... That's the benefit for us as we are not just a research organisations or an advocacy organization, we run services[439]". Another participant stated that they, "make the crisis management,

---

[433] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.

[434] Interview with Raju Ghimire, Voices of Children, Kathmandu, 21 April 2014

[435] Interview with Bimala Gyanwali, Chairwoman, Children-Women in Social Service and Human Rights (CWISH)/ AATWIN, Kathmandu, 20 April, 2014.

[436] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.

[437] Interview with Raju Ghimire, Voices of Children, Kathmandu, 21 April 2014.

[438] Ibidem.

[439] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.

we make our schedule and goal[440]". Furthermore it is claimed that "training, orientation and counseling and another thing is to analyze the risks, and to minimize these risks, for example communication, and to select the appropriate researchers, place, environment, everything should be prepared.[441]" to minimize harms and maximize risks.

The corresponding organisations utilize anonymity as a tool to protect their participants from harm and maintain privacy and confidentiality. Two of the three NGO's claim that "obviously we are not allowed to use names and the real districts when we site cases, and site their codes[442]", another contributor reinstated this as, "we change the name, not keep the caste or sir name[443]" and doesn't provide information as to in which area the child lives in or belongs to. All the participants pointed out that choosing a suitable location is vital for interviewing children, They try and provide a trustful environment for example, "if its in rehabilitation center we have separate rooms and counseling rooms[444]". However with regards to interviewing street children there are different views where one NGO claimed that, "with the street children, in the street or on the spot there are also places, some park or some junctions, so definitely first we ask to them where to sit[445]", on the contrary another asserted that, "when you are researching street children you cant just go straight to the street, just pick up some girls and boys, feed them and interview them, that's a wrong process, even if it's a safe hotel, because for us, we have drop in centers and other programs and network organisations where the children go to[446]".

The information obtained by the children is suggestively stored in the respective NGOs where, "there is no access for the outsiders, its only for the researcher and organisation[447]". All the correspondents claimed that information is not accessible to anyone. One contributor stated that they "… make sure that any research or information

---

[440] Interview with Raju Ghimire, Voices of Children, Kathmandu, 21 April 2014.
[441] Ibidem..
[442] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014
[443] Interview with Raju Ghimire, Voices of Children, Kathmandu, 21 April 2014.
[444] Ibidem.
[445] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.
[446] Ibidem.
[447] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.

we bring out do not re-victimize again and do not ostracize children and we present real views of children[448]" and gives the example of a street child who, "said he has stolen a golden chain and nobody did anything about it then if this information reaches the police who must be looking for this thief, they will go down to the streets in ratnapark where they will bug down on them, therefore you really need to be careful how you relay the message you know, you can say it in a manner that street children are used by thieves, they are exposed to petty crimes[449]".

With regards to compensation, all of the participants have compensated children in one form or the other, although maintaining that monetary compensation is not the preferred practice as "they might feel obligated to answer, they can say something wrong also when they are taking something, in my opinion you have to explain more about the research, that will be one good way rather than given money and material[450]", "and I think if we give something to the children it would be like we are buying something[451]". Nevertheless, tokens of appreciation, snacks, meals, or educational 'goodies' are suggestively provided. It is suggested that when needed, travel costs are provided when children are brought in from various places. Furthermore, one NGO stated that they provide educational programs to participating children[452]. However, when it comes to income generating children one participant shares the experience that "especially the children in trainings, who have jobs, they demand something,[453]". Another participant indicated that they, "compensated the women working in the entertainment sector. They told us if we take their time, they have no leave from the restaurants, as this is their working time. In this case we compensate them, mostly monetarily, other times we did not compensate money,[454]". Hence, two correspondents claimed that in particular interviews when the research involved income-generating

---

[448] Ibidem.
[449] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.
[450] Interview with Raju Ghimire, Voices of Children, Kathmandu, 21 April 2014.
[451] Ibidem.
[452] Interview with Bimala Gyanwali, Chairwoman, Children-Women in Social Service and Human Rights (CWISH)/ AATWIN, Kathmandu, 20 April, 2014.
[453] Ibidem
[454] Interview with Bimala Gyanwali, Chairwoman, Children-Women in Social Service and Human Rights (CWISH)/ AATWIN, Kathmandu, 20 April, 2014.

children, then the children were compensated. One participant indicated that, "The compensation should be thought in a longer term maybe so that the child really benefits in the future in a longer run...[455]", and, "If you have money and you are doing a big research with huge amounts of money then there should be an intervention where more children will benefit from such a support.[456]", rather than compensating individual children monetarily. Hence, here it was suggested that benefits should be like health benefits that should be directed towards the system and children as whole, and not specifically to the correspondents.

Participation of children in research has been through a number of mediums and ways, one Interviewee highlights the use of focus group discussions while another points out about how "some children liked to participate in the documentary, doing some paintings or other things, and later it empowered, they thought I participated in this documentary now I have to read otherwise I want to make a good picture and tell my family [457]". The contributing stakeholders claimed that participatory research methods are used to involve the children in the research but this depends on the nature of the study. Furthermore, "there are very few where children are the team of research[458]". However, two of the three respective NGOs consult with survivors and peer educators, involving previously involved children in the research process. Nevertheless, Participation is mainly considered in terms of consultation with the children, where their views are incorporated into the research process but are less likely to be involved in the interpretation of the results and the fieldwork itself. Hence, one NGO suggested, "for example if we are researching in the street we make a plan to meet the children who are in the street, like this we used to make the plan with them, but in the data interpretation we do not[459]", another contributor asserted that, "in our training the researchers are the survivors, so they say this is not good, this is and all, and we

[455] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.
[456] Ibidem.
[457] Interview with Raju Ghimire, Voices of Children, Kathmandu, 21 April 2014.
[458] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.
[459] Interview with Raju Ghimire, Voices of Children, Kathmandu, 21 April 2014.

revise our questions[460]", and that, "we make the questionnaire or development things and tell them this is prepared, this is right and wrong, and ask if they have any suggestions or feedback and if they want to add something[461]."

It has been asserted that challenges exist throughout the research process. One NGO claimed that harms can occur at any time, and especially in the field, when the researcher is taking interviews and respective measures and counseling is not around claiming that "…One time one of our researchers went to interview a trafficked girl and talking all the things and when she said the stories and she got re-traumatized and she fainted and the researcher took her to the hospital and these things, sometimes these kinds of problems happen[462]". Another participant pointed out that when confronted with ethical dilemmas in the past, "they consulted with the senior and as for the guardians and seniors I managed the research[463]". Furthermore, it was suggested that even when research results provided enough evidence of children's exploitation, and were specified to the authorities, the authorities did not do anything due to 'lack of evidence', and contributors stated their concern of flawed researches that have come to their attention. One participant stated his concern on false information that was about to be distributed which identified parents allegedly selling their children to the entertainment sector i.e. into dance bars and sources of trafficking and sexual exploitation. This report claimed that all parents do this purposefully and did not provide any evidence whatsoever[464]. Another researcher pointed out that research was conducted on street children and HIV prevalence. Here, an organisation or a researcher took blood samples from children in order to get the test results but did not disclose this information to the children[465].

[460] Interview with Bimala Gyanwali, Chairwoman, Children-Women in Social Service and Human Rights (CWISH)/ AATWIN, Kathmandu, 20 April, 2014.

[461] Ibidem.

[462] Interview with Bimala Gyanwali, Chairwoman, Children-Women in Social Service and Human Rights (CWISH)/ AATWIN, Kathmandu, 20 April, 2014.

[463] Interview with Raju Ghimire, Voices of Children, Kathmandu, 21 April 2014

[464] Interview with Bimala Gyanwali, Chairwoman, Children-Women in Social Service and Human Rights (CWISH)/ AATWIN, Kathmandu, 20 April, 2014.

[465] Interview with Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.

3.1.2 International Non-governmental Organisations

An international non-governmental organisation (INGO) is an international private organizations that pursue activities to relieve suffering, promote the interests of the poor and marginalized, protect the environment, provide basic social services, or undertake community development. The INGO's that were interviewed are dedicated in child rights and are known to engage in multiple projects and researches on children. Therefore their contribution in the development of ethical research and their experiences are vital to the understanding of research practices in Nepal.

The international non-governmental organisations interviewed are suggestively following ethical guidelines created in international context of their respective organisations that may, or may not be contextualized and modified with regards to the Nepalese context. When questioned about ethical guidelines and child protection policies one correspondent states that they have their own policy which needs to be signed by everyone in the organization constituting 9 standards that need to be followed during research[466]. This participant stated that their child protection policy needs to be signed by anyone involved in the research process which is a universal policy created by the international office which is applicable to all country offices. Furthermore, the policy needs to be signed by anyone included in the research process, and not following the guideline constitutes that, "you will be fired immediately, zero tolerance[467]". Another participant pointed out that their research involving children started recently, and since then they have been focusing on "following article 12 of the CRC and top ethical considerations when involving research with children[468]", which have been developed by UNICEF, but suggestively they do not have a separate guidelines. This policy needs to be signed by everyone who is taking part in the research e.g. "individuals or community people have to sign first in our child protection policies and only then they can engage in our activities[469]". This child protection policy in place has been "modified in the context of Nepal, so there is an international global child

---

[466] Interview with Dilli Gurugain, Senior Advocacy, Child Rights Governance and Child Protection Specialist, Save the Children, Kathmandu, 23 May 2014.
[467] Ibidem.
[468] Interview with Krishna Giri, DME Specialist, World Vision, Kathmandu, 10 April 2014.
[469] Ibidem.

protection policy and then we contextualize in Nepal context, so the policy does not contain anything about the research, the policy talked about the behavior of how to behave with the children.[470]". It has been suggested that if following regulations and rules that, "it definitely helps both the children and the researcher. So if the researcher does not have such policies or ethical things then maybe the child can be abused.[471]", however, one contributing INGO claimed that although it should be one of the things that are mandatory and allows children to have a choice in what affects them, "It may not directly contribute for the empowerment, but indirectly it does contribute for their empowerment. That encourages them to speak out, so if you can really create that kind of environment then they feel comfortable and empowered also, that's why I think it's not really a tool for empowerment but its contributing factor for empowerment. It is one of the essential aspects of empowerment I think[472]".

The contributors suggested that they have taken ethical approval only when research is health related as "that's a bit tricky in Nepal, there are not, there's an institutional called the national health research council, and if our study or research is related somehow to health, then we go to that council and get approval, but for other cases we don't have such a body yet. [473]". Furthermore, another INGO claimed that only recently they had to take approval from the NHRC on a research which was on gender based violence, and stated that, "Before... we didn't get something like that as we didn't know and when we checked also they said it is only related to health so if you have to take the blood sample or something like that then you have to get the approval[474]". However, then addressing the issue that, " ... this is important but it takes such a long time to get ethical approval from the review board.[475]". Furthermore, this only constituted approval and no monitoring as, "they just give some feedback to our

---

[470] Ibidem.
[471] Ibidem.
[472] Interview with Madhuwanti Tuladhar, General Child Rights Coordinator, Plan International, Kathmandu, 13 May 2014.
[473] Interview with Dilli Gurugain, Senior Advocacy, Child Rights Governance and Child Protection Specialist, Save the Children, Kathmandu, 23 May 2014.
[474] Interview with Madhuwanti Tuladhar, General Child Rights Coordinator, Plan International, Kathmandu, 13 May 2014.
[475] Ibidem.

proposals[476]". Nonetheless, this is when research is conducted on issues that are related to health; hence, when conducting research on social issues, there is no body that evaluates research proposals nationally[477]. Another contributor agreed and highlighted the need for it to be an obligatory ethical board who would evaluate all the processes of research[478].

One of the participants identified that they are not sure who can take such a responsibility to, "monitor those kind of things, there is a lacking of monitoring, so many researchers are coming to Nepal and they are doing research with children and nobody knows who are coming and who are doing anything with the children[479]". Nevertheless, all partakers highlighted the importance of holding researchers and organisations accountable but one asserted that its, "tricky because it's the fail of the government not to have such a body which regulates all these things, so when there is no such body to regulate things, then you cant blame the organisations,[480]" and holding organisations and individuals accountable can only be "in the context if there is an ethical guideline[481]", and, "Without informing the people and without having any policy there will be no basis to do that[482]".

When asked about who should be responsible to create such a body and guideline one participant stated that, "our ministry should be responsible, and maybe the CCWB and the organisations who are working on children issues, the lacking part is that we do not have a national guideline[483]". Accordingly, one participant stated that "we have a new leadership in the central child welfare board and we have been talking to them and we have really been trying to promote that, the central child welfare board might be the body which can be developed as an institution that regulates all the

---

[476] Ibidem.
[477] Interview with Madhuwanti Tuladhar, General Child Rights Coordinator, Plan International, Kathmandu, 13 May 2014 and Interview with Dilli Gurugain, Senior Advocacy, Child Rights Governance and Child Protection Specialist, Save the Children, Kathmandu, 23 May 2014.
[478] Interview with Krishna Giri, DME Specialist, World Vision, Kathmandu, 10 April 2014.
[479] Ibidem.
[480] Interview with Madhuwanti Tuladhar, General Child Rights Coordinator, Plan International, Kathmandu, 13 May 2014.
[481] Interview with Krishna Giri, DME Specialist, World Vision, Kathmandu, 10 April 2014.
[482] Interview with Dilli Gurugain, Senior Advocacy, Child Rights Governance and Child Protection Specialist, Save the Children, Kathmandu, 23 May 2014.
[483] Interview with Krishna Giri, DME Specialist, World Vision, Kathmandu, 10 April 2014.

research that's happening, also not only ethical considerations but also not to duplicate research and research topics as so many organisations working in Nepal [484] ". Furthermore, "there is a realization that we need to develop such kind of things. The CCWB is considering that.[485]". Nevertheless, the participant addressed the issue that "I'm not sure if the CCWB, as the mandate they are responsible for reviewing policy and coordinating and monitoring those things are in their responsibilities but as we see the CCWB right now, they don't have enough human resource who can really work and function to review these…[486]". The argument stated by one of the correspondents was that the composition of the ethical review board should not solely lie in the hands of one organization, and it should comprised of academics, child rights experts and key-stakeholders, including the CCWB [487]. Henceforth, "As CCWB is related to coordinating and monitoring child rights they can be one of the member of the board but I don't know whether, I mean its difficult to say if CCWB can be itself a board or not.[488]".

All of the corresponding organisations provide training in one form or another to their research staff through orientation and workshops. One INGO stated that, "we don't have separate researcher but from the communities we take the volunteers above 18 years and we train them about all the things we have such kind of guidelines[489]". However, it is suggested that there should be a body, "to train, to capacity build people who are actually going to do things, so without you know, building the capacity, we cannot expect everyone to have the same level of knowledge or same type of behavior, so there has to be body who capacity builds people[490]". Further it is asserted that, "there should be a committee or responsible people in the organisations who should monitor or

---

484 Interview with Dilli Gurugain, Senior Advocacy, Child Rights Governance and Child Protection Specialist, Save the Children, Kathmandu, 23 May 2014.
485 Interview with Madhuwanti Tuladhar, General Child Rights Coordinator, Plan International, Kathmandu, 13 May 2014.
486 Ibidem.
487 Interview with Madhuwanti Tuladhar, General Child Rights Coordinator, Plan International, Kathmandu, 13 May 2014.
488 Ibidem.
489 Interview with Krishna Giri, DME Specialist, World Vision, Kathmandu, 10 April 2014.
490 Interview with Dilli Gurugain, Senior Advocacy, Child Rights Governance and Child Protection Specialist, Save the Children, Kathmandu, 23 May 2014.

they have to visit in the field yes, there should be[491]". Another INGO interviewee agreed and stated that, "I think that would be really good if we had some type of organization which would provide training and ensure that these kind of ethical considerations are in ensured by all the researches while working with the children[492]".

The INGOS interviewed claimed that parental consent is taken prior to taking consent from the children, through the use of consent forms and having parents and children consent in writing through signatures or thumb prints as well as verbally. Children and parents are first provided with information about the research "So that information is already there, so we generally try and inform children 7 days in advance unless its very difficult to do so, and provide them with enough time to decide whether they want to participate, so the invitation would say you are invited for this particular issue, this will be discussed and this is what we expect from you[493]", and "anytime they can leave our survey, anytime they don't want to answer questions or something is boring them they can quit the survey and go, so all the things we have to discuss with the children this we train the enumerators[494]", suggesting there is space for negotiability of consent.

The contributors approved that considering harms and benefits is vital in the research and measures should be in place for the protection of children. For their researches children are selected in various ways, dependent on the nature of the study. One participant pointed out the principle of inclusivity, that different groups of children should have a voice in the research[495]. Another indicated the use of random sampling, based on the objectives of the study[496] and the latter stated "to make sure and ensure the gender balance, we make sure that the girls and boys are equally included and their voices are captured at the same time we focus on the most marginalized and children with disabilities and so the children who are most vulnerable we try to ensure in the

---

[491] Interview with Krishna Giri, DME Specialist, World Vision, Kathmandu, 10 April 2014.
[492] Interview with Dilli Gurugain, Senior Advocacy, Child Rights Governance and Child Protection Specialist, Save the Children, Kathmandu, 23 May 2014.
[493] Ibidem.
[494] Interview with Krishna Giri, DME Specialist, World Vision, Kathmandu, 10 April 2014.
[495] Interview with Dilli Gurugain, Senior Advocacy, Child Rights Governance and Child Protection Specialist, Save the Children, Kathmandu, 23 May 2014.
[496] Interview with Krishna Giri, DME Specialist, World Vision, Kathmandu, 10 April 2014.

consultation that they are included in the research work but at the same time if it's a child labour related project we will definitely be focusing on the children who are working[497]". Also, its pointed out, that when vulnerable children are involved one participant claimed, "we have different sort of structures in the community level in which we work, one for example is in work in child protection is village child protection committee, and that committee has access to all the wards in VDCs so we will know the situation of the children in general, and they will reach out to children in other cases[498]". Thus, harms and benefits are considered dependent on the research and the group of children interviewed. To minimize harms and maximize benefits, the participants suggested that when sensitive topics were researched they incorporated the inclusion of experienced researchers, counselors and a co-facilitator who can immediately deal with that child, the use of risk assessments and mitigation measures, hence claiming, "so we try and analyze all the risks that might be involved in a particular case[499]".

Privacy and confidentiality has been suggestively maintained through anonymity and described in the consent procedure as, "when we talk to the children we tell them there's no need to write your name, and even when we analyse the data we have to share with them also so there's no mandatory in writing the name and our findings will be not be on individual level[500]". Furthermore, another articulated that, "one of the things we also make sure with the children is that whatever the information they have shared will be confidential and will not be, their names will not be mentioned for example who has said what, and that its anonymous, those kind of things we also mention to the children, so children understand how this information will be used[501]".

One participant stated that with regards to privacy and confidentiality, "its generally better to have 2 adults rather than one adult, and to interview a child which is visible but it shouldn't be that you interview a child in a locked room or whatever, the

---

[497] Interview with Dilli Gurugain, Senior Advocacy, Child Rights Governance and Child Protection Specialist, Save the Children, Kathmandu, 23 May 2014.
[498] Ibidem.
[499] Ibidem.
[500] Interview with Krishna Giri, DME Specialist, World Vision, Kathmandu, 10 April 2014.
[501] Interview with Madhuwanti Tuladhar, General Child Rights Coordinator, Plan International, Kathmandu, 13 May 2014.

place should still be visible so it should be that people can hear what the child is saying, it should be in an open place, still confidentiality can be maintained but this all depends and varies from case to case[502]". Another contributor didn't specifically point out the 2 adults principle but asserted that, "We are either conducting in the schools or in the homes but not in the ground or the outside, in separate places nearby the house because sometimes friends and parents may disturb the children but tis very difficult maintain all the things in the community[503]", where the, "the atmosphere should be quiet and nobody should disturb there[504]". It was suggested that data is stored in the respective organization and is not accessible for any outsiders in all the corresponding organisations. With regards to dissemination of findings, one correspondent stated that they disseminate their findings through a Committee dissemination plan including selected stakeholders, "so sometimes parents groups, and children groups but not all children who are involved in the survey[505]", thereafter, the participants in the research decide and validate the findings.

With regards to protection of stigmatization due to dissemination of findings, "if children are interviewed for a particular study, then children will know how that study will unfold in the future and when this report should be produced, and how the report will be disseminated, and one standard of child participation is this feedback[506]". Stigmatization and protection of vulnerable children was questioned and one participants stated that "in many cases when its not very sensitive children say that it can go there you can sight my name, it should not be anonymous, in other cases it has to be anonymous for example if it is an issue which is associated with some kind of stigma or some type of discrimination…[507]". All of the correspondents claimed that it's necessary to evaluate the harm that could occur through stigmatization and pointed at diverse techniques with regards to protection of identities.

---

[502] Interview with Dilli Gurugain, Senior Advocacy, Child Rights Governance and Child Protection Specialist, Save the Children, Kathmandu, 23 May 2014.
[503] Interview with Krishna Giri, DME Specialist, World Vision, Kathmandu, 10 April 2014.
[504] Ibidem.
[505] Interview with Krishna Giri, DME Specialist, World Vision, Kathmandu, 10 April 2014.
[506] Interview with Dilli Gurugain, Senior Advocacy, Child Rights Governance and Child Protection Specialist, Save the Children, Kathmandu, 23 May 2014.
[507] Ibidem.

All Interviewees claimed to compensate children with tokens of appreciation and, "sometimes they are provided with snack or meals as required but monetarily we don't because we think that that's not going to set a good practice[508]". Furthermore, it was iterated by another participant that, "I'm not sure about compensation but in ethics, I studied the ethics, and we didn't provide any compensation like money or something like that but we provide them with some lunch, some snacks, tea… sometimes we also provide them with colour pencils if they are involved in the writing or drawings so they have to have some pencils and we do not take them back[509]". All contributors claimed that monetary compensation does not set a good practice and that, "In Nepal the development field has suffered from this, if you see some, in several cases if you don't provide the money, people don't participate, and I don't think that's a good idea, if that particular issue is of interest to you then you should participate, if you have time, but if that issue is not important to you, then you shouldn't participate, its not money related thing[510]". Furthermore, this was reclaimed by another participant as, "yes, it becomes a kind of a business and we don't feel comfortable, but if you have to bring the children from a far distance or some point those transportation costs and if we are bringing children then definitely we do accompany children and may provide the travel costs if its required. Otherwise we don't compensate[511]".

The respective participants promulgate the importance of inclusion of children in research processes but have different opinions as to their current effectiveness. Participation is currently both "child lead and child informed so research programming and when its child lead they are leading on their own[512]". One contributor claimed that, "in the evaluation time we train children, the child club children themselves conduct the FGD with the parents or with other stakeholders[513]". On the contrary another participant stated that research although there is a move towards more participatory methods it is "mostly its research on children to be honest, we tried to that together and in the team

---

[508] Ibidem.
[509] Interview with Krishna Giri, DME Specialist, World Vision, Kathmandu, 10 April 2014.
[510] Interview with Dilli Gurugain, Senior Advocacy, Child Rights Governance and Child Protection Specialist, Save the Children, Kathmandu, 23 May 2014.
[511] Ibidem.
[512] Ibidem.
[513] Interview with Krishna Giri, DME Specialist, World Vision, Kathmandu, 10 April 2014.

we tried to include the children in the research but somehow it is not, it did not do too well[514]". When asked about participatory methods and whether consequently children are empowered one contributing INGO asserted, "definitely, because when major cause of conflict in Nepal was lack of inclusion, people were excluded from several, from accessing resources, from accessing whatever services and inclusion is obviously a must[515]". One partaker gave an example how participatory methods can be helpful by giving an example of how children suggested that the results were flawed because of sampling. This participant stated that one should always be in dialogue with the children, as they have proactive suggestions[516]. However, It was suggested that inclusive participatory methods, "will always be costly, always consume a lot of time because you need to give extra effort to make things inclusive and participatory but the good thing is that there will be very good ownership of the contents of the findings and the recommendations on the side of children and on the side of whoever is involved so it's a trade off between ownership vs. costs and time[517]". Furthermore, another contributor stated their difficulties with participatory methods as they, "tried but in terms of time it's a demanding time for the children to involve them in the whole process and partly the researcher how far they are comfortable experience of working together with the children, that's another challenge and so we tried, they participated but we were not that successful[518]".

Diverse challenges were explicated by the participants in international organisations. One participant pointed out how privacy can be compromised when taking interviews in the child's home. Hence, here the researcher was taking a reading skills test and the parents came into the room and punished the child, "like the village people don't have separate rooms meaning father, mother, sister, brother were sitting

[514] Interview with Madhuwanti Tuladhar, General Child Rights Coordinator, Plan International, Kathmandu, 13 May 2014.
[515] Interview with Dilli Gurugain, Senior Advocacy, Child Rights Governance and Child Protection Specialist, Save the Children, Kathmandu, 23 May 2014.
[516] Interview with Krishna Giri, DME Specialist, World Vision, Kathmandu, 10 April 2014.
[517] Interview with Dilli Gurugain, Senior Advocacy, Child Rights Governance and Child Protection Specialist, Save the Children, Kathmandu, 23 May 2014.
[518] Interview with Madhuwanti Tuladhar, General Child Rights Coordinator, Plan International, Kathmandu, 13 May 2014.

one room and if we take the children far away other people are looking[519]". Another challenge identified is the medias influence, and that, "the government should be regulating the private sector, regulating the private sector so the private sector respects the rights of children, that's the role of the government, but probably our government has not been able to focus on that particular issue because there are so many different issues at the moment and the state is in a transitional phase …[520]". One INGO asserted that, "The main problem what I find is that we do the consultation with the children and all those things but after all even the researchers will not bring the different perspectives of the children than the adult…[521]", pointing out that even after the research has been conducted and information has been taken, it is primarily left to the researcher to interpret the findings and make decisions on behalf of the children and indicating that some organisations and institutions that do research on children do not ensure the child rights at the same time[522].

3.1.3 Academia

For the purpose of this research two universities were interviewed to comprehend their understandings of ethical practices and ethical consideration when researching with children. In the following institutions, research was conducted by individual students, as well as the research teams in the university. It has been suggested that there is no formal code of conduct or specific child protection policy but when conducting research students formulate their own guidelines and ethical consideration dependent on their specific topic when submitting proposals. Hence, "they have to think about the ethical issues that we have to be careful, they also mention themselves some sort of ethical issues and we also ask them to see different policies or different guidelines, different rules and regulations, different laws that have been developed in our contexts by different institutions[523]". Furthermore, "if our students are working on

---

[519] Interview with Krishna Giri, DME Specialist, World Vision, Kathmandu, 10 April 2014.
[520] Interview with Dilli Gurugain, Senior Advocacy, Child Rights Governance and Child Protection Specialist, Save the Children, Kathmandu, 23 May 2014.
[521] Interview with Madhuwanti Tuladhar, General Child Rights Coordinator, Plan International, Kathmandu, 13 May 2014.
[522] Ibidem.
[523] Interview with Tika Gautam, Professor of sociology and Anthropology, Tribhuvan University, Kathmandu, 11 May 2014.

those sensitive areas, we ask them to seek the different acts which are formulated by the government[524]".

When questioned about whether there is a need for a policy or guideline nationally one partaker asserted, "I don't think so because in research issues that mostly the ethical guidelines in the core academic fields not only policy sector, if it was created in the policy sector it would be more useful and benefit for that purpose but what we think is that academically, while we are doing research, the academic scholars or the students, they should themselves be aware about the ethical issues.[525]". Nevertheless, although claiming that students themselves need to be aware of ethical consideration it is promulgated that, "if the state or the government develops such kind of ethical guidelines it would also be more helpful for the students, because they have to check themselves what different ethical issues have been developed by the state or the government and what we are learning in our course books, and how do they match[526]".

It is asserted that in academic institutions, the student researchers, "don't go to an ethical review board because we do not have it but what we do is they take approval from our institution[527]". Furthermore, it was identified that although there is the NHRC, "the health research council has its own ethical board and I think its not allowed to ask, it works only works for the health research council within that one, neither it supports or interferes with research in other areas, no other researcher or institution go there to take permission from that ethical board[528]". Furthermore, another university academician indicated that recently approval was taken from the ministry of women and children's social welfare through an acceptance letter. Suggestively, only approval is given, monitoring of research in practice is not done, and students are left to be independent researchers[529].

---

[524] Interview with Rajat Bastola, MA, Kadambari College, Kathmandu, 25 May 2014.
[525] Interview with Tika Gautam, Professor of sociology and Anthropology, Tribhuvan University, Kathmandu, 11 May 2014.
[526] Ibidem.
[527] Ibidem.
[528] Ibidem.
[529] Interview with Tika Gautam, Professor of sociology and Anthropology, Tribhuvan University, Kathmandu, 11 May 2014.

When asked whether there is a need of an institutional review board one participant identified that, "in the discussion on national level workshop, participants including us have raised the issues, and the ethical issues, so if the government has formed the ethical board and the different proposals are reviewed by that ethical board, then they can do their research based on those rules and regulations and conditions that have been given by that ethical board, and also provides the guidelines, supports in different ways and also suggests to do or not to do the research in that particular area[530]". Furthermore, one contributor claimed that it is required, as in research, "…the basic objective is for some kind of intervention but some researches are just highlighting the issue and just doing it, so there should be a body to see whether to implement things or not, and this would monitor every part of research[531]". When asked about who could actually take such a position in Nepal one partaker stated, "I think the central child welfare board could be board, could be one body because it's another ministry and could look after what is going on[532]". On the contrary, it was asserted that the composition of such a body should be, "… a miscellaneous one, I think non of the single unit, because ethical issues are related to top to bottom level, that may be institutional to the individual… so there must be a combination of different people from different institutions and organisations, so that board may not be from a single institution I think because ethical issues are very serious and sometimes they are related to local people, sometimes institution, somewhat the state, so it must be a combination of different experts[533]". When asked about accountability and penalization of ethically wrong researches involving children one interviewee maintained, "that should not be, penalization is maybe in the case of when the rules and regulations are effective in the country[534]", on the contrary another contributor asserted, "they should be held accountable, most organisations have now the ethical values but in practice who is there is monitor[535]", but agreeing that this is only possible when regulations are set.

---

[530] Ibidem.
[531] Interview with Rajat Bastola, MA, Kadambari College, Kathmandu, 25 May 2014.
[532] Ibidem.
[533] Interview with Tika Gautam, Professor of sociology and Anthropology, Tribhuvan University, Kathmandu, 11 May 2014.
[534] Ibidem.
[535] Interview with Rajat Bastola, MA, Kadambari College, Kathmandu, 25 May 2014.

With regards to training both contributors claimed that they provide training sessions and orientation classes, which teach the students or researchers in an orientation class how to conduct research in the beginning of their respective studies or orientation. However, it is identified that only one of the initial days, ethical issues are discussed on how to be ethical in secondary as well as primary data collection[536]. It is proposed that although there are significant differences between academic and non academic research, "the ethical guidelines that has to be followed in non academic research should also be the same one in the academic field, so both researchers in the non academic and academic field should be aware of all kinds of ethical issues because they are equally important for stakeholders and civil society[537]". Moreover, this participant suggests that training of researchers can be provided in the academic field. When one interviewee was asked about whether the institutional review board could be a training facility or look over training of researchers it was claimed that, "CCWB can be the one but it has many functions so we can have another separate body to only look after the research so that we can ensure the quality, but I'm not sure about CCWB because they cant do so many things, so if they have a special body or special branch only to do monitor the research, then it would be good[538]".

Both participants maintained that consent cannot be obtained in written form, "it's verbal, because many of the children they do not know how to write or read and similar things so they take permission verbally[539]". Additionally, "First we took it from the parents but when we were in the field we found difficulties, we found that it's not possible to take it from the children who are below 10 years old because they cant understand[540]". Moreover, "there are many issues and different factors that the students or researcher should take into account like if you work in hotel child labour you have to take permission from both, the master of the hotel and also the children, if there are also parents they have to take permission from the parents, so they have to ask those things

---

[536] Interview with Tika Gautam, Professor of sociology and Anthropology, Tribhuvan University, Kathmandu, 11 May 2014.
[537] Ibidem
[538] Interview with Rajat Bastola, MA, Kadambari College, Kathmandu, 25 May 2014.
[539] Interview with Tika Gautam, Professor of sociology and Anthropology, Tribhuvan University, Kathmandu, 11 May 2014.
[540] Interview with Rajat Bastola, MA, Kadambari College, Kathmandu, 25 May 2014.

with the children or not because sometimes they information that has been taken from the child may harm their life again if its known by the master or sometimes it may harm to the parents of the child…[541]". Furthermore, one contributor stated that especially when conducting interviews with children under the age of 10, they faced problems. However, when this occurred parental consent was obtained and, "it was written, we explained about the research and the objectives and how we are doing and why we are doing this, and after that they agreed and then we made them sign and if they were skeptic and want to leave in between we let them[542]". Suggestively, the parents and children received information as to the objectives, and reasons for their participation. With regards to this, one participant highlighted, "you need to be prepared about what language you are taking, how you phrase the sentence and how, if you have adults you can say, this is the consent form and this will be confidential. But in the case of children it may be different ethics, so I think it's a very challenging job to tell students that we are following some guidelines[543]".

One contributor highlighted the importance of considering harms and benefits, but claimed that, "I think it is in policy research but we are working on academic research. Our research is pure research and it is not possible to do this kind of comparison, cost benefit like of things, if it's a policy kind of research I think its necessary and also it should be done.[544]". On the contrary, another academic researcher addressed the issue of harms occurring anytime of the research, and that the researchers, "most of the time they are not prepared, in paper we have been talking about this ethical issues, in paper we know it, but in practice its very difficult, sometimes we force again and try to rephrase the sentence and questions again and again to get the answers and in some cases I've also seen the practice like calling for some kind of training and all and giving them good things to eat and taking information[545]". It was recommended that, harms and benefits should be considered by the students and research teams. However,

---

[541] Ibidem.
[542] Ibidem.
[543] Ibidem.
[544] Interview with Tika Gautam, Professor of sociology and Anthropology, Tribhuvan University, Kathmandu, 11 May 2014.
[545] Interview with Rajat Bastola, MA, Kadambari College, Kathmandu, 25 May 2014

the participants did not adequately state what measures would be in place to counter forms of harm.

One of the respondents claimed that they try to keep a safe environment when research involves children as, "…we try to take it in the safe environment but it also depends on the time you take it,[546]", but doesn't further iterate where these interviews are taken. With regards to storage and access of data one participant stated that, "we usually store in our locker, we don't have a special storage but we try to keep it as confidential as possible[547]". Furthermore, "we limit them to collect the information which is only useful for their dissertation so they collect information which is necessary for a dissertation… they write in the dissertation and thesis and they provide to the department and university which is made public[548]".

Disseminating the findings one of the participants identified that, "till now its only to get the degree, the dissemination is only in the department and if the dissertation is very beautiful or it is very high quality dissertation we refer it to an institution who asks for high quality research and sometimes we also disseminate to the foreign university for the scholarship[549]". On the contrary, another participant claimed they disseminate their findings, "to all the organisations we disseminate and other to parents and children, and we also acknowledge the children as respondents, but if we have used children to get other children or we have involved in one way or other the children, then its very necessary to acknowledge them in the research[550]".

With regards to compensation, one contributor stated that participants in researches are not provided with any form of compensation and that, "monetary compensation on behalf of the organization is ok, if they have some grants and can help the children its ok. But only for the sake of getting information is not[551]". The other academic contributor claimed that the researchers or students may have compensated in one way or another, but minimally as, "they are self funded, so that compensation or

---

[546] Ibidem.
[547] Ibidem.
[548] Interview with Tika Gautam, Professor of sociology and Anthropology, Tribhuvan University, Kathmandu, 11 May 2014.
[549] Ibidem.
[550] Interview with Rajat Bastola, MA, Kadambari College, Kathmandu, 25 May 2014
[551] Ibidem.

support may be very minimal, maybe meal, some breakfast, maybe some piece of clothes, maybe primary health care, medicines, that sort of things they give, they do not provide these things thinking that its compensation for their time[552]", further claiming that children, "might have feelings, they might be happy to talk about problematic things or feelings so our students may not give this kind of compensation but based on their sharing's they support[553]".

Both academic institutions maintained that the research on children was less participatory, and they are only involved in participating in the data collection as one participant emphasized, "if children are involved in the research process they will not be able to help in every aspect but if we take their consent or take their views and if we involve them when they are big enough like volunteers [554]". Hence, although information was distributed to the children and people concerned, participation was considered minimal in their researches.

One challenge recognized by a participant was how ethical guidelines can make research more ethical. The participant pointed out that, "from the ethical point of view what I think is whether the children are actually interviewed from a humanitarian perspective because ethical guidelines that does not tell about it, whether if we do research on child is good or bad, or to some extent it is good and to what extent it is bad, there is no any criteria and boundaries of identifying what's good and bad area of doing research but whatever they do I think it's a good point of view is that it shows the realistic scenario of the child living in our society and also it is the structure of society[555]". Another participant pointed out that, "most of the cases I have already told, voluntary participation and informed consent is easy to say but how we put that in the case of children, that's very difficult and other thing is like the questionnaire may sometimes hurt them and we don't know, because when we do research we have read

---

[552] Interview with Tika Gautam, Professor of sociology and Anthropology, Tribhuvan University, Kathmandu, 11 May 2014.
[553] Ibidem.
[554] Interview with Rajat Bastola, MA, Kadambari College, Kathmandu, 25 May 2014.
[555] Interview with Tika Gautam, Professor of sociology and Anthropology, Tribhuvan University, Kathmandu, 11 May 2014.

some literature so we have expectations of getting this but if they want to answer or not is something we need to be aware about[556]".

3.1.4 Research Institutes

A research institute is an establishment endowed for doing research. Research institutes may specialize in basic research or may be oriented to applied research. Although the term often implies natural science research and health related researches, there are also many research institutes in the social sciences as well. For this research, two research institutions were contacted and interviewed, furthermore it is important to note that although research institutes are mostly independent in nature, they are often ad hoc organisations to universities and may fall under the auspices of them respectively.

No specific child protection policy or code of conduct but one of the participants claimed to, "follow all the ethical guidelines because in our past we have had experience of working in the field[557]". Another key-stakeholder claimed that, "I don't know if there is anything, academically in our projects we say we take care of the ethical, we have ethical considerations and we take all the important finds but legally I don't know, we don't go by the legal system that way but the universities have its own system.[558]". Both interviewees suggested that following ethical guidelines can safeguard the children and their rights, nevertheless, "taking children as a subject is a different thing and involving children in the research is a different thing, so we try to really involve the children, its not just asking them, involving them in discussions, in drawings, that way we are not only taking the kids only as a subject as a part of the research, so that's how we usually try to do[559]". It was identified that the NHRC is the ethical review board that is responsible for approval but that it is primarily health related, "and in other cases the ethical committee of the funding organization, they pass it, like they have their own committees depending on which organization is funding our study, they have their own committees and they pass it.[560]". On the contrary one participant stated, "No, actually the university has to do that...we do not need to go

---

[556] Interview with Rajat Bastola, MA, Kadambari College, Kathmandu, 25 May 2014.
[557] Interview with Pranita Thapa, Research Officer, New Era, Kathmandu,16 May 2014.
[558] Interview with Krishna Shrestha, Professor of education, CERID, Kathmandu, 8 June 2014.
[559] Ibidem.
[560] Interview with Pranita Thapa, Research Officer, New Era, Kathmandu,16 May 2014.

anywhere for approval, but again when it comes to collaborative research with other international organisations, so at that time we need to look at what are the ethical considerations[561]".

When asked whether there is a need for an ethical review board designed for research involving children on participant stated, "yes definitely, that's we have thinking, that there is besides the NHRC. The NHRC primarily do the health thing but of course they say that any kind of research involving human subjects should be passed and all but yes for all the special reasons for a child[562]", and another specified, "so far I don't think there is anyone, only some child rights activists they may be talking about that, but there is no institutional body to look after those things, that's what I'm really concerned about[563]". Responsibility of taking such a position was considered as, "maybe NHRC also should look at that part, research council… maybe all those organisations working on child rights, prevention and all those things they should come up with something like in the research field also they should come up with this idea forming a national body, so whoever does research with children[564]". When asked about who should be responsible of establishing such a body and policy it was claimed that, the, "government needs to develop some policies and programs … the government should have a policy and also a program to check that, but at the same time the organisations, NGO's, the private sector or even the civil society needs to form such an organisation who can take care of such issues.[565]". Suggestively, this body needs to be effective as, "we have limited time and we have to finish the project in such limited time and if that board is going to take a long time to approve our research proposal, that's going to create lots of problems so in that way it should be prompt, it should be like giving guidance, like a mother figure thing, that would be good and really helpful[566]".

When asked about accountability and possible penalization of researches one participant specified that penalization should be done in both, "organizational research

[561] Interview with Krishna Shrestha, Professor of education, CERID, Kathmandu, 8 June 2014.
[562] Interview with Pranita Thapa, Research Officer, New Era, Kathmandu,16 May 2014.
[563] Interview with Krishna Shrestha, Professor of education, CERID, Kathmandu, 8 June 2014.
[564] Interview with Pranita Thapa, Research Officer, New Era, Kathmandu,16 May 2014.
[565] Interview with Krishna Shrestha, Professor of education, CERID, Kathmandu, 8 June 2014.
[566] Interview with Pranita Thapa, Research Officer, New Era, Kathmandu,16 May 2014.

or institutional research, not only the individual researcher but also the organisation should be penalized for the wrong doing[567]". On the contrary, one participant claimed that, "I can't say…they are wrong. But I believe that all the organisations and research organizations, they share that they are ethically bound to follow these things, but I don't know, I cant say about other organisations but as a research institute we have certain ethical guidelines that we follow, I think all the organisations do it but penalization, I don't know [568]", also iterating that a body is needed and this is lacking as no one can be held accountable for misconduct and everyone follows their own agenda.

One of the research institutes stated that they get funded by both international as well as donor agencies which approve the researches in their own country and if related to health of the child, approve the research by the NHRC and claimed that, "once we had research done among children who were violence affected and there we had an ethical committee in-between us, some distinguished people who were in the committee and they reviewed the papers and questionnaires[569]". They claimed that the influence of funding agencies is entirely up to the respective donors and, "it depends, like some of them want to be involved in each and every step of the way, as we move on they want to be informed about it and want to be told they want to be part of the decision making and everything while others, there are also other clients who once assign the project or assignment, that's then entirely our responsibility[570]". On the contrary, one partaker suggested that, "so far as I said I have been working with international organisations for more than ten years and basically they don't interfere at all, sometimes we do national case studies, its international but I was involved in so many national, and we get international kind of template, for conducting the research that[571]".

One of the participants maintained that all organisations provide training to their enumerators and researchers as, "no study can be taken without training, without training the research members, they have to know they are going to the field, why they are going to collect data, what are the risks of the study, who are the study populations,

---

[567] Interview with Krishna Shrestha, Professor of education, CERID, Kathmandu, 8 June 2014.
[568] Interview with Pranita Thapa, Research Officer, New Era, Kathmandu,16 May 2014.
[569] Ibidem.
[570] Ibidem.
[571] Interview with Krishna Shrestha, Professor of education, CERID, Kathmandu, 8 June 2014.

they have to know it, so training is provided by all the research organizations as far as I know, its necessary, and yes informed consent and ethical things should be, it should be part of the training. [572] ". Furthermore, when asked about training on ethical consideration one addressed the issue and stated, "so actually you know, I don't think you can have a special training just on the ethical considerations, but the ethical should be part of every research[573]".

Both institutes claim that consent is taken in one way or the other. One addressed consent as, "its verbal as well as written, we make them understand tis not very easy dealing with the children, you feel like they have understood everything when they do not have, actually they haven't understood anything[574]". Further reinstating that, "you get the consent of the parents, you talk to the guardian and you talk to the child and you get that information[575]". Although both participants claimed that informed consent is necessary to maintain ethical standards it is not further iterated as to how and when exactly parental consent is obtained. One participant shortly highlighted obtaining parental consent or consent of the guardian while the other does not address parental consent at all. Furthermore, whether consent is renegotiable for participants is not addressed by both participants. Adequate Information has been addressed as the following by one institute, "we make it a point that they understand what, why we are talking to them, why they are there and why they have been selected, what is the procedure and what we expect from them[576]", and, "we do interact with the kids but we also make them understand why we are there and why we are discussing with them about the certain topics[577]". One institute pointed out that when studying vulnerable populations for example children and families affected by HIV/AIDS, that not all information is disclosed due to stigmatization in the community[578].

One participant indicated that harms and benefits are dependent on nature and objective of the study. Thus, "if we are going on a study which wants to know of the

---

[572] Interview with Pranita Thapa, Research Officer, New Era, Kathmandu,16 May 2014.
[573] Interview with Krishna Shrestha, Professor of education, CERID, Kathmandu, 8 June 2014.
[574] Interview with Pranita Thapa, Research Officer, New Era, Kathmandu,16 May 2014.
[575] Ibidem.
[576] Ibidem.
[577] Interview with Krishna Shrestha, Professor of education, CERID, Kathmandu, 8 June 2014.
[578] Interview with Pranita Thapa, Research Officer, New Era, Kathmandu,16 May 2014.

condition of the HIV affected children, then we go to the families that are affected, if you want to know about the displaced children we do our sampling in such a way that displaced children are included[579]", Another research institute claimed that they use stratified and random sampling and harms and benefits are considered in the initial phase in the process of "designing the research methodology.[580]". The measures in place to minimize harm were identified as training of researchers prior to investigation, protection of identities through anonymity, and a referral system when children are identified as vulnerable. Both participants identified that when vulnerable children are interviewed, and there is a form of distress, researchers provide referral services and counseling to the participants.

With regards to confidentiality, one of the participants specified that, "we don't take the names… and no information shared with anyone[581]". However, "sometimes its very difficult because your research ethics does not tell you to maintain the privacy at any cost, but it happens that working in such vulnerable population, it happens such that it becomes important to give some counseling[582]". When asked about confidentiality and anonymity of participants another stated, "usually yes, we go through a large number of kids and sometimes we look at the figures we don't identify the individual kids, they are merged into a certain number and then we are basically going with the percentage[583]".

Both partakers claimed that issues arise with regards to the setting of the interview as, "sometimes its very difficult to talk to the child in a very private setting also because the mother, the father, the uncle, the friends, they want to be part of it so in that cases we have to meet the child once, twice, thrice, to get the information[584]". When asked whether they speak to the child privately one participant stated that, "sometimes it happens, practically, they just don't want to leave the child with us,[585]". Furthermore, another interview shared an experience where, "the parents slapped the

---

[579] Ibidem

[580] Ibidem.

[581] Interview with Pranita Thapa, Research Officer, New Era, Kathmandu,16 May 2014.

[582] Ibidem.

[583] Interview with Krishna Shrestha, Professor of education, CERID, Kathmandu, 8 June 2014.

[584] Interview with Pranita Thapa, Research Officer, New Era, Kathmandu,16 May 2014.

[585] Ibidem.

kid, a 4 year old child just for not being able to answer my question. So you know it was really painful for me to see that because for my reason this kid got slapped, and it was not his mistake at all, you know it doesn't mean whatever question I ask the kid needs to have an answer so that kind of thing happens[586]". This is further maintained as, "sometimes we say, a guardian or parent has to be there, but we cannot be sure that that particular parent or guardian is child friendly, that the child trusts that particular parent or guardian[587]". Both interviewees claimed that data was safely stored and inaccessible for outsiders, the procedure followed was that, "the data collectors give the information to the supervisor, the supervisor is responsible to keep it with him or her, he or she has access to the information and from there it is transported to our office where every, secrecy and privacy is maintained in all the steps, they stored with password protected computers[588]", this was agreed by the other research institute claiming; "so they are all stored in our computers and we do have backups if something goes wrong then we have some problem and its all stored in the computer[589]".

One contributor indicated that there's a gap between theory and practice in ethical consideration, as when researchers are involved in remote areas, "you are a stranger, you are a new person coming from a city, you attract that and get the attention so when you talk to the child obviously, the other child or the other community people start asking questions...[590]". Furthermore, researchers are instructed that, "if you feel that there are any kinds of risks and harm that you're talking might cause to the child then don't talk, so better having one less respondent in our research than putting them into a vulnerable situation or into harm, so all our researchers are given instructions, strict instructions.[591]". Moreover, the health related institute claimed that dissemination of the findings is not done so stigma is not inherent, especially on the individual level[592]

---

[586] Interview with Krishna Shrestha, Professor of education, CERID, Kathmandu, 8 June 2014.
[587] Interview with Pranita Thapa, Research Officer, New Era, Kathmandu,16 May 2014.
[588] Ibidem.
[589] Interview with Krishna Shrestha, Professor of education, CERID, Kathmandu, 8 June 2014.
[590] Interview with Pranita Thapa, Research Officer, New Era, Kathmandu,16 May 2014.
[591] Ibidem.
[592] Interview with Pranita Thapa, Research Officer, New Era, Kathmandu,16 May 2014.

where as the other pointed out that children were actively involved in the outcomes and evaluation of the outcomes, giving an example of a school based research[593].

With regards to compensation, one interviewee explained that, "we make it a point that we tell all the children that yes, you are talking to us and giving us information that is very important, which will go on in the long run to help children, like you tell all those things but we don't allow giving any compensation[594]" and, "The information you provide us are going to be vital in making such programs perhaps or for policy makers, but we are not doing anything for you directly, that we do every time.[595]". However, further this participant stated that when numerous interviews are conducted with the same people and children they, "might just give a little bit of a small gift.[596]". Another partaker stated that as the research is taking place they, "provide some snacks, something, for the kids to enjoy, the other is we distribute pens and pencils, papers...[597]", As a token of appreciation. The former interviewee asserted that for practical reason, they have recompensed for transportation costs.

One partaker highlighted the issue of when children are participating and they are income generating children, "if a person has to give their child a few times we have to compensate it because its sometimes their income, because the child might be getting some money for their labor work but if you are not compensating its not good for them, but at the same time you know if you are paying then the person is just speaking for the money, so that is again an issue but we don't encourage to do this[598]". This participant pointed out his concern of monetary compensation as it spoiled the children, especially who were income generating as they were getting paid more for a 2 hour interview than a days work, and further stated that in the practice, "we changed our modality and then we started to give something compensation like, like distributing soaps, for the hand washing or even distributing tea, tea bags and sometimes we even used sugar, half a kilo of sugar[599]".

---

[593] Interview with Krishna Shrestha, Professor of education, CERID, Kathmandu, 8 June 2014.
[594] Ibidem.
[595] Interview with Pranita Thapa, Research Officer, New Era, Kathmandu,16 May 2014.
[596] Ibidem.
[597] Interview with Krishna Shrestha, Professor of education, CERID, Kathmandu, 8 June 2014.
[598] Ibidem.
[599] Ibidem.

Both participants asserted to use participatory methods of data collection, where one was more likely to use individual interviews and the other the use of focus group discussions. One participant claimed that, "sometimes it's on children and sometimes its with children. Its both ways[600]", however, children are not included in the planning or interpretation and are primarily only involved in the data collection when they are interviewed and observed[601]. Furthermore, the second participant stated that children are actively involved and gives an example of children in school, who in collaboration with the teachers, school management and the parents, had a significant impact on the participation and outcome of the study as, "the voices of the children is more strong than and more powerful, and they know what changes they need to have [602]". Additionally, in the health related key-stakeholder it was claimed that, "they always have and their views are taken into account, they are noted down and we do make it a point to see through everything that they are saying.[603]". However, she further states that, "I think we have been fair enough not having children because our studies are basically what are their health status, that's basically what our researchers need to understand, so that can be understood without their participation in the process[604]".

One major challenge and issue identified by one of the research institutes was cultural differences within nepalese communities as, "Nepali people don't use the other language groups and at that time even the parents and not only the kids, their view is so different, and using beatings, abusive verbal language is very common in some communities[605]", pointing out that they had to reevaluate the way they would research with the community. The research institute primarily working on health related issues claimed that getting general information is not an issue as, "you get the consent of the parents, you talk to the guardian and you talk to the child and you get that information, whatever, you want to know their heights, their weights, what they eat and all that, that's quite easy[606]", but when it comes to vulnerable population ethical issues arise as

---

[600] Interview with Pranita Thapa, Research Officer, New Era, Kathmandu,16 May 2014.
[601] Ibidem.
[602] Interview with Krishna Shrestha, Professor of education, CERID, Kathmandu, 8 June 2014.
[603] Interview with Pranita Thapa, Research Officer, New Era, Kathmandu,16 May 2014.
[604] Ibidem.
[605] Interview with Krishna Shrestha, Professor of education, CERID, Kathmandu, 8 June 2014.
[606] Interview with Pranita Thapa, Research Officer, New Era, Kathmandu,16 May 2014.

to handle the situation and in these cases, "such researchers need to be backed up by good programs and service centers, or services that can really help the child[607]". Furthermore, this participant stated that, "In our rural context and community context its very difficult to talk to the child in a private setting, so a researcher has to make it a point that in order to sometimes we say, a guardian or parent has to be there, but we cannot be sure that that particular parent or guardian is child friendly[608]", suggesting that privacy and confidentiality are not always as easy to maintain as it is suggested in guidelines and policies.

3.1.5 Governmental Organisations

Governmental child rights orientated organisations were interviewed consequently, to establish an understanding of what the Nepalese governmental organisations view is on ethical research practices involving children.

It has been suggested by a governmental organization that child protection policies exist on national level, which need to be followed by all researchers as, "we have, an act is also a sort of a guidelines actually, right? We have the children act, we promulgated it after ratifying the UNCRC in 1990 and then we have regulation on children, we have child labor offence and punishment act, we also do have child policy which just came into affect in the last 2 years, and we have a national policy on children, national plan of action on children, and we also have the guidelines to run the child welfare homes, so we do have different kinds of policy documents, actually they are sort of guiding documents to work in this area especially child protection, child right promotion and child development per se[609]". Nevertheless, it is claimed that, "explicitly in work form we normally do not have any ethical code of conducts[610]". On the hindsight, another governmental organization claimed that, "we have children policy...not child protection policy ...we have children policy and that has mentioned many things about child protection but I think it has not mentioned about ethical

---

[607] Ibidem.
[608] Ibidem.
[609] Interview with Dr. Kiran Rupa Kheti, Chief of Child Labor Program and Child Rights Protection Section, Ministry of women and children social welfare, Kathmandu, 4 June 2014.
[610] Ibidem

consideration relating to child protection with ethical consideration.[611]". Furthermore, it was asserted that, "No. Legally...I am the student of law also. Legally there is not any ethical consideration developed by government but may be some research institute or some NGO or some INGO may have these guidelines.[612]".

When asked about following guidelines on the field it was claimed that guidelines were created accordingly to researches through a committee in the ministry "but we don't explicitly mention the ethical part actually, so far[613]". Both governmental organisations stated that the organisations in Nepal have in some way or another formulated their ethical considerations while researching on children, but on contributor expressed his concern as they, "are just telling that they are following international guidelines. I know nobody goes through that international guidelines....[614]", further iterating on his own experience working in different organisations as, "I have worked with many...so called research organizations/researchers but they never told me that this is the ethical consideration..[615]". What they ensured was that, "They taught on how to gather the information but they didn't talk on the ethical consideration topic. But they did focused take the consent. There is a legal obligation to take the informed consent. They have been following that law. But they have practically maintained some ethical concerns but not given training on ethical aspects.[616]". Nevertheless, further claiming that although they didn't provide ethical checklists or trainings "… they have kept in the back of their mind about CRC and best interest of child and how by creating child friendly environment the questions should be asked to the children...these are in practice practically but theoretically or giving training... its not done... [617] ". Ethical considerations have been written down in reports but, "There is the need of such ethical

---

[611] Interview with Jhanahari Bhattarai, Title, Central child welfare Board (CCWB), Kathmandu, 10 June 2014.
[612] Ibidem.
[613] Interview with Dr. Kiran Rupa Kheti, Chief of Child Labor Program and Child Rights Protection Section, Ministry of women and children social welfare, Kathmandu, 4 June 2014.
[614] Interview with Jhanahari Bhattarai, Title, Central child welfare Board (CCWB), Kathmandu, 10 June 2014.
[615] Ibidem.
[616] Ibidem.
[617] Ibidem.

consideration for the field workers, not for the person who writes the report. So I don't know if they follow them or not.[618]".

Both governmental organisations asserted the need of a body who can take such a responsibility of creating a code of conduct or child protection policy one interviewee specified that, "Research based child protection… I think it has not mentioned such things. But it is important. It is necessary. It can help for child protection. Actually we need such policy also. If we develop such guideline, we will incorporate child protection issues on that guideline[619]". When asked about ethical approval from an institutional review board, one contributor addressed this issue by stating that, "no we don't need any approval. According to existing rule of the land we do not need any authority to do that, because its under our demand, research involving children, women, social welfare falls under the prerogative of my ministry, so we do not need to get any approval from the external agencies[620]". The other interviewee claimed that their organization does not research and it is strictly on "monitoring activities/monitoring work.[621]".

When inquired whether there is an ethical board or whether there is a need the respondent of the ministry claimed that, "yes to some extent, actually these years our budgets we have proposed to establish a center like that but ultimate goal is to create an institution like the Nepal health research council, actually that will be a authoritative body from which we need to seek permission before doing any kind of research on the domain of the children, so perhaps we are moving towards that direction but its in a conception phase and we are trying to allocate some budget for this purpose from this very..[622]". Further reinstated by the other partaker was that, "I don't know if I am clear but CCWB has established a research section. Within 2 years we will form a research council. Within 2 months, we will start the work of research and information section,

---

[618] Ibidem.
[619] Ibidem.
[620] Interview with Dr. Kiran Rupa Kheti, Chief of Child Labor Program and Child Rights Protection Section, Ministry of women and children social welfare, Kathmandu, 4 June 2014.
[621] Interview with Jhanahari Bhattarai, Central child welfare Board (CCWB), Kathmandu, 10 June 2014.
[622] Interview with Dr. Kiran Rupa Kheti, Chief of Child Labor Program and Child Rights Protection Section, Ministry of women and children social welfare, Kathmandu, 4 June 2014.

which will prepare ethical guidelines. The organization/institutes that are going to conduct a research will have to come to CCWB, seek approval, get their content finalized and see duplication. We will start the work from 2 months but to be as the research council, it will take around 2 years. There is no foundation. We do not have a mandate. So we will draft the mandate[623]".

Both contributors asserted that the CCWB will be taking the position of becoming the institutional review board, for example one stated that, "we are planning to have this sort of body to be the CCWB, the child welfare board at the moment but that body will be directly monitored by the ministry also, I mean it can be kept anywhere, it doesn't matter as long as it works smoothly actually, performance and delivery is important thing, rather than in which domain it should remain, so we are free to think about it and at the moment we have proposed it and most probably one of the entity, the central child welfare board[624]". When asked whether they themselves can take such a position it was claimed that, "of course, yes, but for that to happen the existing human resources are not adequate so perhaps we have to add more human resources within the ministry, and perhaps this unit needs to be further expanded in terms of human resources and in terms of the scope that has been vested on this section and on this unit, of course the possibility is there and we are very much positive[625]". Furthermore the contributor stated, "we recently forwarded a proposal to Ministry of Women, Children and Social Welfare and it has passed the program for the next fiscal year and they have included that program ... And they have included that program and after 2 months actually...after 2 months we will start the activities. First we will develop a guideline of that research and information section and that section will produce some sort of guidelines to do research or to monitor the research and research institute and content and ethical consideration while doing research.[626]". However, further stating that, "We will start some activities. We don't have now. We don't have ethical

---

[623] Interview with Jhanahari Bhattarai, Central child welfare Board (CCWB), Kathmandu, 10 June 2014.
[624] Interview with Dr. Kiran Rupa Kheti, Chief of Child Labor Program and Child Rights Protection Section, Ministry of women and children social welfare, Kathmandu, 4 June 2014.
[625] Ibidem.
[626] Interview with Jhanahari Bhattarai, Central child welfare Board (CCWB), Kathmandu, 10 June 2014.

consideration. We have to draft that. We have to ...Ministry should approve that ethical consideration then only we can implement that. It takes time but we will start our activities after 2 months definitely.[627]". Although it was not stated how the review board will be composed it was stated that, "We will discuss about the ethical consideration while researching with children with child right based organization, with the other experts who are working in child research...we will consult with them and we will finalize the ethical consideration guideline.[628]"

It was claimed by both organisations that researchers and organisations will be accountable for misconduct only, "once the entity is there and is guided by the policy guidelines and procedural guidelines, then definitely those will violate, will be brought into justice[629]", further iterating that measures will be figured out by reviewing the literature, "and see what is the practice all over the globe and also consult the experience of south Asia in which we reside and with experience and the bodies we will perhaps think about it and plan everything[630]". On the contrary, it was stated that individuals and organisations can already be held accountable, "Actually if their works violate the rights of children we can take action. We have such law.[631]", and, "It is not necessary to mention the researcher. Researcher if he harms the child he should ...get such thing...it is not necessary to mention like this. It is not possible in law to mention like that but if anybody violates children's right then they will be punished…[632]".

When asked about training and whether training on ethical considerations one participant stated that they, "normally doesn't do it because we carry out research with the head of the consulting forms, but before getting into contract with them, normally we give them clear instructions, how to get into the research and what areas are to be covered, so normally we provide some sort of guidelines for them and we have clear, what is the duration of the research and how to do it, what are the districts to be

---

[627] Ibidem.
[628] Ibidem.
[629] Interview with Dr. Kiran Rupa Kheti, Chief of Child Labor Program and Child Rights Protection Section, Ministry of women and children social welfare, Kathmandu, 4 June 2014.
[630] Ibidem.
[631] Interview with Jhanahari Bhattarai, Central child welfare Board (CCWB), Kathmandu, 10 June 2014.
[632] Ibidem.

covered…[633]". With regards to current organisations working in the field of child protection and the rights of the child one participant iterated, "I am not saying that they do not know or care about ethical considerations to be taken care of in the research process, all the NGOs, INGOs know about that, have read international guidelines but when I was involved in the research, the enumerators who took the information, they were not given needed training but all have worked and considered to create child friendly environment.[634]".

One of the participants claimed that up until now, no institutional body in Nepal is providing training on ethical issues in particular, and when questioned whether they themselves as an institutional review board may provide the training it is claimed that, "Yes both. We will approve, give some kind of permission to the researcher…research institute will get training; will build the capacity of such institute. We will give training definitely.[635]", however, "it is not giving training currently but we will have such provision. We will draft it…some guideline of that Research and Information Section…it is not actually section…now we will have research and information council and the mandate of that council will be capacity building, giving approval for research, giving approval…[636]". The other governmental contributor then further claimed that, "training and capacity development will be there, not only CCWB but also with the ministry also, it depends on the nature of the research and the coverage and the scope of the research as well, but its too obvious that you need to give training to the enumerator before sending them to the field, and more than that the issue of dealing with children is challenging job actually, you need to read the sentiment of the kids and you deal with them…[637]".

With regards to the influence of funding agencies, it has been asserted that, "Donor agencies determine what sort of result they want. It is not the researcher who

---

[633] Interview with Dr. Kiran Rupa Kheti, Chief of Child Labor Program and Child Rights Protection Section, Ministry of women and children social welfare, Kathmandu, 4 June 2014.
[634] Interview with Jhanahari Bhattarai, Central child welfare Board (CCWB), Kathmandu, 10 June 2014.
[635] Ibidem.
[636] Ibidem.
[637] Interview with Dr. Kiran Rupa Kheti, Chief of Child Labor Program and Child Rights Protection Section, Ministry of women and children social welfare, Kathmandu, 4 June 2014.

determines what sort of research result will be out. But donor who is providing the money, he will determine the result of the research here in Nepal. I don't think researchers are working independently.[638]", furthermore claiming that funding agencies do the current monitoring and evaluation of researches. It was further maintained that, "they are more concerned with this area rather than government entities themselves actually, because normally when they go for such interviews, in depth interviews or focus group discussion normally they get consent from the stakeholders[639]".

When asked how the consent procedure works it was claimed that up till now, getting informed consent was the main ethical 'obligation' and training of researchers is minimal. One partaker stated that, "you know to large extent yes we do, but you know I should be very honest in saying that all the researches may not have the knowledge in that time, and some of the enumerators are very raw type of people who have been giving one week or 2/3 days of training so some sort of violation of the privacy or confidentiality may be there but largely its honored and respected I think[640]", further sharing his experience when he was a researcher and did not get enough experience ebfore going to the field. The other participant claimed that it is more important to take consent from parents or guardians, "because it is thought that children are incapable of giving their own decision. Generally the children cannot make their own decision. So what is going to be the benefit of taking the consent from the children in the research? But we have to share the purpose and their participation should be ensured, informed consent can work...but...[641]", Further iterating that, "Because we say that children cannot take the decisions like the adults, so even if we take their informed consent...In terms of participation we can take the consent but if we see it legally, even if we take informed consent from them or not , take their signs or not..It is going to be invalid. That is not valid legally[642]".

---

[638] Interview with Jhanahari Bhattarai, Central child welfare Board (CCWB), Kathmandu, 10 June 2014.

[639] Interview with Dr. Kiran Rupa Kheti, Chief of Child Labor Program and Child Rights Protection Section, Ministry of women and children social welfare, Kathmandu, 4 June 2014.

[640] Ibidem.

[641] Interview with Jhanahari Bhattarai, Central child welfare Board (CCWB), Kathmandu, 10 June 2014.

[642] Ibidem.

Both participants stated that evaluating the harms and benefits prior to research initiation is necessary one claiming that, "unless until you go through the track record of the respondent its not advisable to make any research of them actually, probing them, asking them maybe sometimes re-victimizing them, reminding them about the trauma from the past, so you need to be very much careful before selecting your respondents[643]". Another pointing out that even informed consent has been taken, harms can occur as, "the child might not have known all the consequences...and not knowing that ...he might have provided the consent...but on the basis of the questions asked to the child...that effect might be long term...for example: if an orphan, or street children or sexually abused child is interviewed taking the informed consent... And its effect might be seen after 4 days....[644]", further stating that when this occurs researches can be held liable through legal measures.

The contributors claimed that compensation should be done, but assert that monetary compensation is not accepted generally. According to one participant "research principle or accepted principle it is not good. Really not good. If you are working with the child labor our law allows the children of 14-16 years of age to work... At that time you have to compensate but accepted principle of research does not allow compensating.[645]". Another partaker addressed the issue by claiming that, "it's a very difficult question actually… So when you involve them, perhaps some sort of compensation, maybe advisable but not always, you cannot pay kids in monetary form, you cannot give money to them, but perhaps some supplementary type of things for their studies could be done, for example you could give copies of books[646]". Moreover, it was claimed that children should not know prior to the ending of the research as, "we can consider the timings for the compensation. That means you are not going to tell the children "I will compensate you". If you say so then we can get any information, we might also get the wrong information, you might be alluring/motivating the child to give

---

[643] Interview with Dr. Kiran Rupa Kheti, Chief of Child Labor Program and Child Rights Protection Section, Ministry of women and children social welfare, Kathmandu, 4 June 2014.
[644] Interview with Jhanahari Bhattarai, Central child welfare Board (CCWB), Kathmandu, 10 June 2014.
[645] Ibidem.
[646] Interview with Dr. Kiran Rupa Kheti, Chief of Child Labor Program and Child Rights Protection Section, Ministry of women and children social welfare, Kathmandu, 4 June 2014.

answer and possibility of exaggeration. This will misguide the result of the research. So we can compensate in the end[647]".

When speaking of children's participation, "as far as the we are concerned we try to involve children, whatever the modality is, whether we do it directly or whether we do it with the INGOs, developing partners or NGOs so normally we ask them to involve children in all extent possible[648]". On the contrary, it was claimed that, "This is dependent upon the content of the research. This is not practical every time but it is better if there is participatory approach[649]". One contributor shared his experience of how children are participating and claimed that, "in some of the cases I mean the researchers are really successful to involve children but in some other cases I have noticed they are just made the subject of the research, without their real involvement, they are like silent witnesses at the corner and you just talk to the adult in the society, and you say that its finished[650]", furthermore expressing the concern that, "I also believe we have a big child participation issue in Nepal actually, you know child participation does not entail that all the time, physically we need to involve the children[651]", and, "we cannot really value their presence and we talk really about things their presence is meaningless in a way, so we need to be careful as a researcher where they should be involved[652]".

One contributor addressed the importance and positive aspect of participatory methods by asserting that, "When it is participatory it is more live, they cannot express everything verbally so you can get some clues from his appearance and their other behaviors. We can be face to face and talk with the children on one to one basis. We can use different tools. For example picture, drawing pictures. So while the child is drawing pictures we can sense on what matter the child is focusing. We can even teach the child

---

[647] Interview with Jhanahari Bhattarai, Central child welfare Board (CCWB), Kathmandu, 10 June 2014.
[648] Interview with Dr. Kiran Rupa Kheti, Chief of Child Labor Program and Child Rights Protection Section, Ministry of women and children social welfare, Kathmandu, 4 June 2014.
[649] Interview with Jhanahari Bhattarai, Central child welfare Board (CCWB), Kathmandu, 10 June 2014.
[650] Interview with Dr. Kiran Rupa Kheti, Chief of Child Labor Program and Child Rights Protection Section, Ministry of women and children social welfare, Kathmandu, 4 June 2014.
[651] Ibidem.
[652] Ibidem.

about the research process.[653]", furthermore reestablishing that, "If we want to be more children focused, we should follow child friendly methodologies. It is better to have child friendly methodologies. But in doing that we should stick to the international principles/accepted norms and principles[654]".

The governmental organisations stipulated a number of challenges that exist. One addressed that, "in the case of media… sometimes I feel that this issue of children and child issues is not duly taken care of the media, the news may come there, but its one of the middle pieces, so perhaps its still major item, consumable item for media,[655]". Furthermore, iterating that, "in Nepal the basic norms of research have largely been ignored actually, if you look at research articles, journal articles or papers, perhaps they don't have to cite but all write ups don't have proper citations, sorry to say that, one part is that and another part is the tendency of copying as in where its form, from the internet or wherever[656]". Another governmental participant pointed out that guidelines themselves can't make research ethical as, "We also were thought about creating a comfortable environment. Back of our mind we always have CRC, best interest of children. I think that is the ethical consideration. It is not necessary to write in paper...[657]".

3.2   Discussion of Findings

This section will discuss the results accordingly to the literature reviewed in chapter one and with respect to the research questions. Hence, we will initially look at the differences in experiences and practices of academic and non-academic researches were, whether the current ethical obligations are in line with internationally recognized standards as signified in chapter one, and lastly we will discuss what measures can be taken to improve the ethical 'environment' in research practices in Nepal. This will initiate the discussion of the need of an obligatory ethical mechanism e.g. ERB and a

---

[653] Interview with Jhanahari Bhattarai, Central child welfare Board (CCWB), Kathmandu, 10 June 2014.
[654] Ibidem.
[655] Interview with Dr. Kiran Rupa Kheti, Chief of Child Labor Program and Child Rights Protection Section, Ministry of women and children social welfare, Kathmandu, 4 June 2014.
[656] Ibidem.
[657] Interview with Jhanahari Bhattarai, Central child welfare Board (CCWB), Kathmandu, 10 June 2014.

code of conduct, and we will exemplify that there is a need of regulatory mechanisms to improve research ethics as specified through the accounts of the contributors and literature.

3.2.1 What are the Key differences and simillarities in practices between Non-academic and Academic Researchers?

As the results have clarified, there are a number of differences and views about ethical considerations when research involves children. Nevertheless, in this section we will look at the key differences and challenges between academic and non-academic researchers. When we speak of non-academic researchers we mean; international organisations, non-governmental organisations as well as governmental organisations, and subsequently academic researchers are primarily universities, colleges and individuals in research institutes. Hence, we will look at the key differences between academic and non-academic researchers.

There are major differences between non-academic and academic researchers in Nepal. Nevertheless, One of the major similarity in ethical considerations is the process of ethical review as there is no regulatory mechanism that reviews proposals when it comes to social research. Social Researches on children undertaken in non-academic fields do not have to seek ethical approval when conducting research on the ground unless it is subject to health related researches in which case, they are directed to seek ethical approval from the NHRC or when their funding agencies encourage such procedure. In this case, it has been suggested that funding agencies may also provide their own guidance and receive ethical review in the own countries. Nevertheless, as suggested by both; international organisations and non-governmental organisations, this is not compulsory and the NHRC does not have the measures in place to hold researchers and organisations accountable for misconduct. Moreover, it was suggested that even when approval was gotten from the NHRC, there is no monitoring of researches and that this is genuinely needed. As highlighted in the previous section, in academic researches ethical review is primarily made by university supervisors and potentially funding agencies that allow researches to be undertaken by students without any formal ethical clearance by any body.

Differences exist in numerous ways. Students are independently researching on the ground and ethical guidance is primarily left to the respective supervisors whereas non-academic researchers have specific rules e.g. the 2 person rule as mentioned by a researcher or work as a team. Ethical considerations are simply highlighted by students and they are free to go on and do their researches, even when the population studied is vulnerable e.g. street children. Hence, as mentioned in the literature and international guidelines, especially when dealing with vulnerable populations, researchers need to have referral mechanisms and supportive programs to engage the children when necessary and in this case, student researchers and academicians may not have that readily available. Furthermore, when dealing with such populations, researchers should have the experience or the guidance of someone who does. Hence, with regards to research undertaken by students, this is not in place and they are left on the field without any regular guidance in which case, children who they involve are disposed to to exploitative unethical research practices. Consequently, As suggested in the literature, university ethics committees should accordingly be transformed so that there is a better system for monitoring student researchers. It is difficult to estimate and understand how far academic researchers go into looking at harms and benefits and how they select children for researches, as it was mentioned they are left to themselves this creates an environment where unethical research practices can occur. In this case, non-academic key-stakeholders have maintained measures and risk-benefit analysis to understand the outcomes of the research as they are policy and intervention driven, whereas academics have been researching for their personal academic degrees.

Informed consent has been suggestively attained in both academic and non-academic institutions and is maintained as a necessary procedure. In Non-academic researches children are suggestively provided with adequate information and have the space and time to review their participation and are able to negotiate their consent but this is however dependent on the organisation and organizational level. This is however less so with regards to individual academic researchers where researchers go onto the field selecting children on their own accords and take interviews in the moment. Here it is not suggested that they don't take consent, but its not known what they do on the field as they are left to be independent researchers. In this case, negotiability of consent does

not exist and information is taken from children without any regulation and they are not given the space to acknowledge their contribution e.g. through approving the results and the dissemination of the findings by the participants. It is important to mention that suggestively, this is not necessarily in the case in research institutes, but primarily when individual students conduct research on children.

Suggestively, privacy, confidentiality and anonymity are of major issues in both academic and non-academic researches where it has been suggested that issues come up when research is undertaken on the field. Although non-academic researchers have provided locations where safety regulations and mechanisms exist to safeguard the child, some of the participants highlighted the issue of privacy and confidentiality being compromised on the field. Furthermore, the researchers in academic fields conduct interviews and questionnaires on the field where a curious local individuals or parents have interrupted researches. However, both academics and non-academic researchers have pointed out that this is a major challenge and given examples of how researchers have had to overcome issues of confidentiality. As suggested in the literature, the location plays as a significant viariable and should be considered dependent on the children and context.

One similarity between academic and non-academic researchers is the issue and consideration of compensation. In this case researchers in both fields have maintained that it's not a good practice to compensate children monetarily but still have compensated children in one form or the other. According to the literature this may signify incentives for participants, therefore, it should be discussed on a national level with key stakeholders what type of incentives should be viable when conducting research with children. Furthermore, as the literature suggested, there should be dialogue and communication with key stakeholders and community advisory committees to understand the nature of compensation, and create an age dependent model of reimbursement and compensation. Some participants highlighted the issue and need of compensating income-generating children, which may lose their income as a consequence of the research practice. As suggested in the literature income generating children should be compensated for their lost incomes accordingly but it should not result as an incentive for children.

With regards to participation there are major differences as non-academic organisations have tried to incorporate children's views through participatory methods and include them in various processes through focus group discussions, to child lead researchers, either with success or without, as suggested by the participants. Active participation of children has been enforced in non-academic research organisations, Peer educators and child lead researches have been done to incorporate the views of the children and further selection of research participants. However, as suggested by the literature, research is still adult centric and has been suggested by the participants, but there is a move towards research procedures that are more participatory and empowering of children which the participants have acknowledged and strived for. With regards to academic researches, participation is minimal, in which children are observed and the researcher have done questionnaires and individual interviews, hence, being forms of passive participatory methods in which children don't have much influence in the research processes and are retained their participatory rights. Furthermore, one research institute indicated that with regards to their research, participatory methods were not used because their research was based on health and in this case it was not necessary to include children's views. As the literature suggests, participation can improve credibility of data and consequently empower children by incorporating their views and therefore should be used in both social and health related researches.

A number of times it has been highlighted by key-stakeholders how much importance ethics plays in accordance to the media. Both academics and non academic institutions highlight the need to have ethical considerations for the media as often children and parents are filmed or photos have been taken where the individuals are not informed, constituting to possible harm through stigmatization and compromised confidentiality. As suggested in the literature, this is not in line with the international ethical guidelines. Hence, suggestively its not only research institutes and organisations that may consequently harm the child through their activities. Therefore, it is important to include different stakeholders to understand their experiences and practices further.

3.2.2 Are the current ethical guidelines and framework in line with the internationally recognized guidelines?

The current ethical guidelines and framework are based on medically related research practices in which the main focus lies in the gaining of informed consent and are based on the duty-based approach as suggested in the literature in chapter one. Although the respect for human rights is stated in the document, there is a lack of consideration on children and how these rights should apply. On top of that, guidelines from the NHRC are formed primarily for research conducted on health related issues and does not approve social researches. As suggested in the international guidelines and literature reviewed international guidelines have incorporated the provisions of the UNCRC and highlighted the need for children's participation and involvement in research processes. As Nepal has signed and ratified the UNCRC it lies in the auspices of the convention, which as suggested in the literature review, is the rights based approach. However, the code of conducts and guidelines that participants explicated are varying and are dependent on the respective institution or organisation, and either the participants claimed overlaps in tensions or leave out specific ethical considerations over others e.g. informed consent is seemingly the most important consideration. Furthermore, different institutions follow different regulations and rules dependent on their fields and experiences. There are various opinions and suggestions that have been made by the participants on having an ethical code of conduct or policy that ensures the safety of the child, and most participants have pointed out that they follow some ethical considerations when conducting research on children but the ethical obligations are limited and are not monitored. It is important to note that the non-academic organisations are primarily working on child rights issues and have protective mechanisms in place when conducting research. They have code of conducts and child friendly strategies in place and have dedicated their work on the protection of children where as academic institutions work on various issues and have more broad 'mandate'. Henceforth it must come to no revelation that the non-academic researchers are well better equipped and knowledgeable about research with children. On the contrary, researchers in academic fields, specifically universities do not have the same structures and 'ethical protection' and guidance when conducting research. Therefore, both non-

academic and academic researchers have pointed out that there's a need of a unified ethical code of conduct, which is nationalized, as no one knows who is undertaking what research. Suggestively, Ethical considerations are just written down on paper and not actively pursued which goes against internationally recognized standards, especially when dealing with children, as ethical issues arise at any given time, and context and should be accordingly measured. Hence, although formally ethical guidelines and frameworks seem to be in line with international standards, the practicality of it is not there.

Non-academic organisations have either formulated their own code of conducts and guidelines or are in the auspices of their respective international organisations. INGO's have inherited their respective international protocols and ethical code of conducts in the context of Nepal and have tried to incorporate the provisions in their guidelines and NGOs have seemingly followed through. Accordingly, the guidelines and policies that these organisations follow are in line with international ethical guidelines but as promulgated by the participants, ethical issues still arise even when guidelines and code of conducts are in place. Academic institutions suggestively follow their own ethical considerations that are promulgated by their respective institutions and when undertaking research, ethical considerations are in place, and adapted dependent on the research objectives. However, these again vary between institutions and organisations. A number of participants claimed that when they were in the field in the past, they were not directed to any ethical guidance or guidelines, which in accordance to internationally recognized standards is not in line. Furthermore, many participants pointed out their concern about the ethical considerations and how 'other' organisations were handling research, claiming that some organisations were simply undertaking research but did not necessarily work for children's protection.

3.2.3 What measures can be taken to improve ethical research involving children in the context of Nepal?

As initially highlighted in the literature and then further reinstated by the participants of this research, there are a number of challenges and issues with regards to ethical considerations in Nepal, both in academic and non- academic fields. Hence, now we

will look at the measures that can be implemented and applied to improve the safety and rights of the child when research is done on the ground. Firstly, it has been suggested that there's a need to nationalize an ethical code of conduct when conducting research involving, so that there is a common ground on ethical considerations with all key-stakeholders. However it is important to note that as the literature has suggested a numerous times, and in conformity to the governmental organisations point of view, guidelines, code of conducts and simple review of research proposals are not adequate for the ethical issues that arise in researches but should be in collaboration of a reflexive standpoint as 'the map is not the territory', and keep in mind the 'best interests of the child' as promulgated in the UNCRC which Nepal has signed and ratified. As children are 'experts of their own lives', they should be included in all the processes and further understand what measures are necessary to improve research credibility. As, the literature suggests one way to do this is to this is to utilize participatory methods that realize the experiences children have had through the use of different 'active' methods and can close the gap that is made due to power relations in the society. Hence, one measure is also to universalize the UNCRC into the national code of conduct or child protection policy and create an environment where children have the space to express their views and empower themselves.

Suggestively, universalized guidelines can create and atmosphere in which these notions can substantiate and universalize conducts in different fields. Hence, as suggested by a participant, guidelines need to be mainstreamed to all institutions and organisations, respectively, and need to be nationalized so that misconducts can be situated, observed and individuals and organisations can be held accountable in both academic and non-academic researches according to the context of nepal. On the contrary, one participant suggested that ethical guidelines are moral bindings, and cannot really be situated so that organisations or individuals may get penalized. Dialogue needs to be created in between academic and non-academic fields as they provide different accounts and experiences in research conducts.

Furthermore it is important to note that childhood and methodological implication are prone to space, time and context, and therefore need to be dynamic as suggested in

chapter one in the literature. Once a code of conduct is created it cannot be absolute and needs to be substantiated in accordance to specific contexts. However, to manage such an excessive task, the literature and participants suggested the use of ethical review boards that look over proposals and researches and local advisory committees to create dialogue between researchers and researched which could consequently hinder 'over' and 'under' researches. Once, such a review board is established, databases and accounts of researches can be created to block researches that have already been done or give accounts of what researches still need to be done, which gives leeway for organisations and individuals to use their resources more efficiently and has been suggested by participants and promulgated in the literature. Furthermore, this 'database' can create a source for secondary sources, and improve research efficiency. This can be initiated by the CCWB and can create a national forum with key-stakeholders, it is suggested that creating multidisciplinary research ethics committees can behave as a national forum between disciplines and suggestively healthcare ethics committees can learn from social research, and vice versa as suggested in the literature. However, it is pointed out that this will not solely establish ethical practices, and needs to be approached together with researchers recognition that ethical issues can arise at any given time. Encouraged by the literature and participants, If these are combined it is possible to create an environment where research involving children can become more ethical and children's rights can be maintained and give leeway for empowerment through participation and age appropriate methods in the guidelines. However, two non-academic participants claimed that it may not directly empower children and improve the rights of the child but provide a basis and consequently empower children. Furthermore, it has also been suggested that this may censor children's voices as it creates a barrier of adult gatekeeping and as suggested by a participant who seek ethical approval from the health research council, can take a vast amount of time, giving time constraints and pressure for the researcher. Hence, it should be carefully thought through and prompt in ethical review, including experts of children in different fields, parents and children themselves as suggested by the participants and literature. Furthermore, research ethics committees, especially in majority world contexts, both in academia and otherwise are still based on medical and health related researches that

only give approval and review proposals when it's in their specified fields. Although it has been mentioned that a research council exists that reviews proposals with regards to health related researches, the mandate does not fall for researches that are social researches involving children. Therefore the need of an ERB on research with children is even more of concern. Hence, Furthermore, if this is created with adequate resources and expertise, research training on ethical considerations and issues can be communicated to everyone which has been promulgated by both, the literature and the research participants as the need for capacity building. Hence, the ethical review board can become an ethical learning committee which can consequently mainstream the code of conduct which has childrens rights incorporated. Hence, if the code of conduct and ERB incorporates a rights-based approach as considered in the literature and further promulgated by international ethical guidelines, active participatory research can be initiated in all institutions where children have the right to express their views on matters that are of concern to them.

It has been suggested that either a governmental organization or an independent body should take on such a position. Some participants have asserted that this position could be taken on by the ministry of women and children's social welfare or be an adhoc institution of the NHRC. However, most accounts have suggested that the CCWB has the mandate to become such a body and is already started activities in this direction and can bring together key-stakeholders and concerned researchers in the same 'umbrella'. Furthermore, as promulgated in the literature and by participants, the primary responsibility to protect children is by the state. Nevertheless, it has been promulgated that this task may be too much for the organisation to handle by itself due to overburdening and resource allocation. Suggestively, it should be a combined effort by stakeholders formulating the code of conduct as they have the experiences and already existent child protection policies in their respective organisations. Hence, establishing a code of conduct initially may be the right direction that the CCWB can enforce in different institutions that work with children. Both non-academics and academic contributors claimed that the composition should entail having individual experts from all concerned institutions in this field. Furthermore, Although they have already started

the initiation and proposal and are bringing together all the key-stakeholders that work with regards to children's protection, it is necessary to involve the local community with regards to specific issues, as mentioned in the literature, and get advice and information as to the experiences and issues with respect to compensation, confidentiality, informed consent and harms and benefits associated with research processes. It has been suggested by the literature and the participants that when this body is established, misconducted researches can be scrutinised and nullified. Therefore, making researchers and organisations accountable for wrong doings. However, as suggested by the researchers, this is only possible when a unified code of conduct or policy is put in place. Furthermore, it is noteworthy that power relations are formulated not just in research practices, but are created through the cultural contexts. Therefore awareness raising campaigns may be a measure used by key stakeholders to transform the image of the vulnerable child to one in which the child is autonomous, and has the right to express his/her views in matters that affect them. For the researcher, the literature suggests that training, and specifically training to be reflexive is necessary for to gap the bridge of power relations and create an improved child friendly research. Therefore, another immediate measure that can be taken are workshops on reflexivity and ethics that may be mainstreamed in all institutions . Hence, it has been suggested that the CCWB provides capacity training for researchers both in academic and non-academic institutions and has the potential to mainstream these workshops in different institutions and organisations. Most participants claimed that when this body is underway, the rights of the child can be safeguarded and directly or indirectly, empower children.

4 Chapter 4: Conclusion and Recommendations

4.1 Conclusion

The present thesis attempts to highlight the ethical nature of research conducted in the context of Nepal with children. The purpose was to identify issues, gaps and challenges that are apparent and signified by key-stakeholders. The research community in Nepal, both in academic and non-academic researches have exemplified the concern and need to improve research ethics when researching with children and have provided

an extensive account of challenges, issues, and considerations when conducting research that involves children. The involved key-stakeholders are striving for betterment in research and research ethics for the protection of the child and have presented various ethical challenges that exist in Nepal. It was found that there is a need for an obligatory unified ethical framework i.e. a unified code of conduct and an ethical review board when researching children in Nepal, so that children are protected, respected and their rights and participation is promoted in research activities through these mechanisms. Furthermore, when regulatory mechanisms are put in place the participating contributors suggested that researchers, organisations and different institutions are consequently protected and can be held accountable. However, it was found that ethical challenges and issues are unpredictable, dynamic and dependent on specific contexts, even within Nepal, individuals and different institutions, and therefore need to be further considered accordingly through monitoring of research practices and through the individuals capacity to engage reflexively. There is a clear move towards creating this obligatory framework, but only time will tell how effective this will be, and what consequences it may have for researches and children. Nevertheless, through dialogue and communication, academic and non-academic institutions can exemplify a concerted move towards this process in which there is research that protects, and respects the right of the child. However, it is to be noted that there are still major differences and concerns between the participating subjects, and a greater need to look into further implications of ethical mechanisms and regulations and the involvement of children in all research processes. Hence, how do the children feel about researchers and researches? What are the experiences they have come across and how do they want to be influential? What specific methods and interactions do they desire? It is still vital to understand what children themselves have to include and say with regards to their experiences on research happening in Nepal to further grasp what is needed to improve research with children.

4.2   Recommendations

The following section gives short recommendations as to the measures that can be taken to improve research involving children in the context of Nepal:

- Establishing a unified, combined ethical code of conduct incorporating a rights-based approach between non-academic and academic researchers including the media clarifying the ethical guidelines and issues.

- Establishing a multidisciplinary ethical review board specifically entitled to review research proposals that involve children in both academic and non academic institutions, and including individuals with expertise in research with children, psychologists, parents, children and key stakeholders.

- To create a database which will hinder and block over and under research of research participants.

- To create work-shops for researchers to share experiences and reflection on ethical challenges and issues between different institutions.

- Communication and dialogue between institutions, organisations, and local community. To create a national forum for individuals researchers, organisations and institutions to share their experiences in practice of research.

- Involving children in all processes of research, moving towards children as researchers for themselves.

5 Appendix

5.1 Bibliography

Abebe, T. (2009). Multiple methods, complex dilemmas: negotiating socio-ethical spaces in participatory research with disadvantaged children. Children' s Geographies, 7, 451-465.

Abebe, T. (2012). Reflexivity and Dialogue: Methodological and Socio-Ethical Dilemmas in Research with HIV-Affected Children in East Africa, Ethics, Policy & Environment, 15:1, 77-96.

Ahsan, M. (2009). The potential and challenges of rights-based research with children and young people: Experiences from Bangladesh. Children' s Geographies, 7, 391-403.

Alderson, P. (2004). Ethics. In S. Fraser, V. Lewis, S. Ding, M. Kellett & C. Robinson, (Eds.), Doing research with children and young people, (pp 97-112). London: Sage Publications.

Alderson, P. & Morrow, V. (2006) Multidisciplinary research ethics review: is it feasible?, International Journal of Social Research Methodology, 9:5, 405-417.

Alderson, P., & Morrow, V. (2011). The ethics of research with children and young people. London: Sage Publications.

Bae, B. (2009) Children's right to participate – challenges in everyday interactions, European Early Childhood Education Research Journal, 17:3, 391-406.

Bell, N. (2008). Ethics in child research: rights, reason and responsibilities. Children's Geographies, 6, 7-20.

(Bell et al) (2008). Research ethics code of practice: summary version (2005), Children's Geographies, 6:1, 95-108.

Carroll-Lind, J., Chapman, J., Gregory, J., & Maxwell, G. (Carrol-Lind et al)(2006). The key to the gatekeepers: Passive consent and other ethical issues surrounding the rights of children to speak on issues that concern them. Child Abuse & Neglect, 30, 979-989.

Cashmore, J. (2006). Ethical issues concerning consent in obtaining children's reports of their experience of violence. Child Abuse & Neglect, 30, 969-977.

Cocks, A. (2006). The ethical maze: Finding an inclusive path towards gaining children's agreement to research participation. Childhood, 13, 247-266.

Conroy, H. & Harcourt, D. (2009) Informed agreement to participate: beginning the partnership with children in research, Early Child Development and Care, 179:2, 157-165,

Corlyon, J., Van der Merwe, A., Katz D., & Ghate, D. (Corlyon et al)(2006), Literature review: Guidelines for ethical research in social policy research with children and young people, Unpublished review for the Ethics Working Group of the International Network of Children's Research Centres, Policy Research Bureau.

CP MERG (2012), Ethical principles, dilemmas and risks in collecting data on violence against children: A review of available literature, Statistics and Monitoring Section/Division of Policy and Strategy, UNICEF, New York.

Cree, V., Kay, H., & Tisdall, K. (Cree et al)(2002). Research with children: sharing the dilemmas. Childand Family Social Work, 7, 47-56.

Edmonds, C. (2005). Ethical considerations when conducting research on children in the worst forms of child labour in Nepal. Switzerland :International Labour Office (ILO), International Programme on the Elimination of Child Labour (IPEC).

Einarsdóttir, J. (2007) Research with children: methodological and ethical challenges, European Early Childhood Education Research Journal, 15:2, 197-211

Ennew, J., & Plateau, D. P. (2004). How to research the physical and emotional punishment of children. Bangkok: International Save the Children Alliance, Southeast, East Asia and Pacific Region

Fisher, E. (2009). The moral consequences of studying the vulnerable: Court mandated reporting and beyond. Narrative Inquiry, 19, 18-34.

Flanagan, P. (2012) Ethical review and reflexivity in research of children's sexuality, Sex Education: Sexuality, Society and Learning, 12:5, 535-544

Flewitt, R. (2005). Conducting research with young children: some ethical considerations. Early Child Development and Care, 6, 553-565.

Gallacher, L., & Gallagher, M. (2008). Methodological immaturity in childhood research? : Thinking through 'participatory methods'. Childhood, 15, 499-516.

Gallagher, M. (2008). 'Power is not an evil': Rethinking power in participatory methods. Children's Geographies, 6, 137-150.

Gallagher, M. (2009). Ethics. In E.K. Tisdall, J. Davis & M. Gallagher (Eds.), Researching with children and young people: Research design, method and analysis. London: Sage Publications.

Ghandhi, S. (2012). International Human Rights Documents. 8th Edition. Oxford: Blackstones statutes.

Nepal, Health Research Council (NHRC)National Health research Policy in Nepal. Kathmandu Nepal. Available at: http://nhrc.org.np/policy, retrieved on May 22 2014.

Nepal, Health Research Council (NHRC)(2006)Health Research System in Nepal. Kathmandu Nepal.

Hill, M. (2005). Ethical considerations in researching children's experiences. In S. Greene & D. Hogan, (Eds.), Researching children's experience, (pp. 61-86). London: Sage Publications.

Holland, S., Renold, E., Ross, N., & Hillman, A. (Holland et al)(2010). Power, agency and participatory agendas: A critical exploration of young people's engagement in participative qualitative research. Childhood, 17, 360-375.

Horton, J. (2008). A 'sense of failure'? Everydayness and research ethics. Children's Geographies, 6, 363-383.

Hampshire, K., Porter, G., Owusu, S., Mariwah, S. , Abane, A., Robson, E., Munthali, A., Mashiri, M. , Maponya, G. & Bourdillon, M. (Hampshire et al)((2012) Taking the long view: temporal considerations in the ethics of children's research activity and knowledge production, Children's Geographies, 10:2, 219-232.

Lambert, V & Glacken, M. (2011) Engaging with children in research: Theoretical and practical implications of negotiating informed consent/assent. Nurs Ethics November 2011 18: 781-801, first published on June 6, 2011.

Lambert, V., Glacken, M., & McCarron, M. (2013) Using a range of methods to access children's voices. Journal of Research in Nursing 2013 18: 601 originally published online 13 March 2013.

Laws, S., & Mann, G. (2004). So you want to involve children in research? A toolkit supporting children's meaningful and ethical participation in research relating to violence against children. Stockholm: Save the Children Sweden.

Lundy, L., McEvoy, L. (2011). Children's rights and research processes: Assisting children to (in)formed views. *Childhood,* 19: 129-144.

Melville, R. (2005). Human research ethics committees and ethical review: The changing research culture for social workers. Australian Social Work, Vol. 58, 370-383.

Mortari, L. & Harcourt, D. (2012) 'Living' ethical dilemmas for researchers when researching with children, International Journal of Early Years Education, 20:3, 234-243.

Nepal Health Research Council (2005). Guidelines For Institutional Review Committees For Health Research In Nepal.

Nyambedha, E. (2008). Ethical dilemmas of social science research on AIDS and orphanhood in Western Kenya. Social Science & Medicine, 67, 771-779.

Powel, MA, Fitgerald, RM, Taylor, N & Graham, (Powel et al.) (2012), International Literature Review: ethical issues in undertaking research with children and young people, for the Childwatch International Research Network, Southern Cross University, Centre for Children and Young People, Lismore NSW and University of Otago, Centre for Research on Children and Families, Dunedin, NZ.

Rice, M., & Broome, M. (2004). Incentives for children in research. Journal of Nursing Scholarship, 36, 167-172.

Ryan, L., Cooper, P., & Drey, N. (Ryan et al)(2012) University Research Ethics Committees as learning communities: Identifying and utilising collaboratively produced knowledge in decision-making. Research Ethics 9: 166-174.

Sanders, R.M. (2003) Medical research ethics committees and social work research: A hurdle too far?, Social Work Education: The International Journal, 22:1, 113-114.

Schenk, K., & Williamson, J. (2005). Ethical approaches to gathering information from children and adolescents in international settings: Guidelines and resources. Washington DC: Population Council.

Shaw, C., Brady, L.M., & Davey, C. (Shaw et al)(2011). Guidelines for Research with Children and Young People. NCB Research Centre.

Sanders, R.M. (2003) Medical research ethics committees and social work research: A hurdle too far?, Social Work Education: The International Journal, 22:1, 113-114.

Schäfer, N. & Yarwood, R. (2008) Involving young people as researchers: uncovering multiple power relations among youths, Children's Geographies, 6:2, 121-135.

Sime, D. (2008). Ethical and methodological issues in engaging young people in poverty with participatory research methods. Children' s Geographies, 6, 63-78.

Spellecy, R., Arnold L. E & May, T. (2008) Children and Parents as Members of the Research Team: Fair Employment Practices Without a Union Contract, Ethics & Behavior, 18:2-3, 199-

214.

Spriggs, M. (2010). Understanding consent in research involving children: The ethical issues. A handbook for human research ethics committees and researchers. Melbourne: Children's Bioethics Centre (Royal Children's Hospital Melbourne / University of Melbourne / Murdoch Children's Research Centre).

Skelton, T. (2008). Research with children and young people: Exploring the tensions between ethics, competence and participation. Children' s Geographies, 6, 21-36.

Thomas, N. (2007). Towards a Theory of Children's Participation. International Journal of Children's Rights 15, 199–218.

Valentine, G., Butler, R., & Skelton, T. (2001). The ethical and methodological complexities of doing research with 'vulnerable' young people. Ethics, Place & Environment, 4, 119-125.

Wendler, D., Rackoff, J., & Emanuel, E.J. (Wendler et al)(2002) The ethics of paying for children's participation in research. The Journal of Pediatrics. Volume 141, 2, 166-171

Wiles, R., Crow, G., Heath, S., & Charles, V. (Wiles et al)(2014) The Management of Confidentiality and Anonymity in Social Research, International Journal of Social Research Methodology, 11:5, 417-428.

Young, L., & Barrett, H. (2001). Ethics and participation: Reflections on research with street children. Ethics, Place & Environment, 4, 130-134.

Yee, W. C. & Andrews, J. (2006) Professional researcher or a 'good guest'? Ethical dilemmas involved in researching children and families in the home setting, Educational Review, 58:4, 397-413.

Websites:

- 'Child-ethics Charter, 2013', Available at: http://childethics.com/wp-content/uploads/2013/10/ERIC-compendium-Charter-section-only.pdf retried on June 23, 2014.

-'Ethical Research Involving Children: Harms and Benefits', P. 30-52, available at: http://childethics.com/wp-content/uploads/2013/10/ERIC-compendium-Ethical-Guidance-Harm-and-benefits-section-only.pdf, retrieved on 19 May 2014.
(from hereon: ERIC Compendium, 2013, p. 30-52)

-'Ethical Research Involving Children: Informed Consent', P. 56-70, available at: http://childethics.com/wp-content/uploads/2013/10/ERIC-compendium-Ethical-Guidance-Informed-consent-section-only.pdf, retrieved on 19 May 2014.
(from hereon: ERIC Compendium, 2013, p. 56-70)

-'Ethical Research Involving Children: Privacy and Confidentiality', P. 74-85, available at: http://childethics.com/wp-content/uploads/2013/10/ERIC-compendium-Ethical-Guidance-Privacy-and-confidentiality-section-only.pdf, retrieved on 19 May 2014.
(from hereon: ERIC Compendium, 2013, p. 74-85)

-'Ethical Research Involving Children: Compensation', P. 88-92, available at: http://childethics.com/wp-content/uploads/2013/10/ERIC-compendium-Ethical-Guidance-Payment-and-compensation-section-only.pdf, retrieved on 19 May 2014.
(from hereon: ERIC Compendium, 2013, p. 88-92)

-'the Nuremberg Code', available at: https://www.princeton.edu/~achaney/tmve/wiki100k/docs/Nuremberg_Code.html, retrieved on May 20 2014.

-'the ten points of the Nuremberg Code', available at: http://en.wikipedia.org/wiki/Nuremberg_Code#The_ten_points_of_the_Nuremberg_Code, retrieved on June 22 2004.

-Lorenzetti (2012)'ethical Frameworks for academic decision-making', available at: http://www.facultyfocus.com/articles/faculty-development/ethical/frameworks-for-academic-decision-making/, retrieved on May 23 2014.

-"Ethical Code", available at: http://en.wikipedia.org/wiki/Ethical_code retrieved on 20 June 2014.

-"History of ethics", available at: http://www.cgu.edu/pages/1722.asp, retrieved on 19 June 2014

-"ethics", available at: http://www.iep.utm.edu/ethics/ retrieved on 19 June 2014.

-'Nepal" available at: http://www.savethechildren.org/site/c.8rKLIXMGIpI4E/b.6150545/k.B8DE/Nepal.htm, Retrieved on 25 June 2014.

-'Nepal', available at: http://en.wikipedia.org/wiki/Nepal, retrieved on 14 June 2014.

-'Global Research Ethics Map: Nepal', available at: https://webapps.sph.harvard.edu/live/gremap/view.cfm, retrieved on June 18 2014.

5.2 Interview Participants:

- Bimala Gyanwali, Chairwoman, Children-Women in Social Service and Human Rights (CWISH)/ AATWIN, Kathmandu, 20 April, 2014.
- Dilli Gurugain, Senior Advocacy, Child Rights Governance and Child Protection Specialist, Save the Children, Kathmandu, 23 May 2014.
- Dr. Kiran Rupa Kheti, Chief of Child Labor Program and Child Rights Protection Section, Ministry of Women and Children Social Welfare, Kathmandu, 4 June 2014.
- Jhanahari Bhattarai, Title, Central child welfare Board (CCWB), Kathmandu, 10 June 2014.
- Krishna Giri, DME Specialist, World Vision, Kathmandu, 10 April 2014.
- Krishna Shrestha, Professor of education, CERID, Kathmandu, 8 June 2014.
- Madhuwanti Tuladhar, General Child Rights Coordinator, Plan International, Kathmandu, 13 May 2014.

- Pranita Thapa, Research Officer, New Era, Kathmandu, 16 May 2014.
- Rajat Bastola, MA, Kadambari College, Kathmandu, 25 May 2014.
- Raju Ghimire, Title, Voices of Children (VOC), Kathmandu, 21 April 2014.
- Sumnima Tuladhar, Executive Director, Child Workers in Nepal Concerned Centre, Kathmandu, 11. April 2014.
- Tika Gautam, Professor of Sociology and Anthropology, Tribhuvan University, Kathmandu, 11 May 2014.

5.3 Acronyms

AATWIN: Alliance against Trafficking in Women & Children in Nepal

CCWB: Central Child Welfare Board

CERID: Research Center for Education and Innovation Development

CWIN: Child workers in Nepal Concerned Centre

CWISH: Children-Women in Social Service and Human Rights

DCWB: District Child Welfare Board

FGD: Focus Group Discussion

INGO: International Non-Governmental Organisation

MoWCSW: Ministry of Women and Children's Social Welfare

NGO: Non-Governmental Organisation

NHRC: National health Research Council

UNCRC: United Nations Convention on the Rights of the Child

VDC : Village Development Committees

VOC: Voice of Children

5.4 Interview Questions

1. Could you please provide a short introduction of yourself and your organization? E.g. your position and how long have you been working in research involving children? What are the current researches and what specific group of children does it constitute? E.g. Street children, school children, child domestic workers, mistreated children?

2. What ethical guidelines and policies does your institution/organization follow when conducting research with children? Is there a code of conduct or a child protection policy that you follow? Do you think a child protection policy or code of conduct can improve the rights of the child and empower children? If so, How? If not, why not?

3. Is there a review and revision of the research aims and methods? E.g. When conducting research is there a committee, a small group or an individual that reviews the protocol specifically for its ethical aspects and approach to children? If, By who? How early before research commences? If not, who do you think has the capacity to take on this responsibility? Do you think an ethical review board focused on children and a child protection policy or code

of conduct can create a more protective environment for researchers and the children researched? If so How? If not, why not?

4. Do you think that organisations and institutions conducting research without ethical approval are wrong in doing so and should be held accountable for misconduct? What measures and consequences can be taken on researchers that do not seek ethical approval prior to research?

5. Are current researchers affiliated with your institution/organization trained on ethical issues when conducting research and how is the training of the research staff provided? If not, Do you think that you instution/organisation should provide the training or the training should be provided externally e.g. by the committee we just spoke of?

6. Do donor agencies encourage following ethical standards? Do they enforce following guidelines and seeking ethical approval in Nepal? What are your experiences and thoughts on funding agencies and their involvement in Nepal? How influential are funding agencies to the research process?

7. How do you select children for researches that you conduct? Do you think there should be a selection criteria when involving children in research? How should this look like? What about vulnerable children in complex situations, how do you approach them?

8. Do you provide information to the children and seek informed consent? How do you provide information to the children and seek their informed consent? E.g. is informed consent verbal or written and in what form in the information provided to the children? E.g. leaflets. How do you think information should be provided to participating children and adults and do you think their informed consent is necessary?

9. How do you maintain Confidentiality and privacy for the child? What is the importance of anonymity, privacy and confidentiality of research participants? Are the children interviewed in a safe environment and what if a child discloses information that points out the child is in harm e.g. child sexual abuse? Where is the information stored and who has access to them?

10. Do you think evaluating the harms and benefits prior to research are necessary? How are Harms and Benefits considered? What benefits are considered prior, during and after the research? How is the dissemination of findings distributed? Are the children adequately protected from stigmatization?

11. Do you think compensation for participants is necessary when conducting research? How are children compensated for their time? Do you believe monetary compensation is viable or are there other methods of compensation?

12. How are children involved in different aspects of research? Are children researched 'on' or researched 'with'? E.g. how are they involved in parts of planning, fieldwork, data analysis and interpretation? Do they have space to express their views and be inclusive in the research process? do you think inclusive participatory methods could improve the rights of the child and empower them? If so, explain, if not, why not?

13. What are your experiences of research involving children? what ethical difficulties have you faced and how have you overcome them? Have you heard of ethically flawed by other organisations/institutions?

5.5 Abstracts in English and German

English:

The present master thesis seeks to provide an overview of current ethical practices, challenges, and issues when conducting research on children in the context of

Nepal. This was commenced due the demand to apprehend what was needed to protect children from contentious research practices and improve the rights of the child when including them in the research processes. An extensive literature review was completed on ethical approaches; issues and conceptions of ethical research involving children in the context of internationally recognized standards and publications. Code of conducts, child protection policies and additional documents related to child research ethics were reviewed and assessed. Furthermore, a purposive qualitative research was undertaken on the ground consistent of academic and non-academic Key-stakeholders to comprehend the practical challenges that exist among the different institutions. Thus, Universities, research institutes, international organisations, governmental organisations and Non-governmental organisations were consulted to understand the current ethical practices and challenges that they have experienced in the field with children. The findings and results are principally to give added value to the existing knowledge and understanding of ethical practice when conducting research with children and to act as a preliminary disposition to the issues of ethical research involving children in the context of Nepal. Consequently, It was discovered that there is a need of regulatory ethical mechanisms and regulations when researching children in Nepal and a combined, concerted effort from different institutions in academic and non academic fields to establish these.

German:

Die vorliegende Diplomarbeit ist eine gezielte Übersicht über die aktuellen ethischen Praktiken, Herausforderungen und Probleme bei der Durchführung von Forschung über Kinder in Nepal. Dies wurde aufgrund der Nachfrage zu erfassen was gebraucht wird zum Schutz der Kinder vor umstrittene Forschung und die Verbesserung der Rechte der Kinder wenn sie in die Forschung mitbeteiligt sind. Eine umfangreiche Literatur Überarbeitung wurde auf ethischen Ansätzen, Themen und Konzepte der ethischen Forschung unter Einbeziehung der Kinder im Rahmen der international anerkannten Normen und Veröffentlichungen. Verhaltenskodizes, Richtlinien und weitere Unterlagen zu Ethische Forschung mit Kindern waren überprüft und bewertet. Darüber hinaus wird eine gezielte qualitative Forschung durchgeführt im Einklang der akademischen und nicht-akademischen Haupt-Akteure um die Herausforderungen in

der Praxis in den einzelnen Institutionen zu begreifen und zu analysieren. Universitäten, Forschungsinstitute, Internationale Organisationen, Nichtregierungsorganisationen und nicht-staatlichen Organisationen wurden zum Verständnis der aktuellen ethischen Praktiken und Herausforderungen konsultiert, die es in diesem Bereich mit Kindern gibt. Die Erkenntnisse und Ergebnisse sind in erster Linie um einen Mehrwert zu den bereits vorhandenen Kenntnissen und Verständnis der ethischen Praxis bei der Durchführung von Forschung mit Kindern und als vorläufige disposition zu den Fragen der ethischen Forschung unter Einbeziehung der Kinder im Rahmen von Nepal. Folglich wurde festgestellt, dass es erforderlich ist ethischen Mechanismen und Vorschriften bei der Sozialen Recherche nach Kindern in Nepal zu regulieren. Es gibt eine erforderlichkeit für einen gemeinsamen, aufeinander abgestimmten Anstrengungen von verschiedenen Hauptbeteiligten im Bereich der akademischen und nicht akademischen institutionen.