

Research Ethics Systems: Lessons from a Comparison between NGO Ethics Guidelines and University Ethics Procedures

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Submitted: 16 September 2020, Accepted: 11 January 2021, Published: 19 February 2021

Volume 29, 2021. p.299-310. <http://doi.org/10.25133/JPSSv292021.019>

Abstract

Non-governmental organizations (NGOs) researching vulnerable groups have tended to receive limited ethics guidance or oversight, while academia is expected to follow stringent and sometimes seemingly restrictive and bureaucratic processes. The research ethics principles of NGOs and academia are quite similar. However, the frameworks and review processes can differ markedly, creating either strengths, weaknesses, or gaps for both sectors. This divergence is an even greater imperative for sensitive subject matters such as research involving child victims of trafficking or sexual exploitation. Building upon an extensive literature review, this paper undertakes a comparative analysis of the guidelines for ethical research developed by ECPAT International, a global network of non-governmental organizations working to combat the trafficking and sexual exploitation of children, and the Institute of Human Rights and Peace Studies, Mahidol University, Thailand. Through interviewing 14 research ethics experts and NGO researchers, the analysis identifies the added benefit of the two quite different ethics frameworks when applying them in the different institutional contexts. The paper concludes by discussing the merits of an overall more comprehensive research ethics system as an alternative, comprehensive research ethics agenda for NGOs.

Keywords

Child rights; independent review; non-governmental organizations; research ethics; systems approach

Introduction

The World Health Organization's 2007 ethical guidelines state:

Interviewing survivors of sexual violence should only be undertaken as a last resort. Interviews with survivors are not deemed necessary or ethical, for achieving our research aims, given the vulnerability of the participants and the potential for adverse impacts; second and third-hand accounts of sexual violence are sufficient (World Health Organization, 2007).

This emphatic statement from the World Health Organization's 2007 ethical guidelines illustrates the intense concern that some agencies feel about the trauma and possible revictimization that survivors of sexual violence may face when participating in research. This apprehension is only heightened in the case of interviewing child victims as their increased vulnerability to a liturgy of harms exacerbates the risks. However, what does 'last resort' mean, and to what extent should the child's right to have a voice and be heard in research be given consideration? This is the dilemma that many child rights organizations undertaking research face on a regular basis. This is also the case for ECPAT International, a global network of 111 non-governmental organizations (NGOs) working in 97 countries worldwide to eliminate the sexual exploitation of children. For ECPAT International, evidence-based research is essential to ensure that its programs and activities benefit from good practice learning and that its advocacy strategies are grounded in the daily realities in the lives of child victims (ECPAT International, 2018).

Yet NGOs often work with strained budgets, competing agendas, and limited research methodologies and ethics training. NGOs frequently work in fragile and dangerous contexts, with children likely to suffer from lifelong trauma. This presents particularly complex ethical issues when undertaking research and sometimes uncertainty about how to mitigate the issues. Academia may also face challenges. Though generally conversant on the key ethical requirements for human research, the academic community may lack the technical and practical expertise specific to research on child sexual exploitation or child trafficking. Even though their research protocols will pass through Institutional Review Boards (IRBs) or research ethics committees, these groups also have their limitations. IRBs are often criticized for being time-consuming, burdensome, risk-averse, and often inexperienced with some of the nuances associated with researching particularly vulnerable groups, such as children affected by sexual exploitation.

This paper examines some of the ethical challenges and dilemmas surrounding researching children in particularly harmful situations, such as trafficking or sexual exploitation. This paper then focuses on contexts where civil society organizations are often the main actors undertaking such research and discusses why the protection of vulnerable children and the promotion of ethical conduct in research is unlikely to be addressed through formal regulatory processes. Of particular concern in this study is that a presumed duty of care with child protection NGOs can lead to assumptions of competence and a perceived 'halo effect' or righteousness. This can mask nuanced ethical values, independent due diligence, and oversight needs.

Drawing from a review of relevant literature, this paper undertakes a case study analysis of ethical research guidelines from two organizations: ECPAT International and the Institute of Human Rights and Peace Studies, Mahidol University. Fourteen semi-structured interviews

were also carried out in the latter half of 2019 with child rights NGO researchers and research ethics practitioners who were purposefully selected due to their years of experience researching vulnerable groups of children. Of the 14 respondents, six were ECPAT network members, four were child rights researchers who had worked for other NGOs, and four were academics working in universities.

Through an analysis of the data collected, the paper concludes by examining a systems approach, which combines ethical guidelines with alternative models of review, built on broader collaboration between NGOs and research ethics experts.

Why are specific ethical standards for researching sexual exploitation of children such an imperative?

A comprehensive literature review by ECPAT International concerning ethics of research on sexual exploitation involving children set the scene in its opening sentence by stating that the impact and scale of sexual exploitation of children (SEC) cannot be overstated (ECPAT International, 2019a). Recognizing the seriousness of this crime against children and how it severely violates their human rights, the review report also laments the difficulties in providing accurate prevalent data. This is due to the hidden nature, the sensitivity of the problem, and the continually evolving status of the phenomenon. Such a context challenges the ability to combat the sexual exploitation of children effectively. It suggests that children themselves are in a unique position to provide valuable new insights that may lead to more effective interventions.

The need for more evidence-based research providing better data is pressing. Research on SEC has been plagued by inadequate and generalized data analysis with questionable research methods and design faults for too long. There are particular challenges associated with accessing and researching sexually exploited children. These issues are similar to other hidden populations due to the control of traffickers and the extreme levels of trauma, stigma, or shame they may be facing. In worst-case scenarios, methodologically flawed research can harm the very children it aims to help or lead to inaccurate policy and practice recommendations. The most effective way to begin to address these challenges is through better scientific and ethical research.

Understandably, donors are rightly demanding that NGO strategies and programs to combat SEC and child trafficking are based on reliable and sound research. However, the blurring of boundaries between an advocacy-focused organization with a driven mission and the researcher's neutrality can bring tensions when research findings do not match institutional interests or decisions are taken not to involve children's voices. The power that donors, service providers, or organizations' leadership may yield can easily create conflicts of interest around voluntariness and bias within the research of vulnerable groups. These power dynamics and influencers are not always readily apparent. For example, NGOs researching SEC often interview children in shelter care but as one respondent for this study stated, "...but then there are concerns over informed consent and the separation of delivery of services from research" (Interview, child rights researcher, 20 September 2019).

Yet, the most pressing demand for better research comes from those children whose lives are directly affected by sexual exploitation. Within the last decade, there have been changing

views on children's role and status within research, and as one academic interviewed for this paper stated, "Don't use children's vulnerability as an easy way out from doing difficult research. It's double victimization – not only have they been trafficked, but we then don't allow them to contribute towards protecting other children" (Interview, academic researcher, 1 October 2019). A better appreciation of a rights-based research framework recognizes that involving children in research can provide both an essential mechanism for expression and be protective and empowering (Simantiri, 2018). Participation in research may allow a child survivor of sexual exploitation to no longer be masked by victimization.

In some cases, the child's participation is empowering and contributes towards their healing (Laws & Mann, 2004). Indeed, it has even been asserted that "[r]esearching with hidden populations, valuing children's expertise and understanding children's lived experience through sensitive research has the potential to lead to positive outcomes in research and in children's lives" (Morris et al., 2012, p. 136). As one academic researcher said, "Some victims want to tell their story. It's empowering for them" (Interview, academic researcher, 26 August 2019). Conversely, excluding certain groups from research, such as abused children, may violate the principles of justice (Becker-Blease & Freyd, 2006).

So, whereas involving vulnerable children in research may benefit the cause, the researchers, and the participating children, the discourse on the necessary ethical child protection framework becomes even more critical. A rights-based approach to research requires specific ethics and methodology.

Unique ethical dilemmas

The ethical principles that guide and regulate human research date back to the end of World War II. The Nuremberg Code (1947) (BMJ, 1996) was adopted following atrocities committed on Jews in the Nazi death camps under the banner of medical research (Grodin, 1992). The Nuremberg Code (1947) remains the cornerstone of ethical human research, particularly around the obligation of consent. It was followed, sadly due to further medical scandals, by the additional elaboration of ethical principles in 1975 by the first revision of the Declaration of Helsinki (Snežana, 2001; World Health Organization, 2001), and in 1978 with the Belmont Report (National Commission, 1979). These ethical principles are not unique to biomedical research. The concepts of doing no harm, respect for autonomy, and respect for persons, beneficence, and justice are now fully recognized as global, universal principles. These concepts are just as relevant to the social sciences and of particular importance when researching vulnerable children.

Yet while these ethical dilemmas may be universal, they also need to be understood within the specific socio-cultural context of the sexual exploitation of children. For example, the principle of non-maleficence and beneficence ('do no harm') has particular salience for SEC research. This is due to the criminal aspect of the activity, the sensitivity of the research, and the risks to the child to their physical safety or psychological well-being following the research. For this reason, several interviewees expressed concern about even talking to children about issues related to sexual violence. One stated,

Assuming there is absolute need to engage this group of children, then I feel strongly that the researcher must not talk or discuss about their experiences of being victims of sexual violence, but it's OK to ask about their opinions on

related issues. For example, the services they are accessing, etc. (Interview, consultant researcher, 28 August 2019).

Traditionally, informed consent has remained one of the complex ethical issues in research involving children (Alderson & Morrow, 2011; Oates, 2020). Is consent from parents or guardians sufficient? What about consent or assent from the child? How do the age, competencies, maturity of the child, and socio-cultural norms around childhood apply? One respondent explained,

I personally believe that a researcher must not engage children who are below 16 years old, due to their maturity to cope when talking or sharing their opinions on topics that they may silently relate the topic of discussion to their own experiences of sexual violence. (Interview, consultant researcher, 28 August 2019).

Interestingly, in a few of the interviews for this paper, there was a reluctance to set an age-based marker for children's participation, as explained by one researcher. They stated, "Absolute prohibitions do not reveal the range of maturity and capacity that vulnerable children may exhibit" (Interview, academic researcher, 1 October 2019).

Furthermore, when researching SEC, parents or guardians may be complicit in the exploitation. As already stated, in the case of a child within the protective confines of shelter care and welfare services, how truly voluntary is that consent if the child feels obliged to participate? (Cronin-Furman & Lake, 2018). One ECPAT International group member went further, also recognizing that children in shelters are still recovering from their experiences. They stated, "We don't allow children that are currently in our shelters accessing recovery services to be interviewed. And for longer-term survivors, we have counselors who make decisions about whether they are strong enough to engage" (Interview, ECPAT group member, 19 August 2019). Also, privacy and confidentiality take on even greater importance concerning the security, safety, and social implications for the child involved in research on sexual exploitation (Abebe, 2009). Across cultures, conceptions of stigma, taboo, discrimination, dependency, not to mention the constructs, interpretations, and values of ethics, can differ greatly.

The problem of 'bad' NGO research

'Bad' research is by no means the sole domain of NGOs. These NGOs may suffer the scorn of academia or government departments for presuming to lack sufficient scientific rigor or for using unrepresentative or biased samples. Yet, in truth, conceptual analysis is mostly absent in NGO research. Studies do not always adequately examine in-depth contexts, cultural perceptions, and power relations – especially pertinent within contexts of exploitation and local childhood constructs (Ennew et al., 2009). At the secondary research level, there are frequent examples of plagiarism, poor citing, and infrequent credible source checking. Little detail in the final report is given to the research methodologies, limitations, or ethical procedures followed, limiting peer-reviewability of NGO research. One consultant researcher lamented the harm that poor quality research could do on children. They said, "Inadequate resources - human, money, time, skills - to go about ethical research properly. As a result, the

process of conducting the research ethically is compromised, and respondents suffer” (Interview, consultant researcher, 28 August 2019).

Even though much has been written about the methodological weaknesses that plague some NGO research, there is always the assumption that in rights-based organizations, the values of respect, accountability, transparency, and justice prevail. In the case of research with children, Article 3 of the Convention on the Rights of the Child (United Nations, 1989) is the core principle of the best interest of the child, if not the governing consideration, ensuring that mitigation strategies to protect children are in place and rigorously followed.

The so-called ‘halo effect,’ universal moral agenda and legitimacy that with child rights agencies are typically credited, assumes that their actions are desirable, proper, and appropriate. One NGO researcher proudly summed up this notion by saying, “Let’s not forget that NGOs have a common sense of decency” (Interview, NGO researcher, 12 September 2019). However, unpalatable though it may be to acknowledge, NGOs in some instances may not always employ the most scrupulous ethical practice. How hard will the NGO push for data from vulnerable children in the battle to retain their influence with donors? One NGO researcher very worryingly acknowledged, “It’s inevitable the research will do harm. I recognize that children will be harmed from our research, but we’re a child rights organization so we have to be seen to listen to children” (Interview, NGO researcher, 1 August 2019). The broader impact of successful follow-up and outcomes to a research project may instill a belief that ‘the end justifies the means,’ an overriding sense of ‘righteousness’ that unintentionally influences the efficacy or even honesty of risk-benefit analyses. At best, ethical values and judgments are often personal and open to different interpretations. At worst, organizations may employ questionable ethical practices to reach their goals (Cronin-Furman & Lake, 2018).

Safeguarding practices: A comparative analysis of an NGO and academic institution’s ethical guidelines for researching vulnerable groups

ECPAT International and its network members have been researching the issue of SEC and child trafficking for decades. Recognizing that sexual exploitation of children is an extremely sensitive research area that requires careful consideration of research ethics, ECPAT committed to strengthening and formalizing its approach to research as per its Strategic Plan 2018-2021 (ECPAT International, 2018). ECPAT noted that ethical considerations in research on sexual exploitation involving children had been identified from time to time. Yet, there is a lack of internationally recognized guidelines to navigate the unique ethical challenge such research poses in the various local contexts where their network operates. To address this, in 2018, ECPAT International began work on a specific project of ethical considerations in research on SEC, undertaking a detailed literature review. Emerging from this project, ECPAT developed some clear and practical guidelines for future SEC research (ECPAT International, 2019b). The ethical guidelines are currently being ‘field-tested’ to validate and improve them through various SEC research projects.

The Institute for Human Rights and Peace Studies (IHRP) at Mahidol University, Thailand, is an academic setting where post-graduate students and faculty staff regularly undertake research with vulnerable groups. Although all researchers submit research protocols for

approval to one of three Mahidol University Social Science Ethics Review Boards, the IHRP has its own 'Guidelines on Rights Based Research and Research Ethics' (IHRP, 2018). A simple review and comparison of the two sets of guidelines are carried out in this section to identify possible strengths and gaps and contrast useful areas of ethical compliance.

Although the two sets of research ethics guidelines have been developed for two different categories of vulnerable respondents, not surprisingly, there are universal similarities as per international guidance. Of the 14 different categories covered in the two documents, only five are specific to only one of the documents. Interestingly, this does not reflect the fact that the ECPAT Guidelines are tailored for researching SEC. Two exceptions in this regard are found with the ECPAT Guidelines, which upfront highlights the need to decide if children should be involved in the research. While the 'yes' or 'no' checklist is helpful, it relies on 'consultation with experts,' which is not defined, to assess issues such as the children's capacity to participate, stage of recovery, or likelihood of a child being distressed in the interview. The IHRP Guidelines only briefly refer to participation and more in the context of a rights-based principle, whereas the ECPAT Guidelines give a much more expanded description of meaningful child participation.

Similarly, the ECPAT Guidelines also give significant attention to responding to disclosures of abuse and exploitation, whether past or current, from children during an interview. In its earlier literature review, ECPAT identified common strategies being used. These strategies included 'red flag' alert systems, referral to relevant support services, and the possibility of legal, mandatory reporting in some jurisdictions. ECPAT further recognized that this regulation might contradict earlier guarantees of confidentiality given to the child. While the ECPAT Guidelines meet all the ethical considerations in this regard, it is less clear on what type of referral mechanism should be in place or what constitutes a 'red flag' alert system. Although references to physical or psychological vulnerabilities exist throughout the document, the IHRP Guidelines do not have a specific section on how to deal with disclosures.

Unlike the IHRP Guidelines, the ECPAT Guidelines do not cover issues such as online research ethics (although ECPAT covers this complex area in specific and separate research projects on online sexual exploitation of children); deception, and non-disclosure of research aims, which the IHRP clearly states that deception is not approved, and it discusses when 'covert observation' may be acceptable; dependency; and 'politics of research.' This latter point is a significant gap in the ECPAT Guidelines as earlier sections of this paper have highlighted the potential conflicts of interest and the perils of research misconduct.

Both documents include helpful and practical risk and harms or benefits analysis tools, although caution is needed with child research subjects as they do not neatly fit into generalized categories. The IHRP Guidelines start with risk classification, presenting unambiguous descriptions of: (i) at risk (for example, research on a sensitive topic that could result in stigma, trauma, harm, or discrimination); (ii) minimum risk (where research participants are not exposed to physical, psychological or social risk above the everyday norm); and no risk (non-invasive projects using observation, existing publicly available data or data collected from experts who are public figures). The ECPAT Guidelines present a 'harms and benefits analysis' table, which helps the researcher list all the potential positive and negative impacts of the research, mitigation strategies for all negative aspects, and a point or rating system. As with other similar tools, the difficulty is in scoring and interpretation as not all impacts are equal or necessarily accurately identified. One NGO researcher bluntly stated, "No researcher is going to be honest in answering the risk-benefits assessment table correctly" (Interview, NGO researcher, 1 August 2019), highlighting the voluntary nature of

the guidelines and the lack of independent or third-party review. Another approached a similar dilemma but from a different perspective. They stated, “The Guidelines are clear, but the challenge is what if you can’t meet the standards – should you proceed with the research?” (Interview, ECPAT Group Member, 20 August 2019).

This highlights a crucial step missing in the ECPAT Guidelines, and indeed in the approach of many NGOs undertaking research. This essential requirement in the IHRP ethics approach is the roles of both a research advisory committee, which is often made up of faculty staff to guide and support postgraduate researchers, and the approval process of the university’s Institutional Review Board (IRB). As one academic researcher put it, “There’s no accountability of NGOs. How are they monitored and held to account when they are doing research? I find it deeply problematic that NGOs don’t have a vetting process” (Interview, academic researcher, 6 September 2019). Another was more constructive, saying, “NGOs need a backstop where there is no formal mechanism in place for review” (Interview, academic researcher, 1 October 2019).

Mahidol University’s IRBs, following international standards and processes, fulfill the same role as most academic or national ethics review committees. They rely on a detailed research protocol and a selection of research tools to assess predictable risks, anticipate benefits, the research design, selection criteria for participants, and processes for ensuring informed consent, security, and confidentiality of respondents and researchers. As one academic researcher and IRB committee member explained, “We recognize, for example, that a Ph.D. candidate has already passed many steps in developing their research plans by the time their project reaches ethics approval” (Interview, academic researcher, 27 August 2019).

There is considerable literature on the functioning and effectiveness of IRBs, including how NGOs perceive the relevance of IRBs to their sector. Even for this study, ECPAT researchers generally had negative feelings. One felt that “Accountability does need to be in place, but I worry if it becomes too bureaucratic.” (Interview, ECPAT member group, 19 August 2019). Another stated that in relation to ethics specifically for children involved in sexual exploitation, “I don’t think that the national level IRB looks closely at these sort of issues” (Interview, NGO researcher, 1 August 2019). IRB evaluations have consistently identified weaknesses in the lack of gender, ethnicity, and disciplinary expertise of the reviewers. One interviewee particularly noted that “Formal IRBs often are not experienced in traumatized populations and children, so it’s not likely that they will be fully useful” (Interview, child rights researcher, 20 August 2019). Vast differences in IRB decisions, fees charged, and potential conflicts of interest, especially in the medical sphere, have been highlighted. One academic researcher lamented that “The role of IRBs has been stretched and have become aligned with legal, regulatory issues” (Interview, consultant researcher, 6 September 2019). Another IRB committee member was more explicit, saying, “IRBs suffer from few supporting staff, limited budget and no money for follow up. We receive 300 proposals per year for review” (Interview, academic researcher, 27 August 2019). NGOs have been particularly hesitant to collaborate with IRBs stating overly bureaucratic and time-heavy administrative processes, unpractical reliance on paperwork such as consent forms, and an overly protective attitude towards vulnerable research respondents in favor of protecting the institution’s interests.

Accurate or not, these perceptions lead to poor collaboration and relations between institutional ethics review committees and NGOs, resulting in an unfortunate gap in ethical capacity support and vetting processes. One NGO researcher emphatically stated, “IRBs are not the be-all and end-all” (Interview, NGO researcher, 12 September 2019).

Moving from IRBs to a 'research ethics system'

If ethical guidelines documents are at best principles to follow, like any set of rules, they do not cover all situations. They may often conflict and require considerable interpretation and judgment. There are rarely clear cut 'yes' or 'no' answers to ethical dilemmas, and the degree of NGO discretionary decision making can make ethical standards appear arbitrary. Potential or actual conflicts of interest, power differentials, and researcher positionality can all threaten the integrity of our research with vulnerable groups and the promotion of shared ethical values. As one child rights expert stated, "There's no accountability of NGOs. How are they monitored and held to account when they are doing research?" (Interview, academic researcher, 6 September 2019).

IRBs, which bring independent reviews of research plans, do not enjoy a widespread productive relationship with NGOs undertaking research. Not all countries where NGOs may be working have effective national IRBs, and academic institutions may not accept NGO submissions. As a result, formal IRBs may not be the most practical mechanism in many NGO contexts. Furthermore, in the case of research into sexually exploited children, one NGO researcher questioned, "Do they have the right expertise? For example, are there any adult survivors on the IRB?" (Interview, NGO researcher, 12 September 2019). More informal, face-to-face communication moving beyond the focus or reliance on IRB operations around ethics values and accountability is required to promote more positive, productive engagement with ethics compliance. As one interviewee stated, "It's not just about formal reviews for NGOs, it's also about having advice and support for the process" (Interview, consultant researcher, 20 August 2019).

Hyder et al. (2009) proposed that in order to ensure a culture of research ethics in an organization, a systems approach or framework should be utilized to broaden the development and organizational features contributing to the protection of research participants. The components of such a framework included institutional commitment (e.g., leadership buy-in, ethics capacity building, research supervision, and workable referral mechanisms) alongside ethics regulatory laws, policy, or civil society guidelines. Along with a vetting process of an ethics review committee to safeguard against pressures and biases, together these elements are all assumed to have a positive effect on the researcher's conduct. Conduct or professionalism needs to be supported with enabling conditions that support opportunities to satisfy personal development goals and instill a willingness to align with standards and rules. The authors argue that an absence of such a systems model can hamper the achievements of ethics guidelines and regulations, or worse, mask the careless or willful unethical conduct of researchers.

Conclusion: A research ethics agenda for NGOs

Research on the sexual exploitation of children is extremely complex, and NGOs are under increasing demands to do more professional, evidence-based, and ethical research. Furthermore, donors are more likely to fund NGO research if they can be assured of the quality and integrity of the research design and methodology. Many NGOs are now setting up standards and protocols, in some cases along similar lines as academia, to guide their research. While NGOs, such as those working with children, are presumed to be doing good

and have the child's best interest as their guiding principle, their research can sometimes sit in a 'no-mans land' with no external accountability or vetting to either government review committees or IRBs.

Collaboration between formal or academic IRBs and NGOs is not necessarily a natural partnership. Perceptions that IRBs are essentially bureaucratic gate-keepers suggest that a more inviting and supportive framework is needed to entice NGOs to invest more significantly in rigorous standards of research ethics. A 'research ethics system' proposes a more 'carrot and stick approach' as it combines regulations, codes, and independent review with a more enabling environment. The consultations with NGO and research experts for this paper has suggested building a research ethics agenda for NGOs that recognizes that ethics are not contingent only on guidelines or IRBs and that a principled approach alone will not work.

The lack of independent and recognized ethical research standards applied to NGO research, and the related accountability, suggests that compliance and driving the research ethics agenda needs to come from the very top levels of the NGO. Whether this is in clear statements within the organization's Strategic Plan (such as with ECPAT International) or from an NGO's Board members and senior leadership, the first step of this commitment will need to be transparently translated into published policies and guidelines to support these goals.

Greater accountability can then come through setting up a quasi-external Research Advisory Committee that can provide a safer, more objective environment for NGOs than a formal academic ethics review board. Such committees, undertaking third-party reviews, can include bilateral collaboration between NGOs and academia and take on an advisory role. Their more informal nature can also provide NGO researchers with face-to-face interaction with ethics experts such as 'Help Desks,' which can provide a positive and supportive advisory environment. NGO personnel undertaking research often know the ethical principles, but they are hungry for the 'how,' and they need support along the way.

In short, for NGOs researching vulnerable groups, ethical guidelines alone will not address the needed level of ethical accountability. Articulating rights-based principles of justice, humanity, and accountability are not sufficient to guarantee the full gamut of ethical requirements. If NGO staff can see on-going ethics support and review as an essential step in the research process rather than an administrative or monitoring burden, then it is more likely that they are appropriately and fully protecting the very respondents that their research is claiming to serve.

Acknowledgments

The author would like to acknowledge the intellectual guidance and advice from ECPAT International and the Institute of Human Rights and Peace Studies, Mahidol University, and the expert respondents to the research questions. Their encouragement in undertaking this study did not create any conflicts of interest or ethical concerns.

The support given by the Right Livelihood Award Foundation through the Global Campus is also much appreciated.

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