



Ethics in Research and Programming with Adolescents: Capturing the Perspectives of International Organizations



Save the Children®

Ethics in Research and Programming with Adolescents: Capturing the Perspectives of International Organizations.

01 EXECUTIVE SUMMARY	4
02 INTRODUCTION	6
03 FRAMING ETHICAL RESEARCH WITH ADOLESCENTS	8
04 PRIMARY ETHICAL CONSIDERATIONS AND CHALLENGES	15
05 THE CURRENT STATE OF ADDRESSING ETHICAL ISSUES: HOW DOES TRAINING AND GUIDANCE WORK IN PRACTICE	18
06 RECOGNIZING ETHICAL ISSUES AND MAKING REFERRALS	20
07 LEGAL RAMIFICATIONS OF WORKING GLOBALLY	23
08 RECOMMENDATIONS TO ADDRESS GAPS AND STRENGTHEN ETHIC	25
09 CONCLUSIONS	29

Executive Summary

Adhering to ethical principles when doing research and developing programs for and with adolescents is of paramount importance and indeed a human right. However, ethics in research and programming with this population globally presents a myriad of stumbling blocks and unique challenges with which organizations must regularly contend. To better understand the scope of these challenges this report presents the perspectives of key leaders representing 17 international non-governmental organizations (INGOs) and a small number of donor agencies supporting adolescent programming and research. Further, this report builds upon the challenges and considerations discussed with organization representatives to develop a set of recommendations to consider amidst the complexities of working ethically with adolescents.

It is understood that there are several established issues in working with adolescents globally as well as a multitude of principles, guidelines, and trainings that have been recognized by the research and youth serving fields over the past several decades. However, with so many different guidelines there is yet to be an agreed upon approach that clearly protects as well as includes young people in research and programs. This said, the report summarizes a set of best practices identified in working with minors under 18 years of age. Beyond the literature, participants discussed the distinction between protocols that provide institutional protections and those that are focused primarily on the young person.

Beyond established protocols, respondents explained the practical considerations and challenges that are faced including: the importance of developmentally appropriate field guidance; for example, the autonomy rights of younger adolescents may not be the same as those for older adolescents; the need for in-depth training of research and service personnel; the need to balance the needs of adolescents and the resource constraints faced by organizations; and the needs of especially vulnerable adolescents (e.g. street youth) whose needs are often not explicitly addressed in either research or programming.



INGO leaders stressed the importance of strong collaborative relationships with established implementing partner organizations based in the countries where work is being conducted. Another issue addressed is power dynamics as well as the limitations of institutional/ethical review board process where meeting the standards of such review boards is viewed by a number of respondents as the minimum protocols rather than the gold standard for ethical practices. An example is the complexity surrounding the referral process when an adolescent involved with research or programming warrants a referral for mental health or social services. Issues raised include: who has responsibility for making such referrals? What happens if the adolescent declines such a referral? Who is responsible for covering the costs associated with the referral? What obligations does the receiving agency have to let the referring partner know that the referral was in fact followed through? Respondents also discussed the legal ramifications of working globally such as: issues with mandated reporting where the rules that govern the INGO may be substantively different from the country laws and policies where they work. Other issues discussed include: the constraints of parental consent requirements, and the cultural differences that may yield discordant perspectives towards the reporting of ethical issues.

The present report concludes with recommendations for general organizational needs in focusing on ethical work with adolescents including: greater meaningful youth engagement throughout project processes; overcoming a “culture of silence” regarding research and programming with adolescents; improved alignment of ethical protocols with the contextual realities where young people live; and considering the opportunity for organizations to provide their own follow-up services as a part of their project. Research-focused recommendations address parental consent processes, adaptability of research instruments and sampling protocols, and the overarching attitude towards ethical protocols and guidelines. Recommendations for organizations included: openly engaging in discussions of ethical conundrums so as to make such discussions less taboo; providing support to employees who grapple with ethical challenges; considering the establishment of universal standards and guidance; greater leveraging of an international ethics resource center; and establishing stronger ethics-focused conversations with donor agencies to manage expectations for resources and timelines to ensure that work can be carried out ethically. Additionally, the perspectives of donor agencies yield recommendations that would see expanded ethics training for program officers, a fostering of capacity-building efforts for grantees, an emphasis on trust-building between donors and grantees to encourage information-sharing, and a greater understanding of the role of donor accountability in conducting ethical work with adolescents.

Taken together, the perspectives of international organizations demonstrated a substantial need to strengthen the standards and practices in working ethically through research and programming with adolescents worldwide. Ethical practices are the cornerstone of both research and program delivery.



– Introduction

Adherence to ethical principles and guidelines in conducting research and providing programs and services to young people is a measure of respect and honoring those with, whom we work. It is also a means to ensure the most effective research and programming reaches adolescents—so said International Non-Governmental Organization (INGO) leaders who were interviewed for this monograph. Such adherence to ethical principles and guidance is also a fundamental component of ensuring the protection and safeguarding of adolescents and youth as they share their experiences, insights, knowledge, and perspectives. Conducting ethical research and programming is generally, an inherent aim of those implementing the work worldwide – researchers and programmers hope to do their work that will support adolescents in thriving in ways that they need. As a representative from one INGO explained:

I think a lot of times, everyone in this field has the best intentions for adolescents, but I think a lot of times what we might think, as adults or as people who are from the Global North as well might have different ideas of what the best situation is.

However, the lack of globally accepted ethical principles specific to the adolescent population to guide research and programming worldwide limits its effectiveness and applicability.

This monograph is based on interviews completed with 17 INGO leaders as well as a small number of donor agencies that support research and programming with young people. It is not intended to be the definitive word on ethical guidance for research and programming with adolescents; rather, the purpose is to share the perspectives of those who work in and lead organizations around the world that are involved with adolescent health and development and provide recommendations for the path ahead. The scope is intended to capture a multitude of research and programming ethical issues ranging across violence, sexual and reproductive health, and disabilities. Interview participants represent a mix of research and programmatic perspectives as it is the intention of this work to explicitly think of the two fields together. This is premised upon the recognition that researchers and programmers often face similar ethical challenges, and therefore there should be a more intentional intersectionality and understanding between the two. Particularly, this will support researchers in applying practical responses based on lessons from programmers and vice versa.

This work represents a collaboration among Save the Children, the World Health Organization and the Global Early Adolescent Study and was led by the Johns Hopkins Bloomberg School of Public Health. The central purpose is to understand the ethical issues faced by service providers as well as researchers, to understand the guidance provided by NGOs and donor organizations to those who work with the adolescents, and to learn from and further develop the recommendations of these program and research experts as they considered the complex set of issues in working with adolescents under age 18 years.



Framing Ethical Research with Adolescents

What are ethical issues in research and programming with adolescents?



As researchers and programmers worldwide have found, there is an expansive set of ethical issues in working with adolescents. Some of the overarching issues recognized by the field include: 1) involving young people in research so that their perspectives are considered, 2) weighing the potential harm and possible benefits of the work that may be unique to this population, 3) obtaining informed consent and assent, 4) ensuring that the privacy and confidentiality of adolescents are respected throughout the research and programming process, and 5) navigating fair compensation in return for their involvement.

Additionally, researchers and programmers must determine the most contextually appropriate response to disclosures of distress and abuse. This further necessitates that an organization decide whether to solely respond when issues arise because of the research or programming, or the organization, itself, or whether to expand response mechanisms to areas in an adolescent's life that are outside of the research or program.

Finally, a major ethical issue can arise when adolescents become distressed during their participation, reveal challenges they face in accessing youth services, or disclose that they are experiencing ongoing harm and need help and there are not



adequate services available. This is particularly problematic when issues arise that are directly related to the research or programming being conducted.

What ethical standards exist?

There are several key principles that have been established in the conduct of ethical research with human subjects. Modern guidance was established following World War II as articulated in the Nuremberg Code (1947), and later followed by the World Medical Association's Declaration of Helsinki (1964). The establishment of well-recognized key ethical central principles in research then came with the publication of the Belmont Report (1979), which outlines the principles of: respect for persons, beneficence, and justice; and additionally discusses informed consent, the assessment of risk and benefits, and the selection of subjects. Since the publication of Belmont report there have been increasing global efforts to ensure that research and programming are conducted ethically. This has also involved a greater scoping of the status of ethics in research and programming involving adolescents to better understand what the field is facing. In more recent years, the groundwork laid has taken a keen eye towards promoting ethical research and programming for adolescents specifically. Towards these ends several guidelines have emerged from INGOs and UN agencies as noted in Table 1.

Table 1. Examples of ethical guidelines developed by INGOs.

Source	Title	Year	Summary
Population Council	https://www.popcouncil.org/uploads/pdfs/horizons/childrenethics.pdf	2005	The document is meant to provide guidance on ethical principles and navigating conversations around ethical issues for various stakeholders gathering information from children and adolescents. It presents key issues, provides practical guidance and summarizes main recommendations.
UNICEF	https://childethics.com/wp-content/uploads/10/2013/ERIC-compendium-approved-digital-web.pdf	2013	The compendium is designed to provide a resource of evidence-based information to guide research involving children. It reviews key ethical principles, provides guidance around harms and benefits, informed consent, privacy and confidentiality, and payment and compensation, offers support for researchers and guidance for starting research, and provides numerous cases studies.
UNICEF	https://www.unicef-irc.org/publications/-1086ethical-considerations-for-evidence-generation-involving-children-on-the-covid19-.html	2020	This paper discusses ethical issues that are specific to collecting data from children during the various stages of the COVID19-pandemic (i.e. emergency, containment and post-emergency phases). The guidance is meant to recognize that in the midst of the pandemic there are specific considerations to account for from the outset, which shapes the issues that need to be addressed.
WHO	https://apps.who.int/iris/bitstream/handle/-9789241508414/273792/10665eng.pdf?ua=1	2018	This resource is designed for researchers in order to address situations and challenges that commonly occur in conducting sexual and reproductive health research with adolescents, who are herein defined as 18-10 years of age. It considers the importance of defining the research population, the principles of autonomy, informed consent and assent, as well as the notion of the “best interest of the child” and its application, and research context information-sharing with adolescents.
End Violence Partnership Knowledge Network, End Violence Lab and Save the Children	https://www.end-violence.org/sites/default/files/paragraphs/download/Resource20%pack20%for20%children.pdf	2021	The guidance pack was developed to provide a resource for researchers to better understand how children’s participation in research, with an explicit focus on violence against children, can enhance the process of building sustainable programming. It is designed with ethical considerations woven throughout the guidance provided with an eye towards recognizing what works in specific contexts.
Save the Children	https://resourcecentre.savethechildren.net/node/7718/pdf/children_participation_humanitarian_guidelines.pdf	2013	This topic-specific guidance focuses on participatory research in humanitarian settings and, while brief, provides a discussion of ethical challenges that may be faced in this area of research and offers practical solutions that can be contextualized and adapted as needed.

Across these varied resources there is general consensus on basic ethical principles for programming and research with children and adolescents. These take on a more special lens because certain areas of research may be more sensitive among adolescents than others and so require more substantial forethought such as what may be more culturally taboo topics such as sexual and reproductive health. Across the grey (non-peer reviewed) literature, recommendations also vary substantially based on the specific research area, but often center on advance planning and communication between stakeholders throughout the research and programming process as well as with adolescents themselves.

Less often recommendations discuss the training or practice-oriented application of certain principles, and more rarely do they discuss referrals and the follow-up process. Understandably, these are context and situation-specific which make generalizability challenging; however, they still provide useful guidance that can be adapted to other contexts. Examples of these as well as training materials are provided in Table 2.

Table 2. Examples of ethics training resources developed by research organizations.

Source	Title	Year	Summary
The Global Early Adolescent Study (JHU)	https://www.geastudy.org/training-suite-ethics	2020	A training module focusing on research with very young adolescents aimed to help researchers and programmers understand adolescent-specific consent and assent, the role of abuse protocols, and the unique ethical challenges in working with very young adolescents.
FHI 360	https://www.fhi360.org/sites/default/files/media/documents/Research20%20Ethics20%20Training20%20Curricula.pdf	2009	This document expands on the training provided in the first edition, released in 2001. Designed for researchers it is meant to provide an overview of ethical principles in working with human research participants, guidance towards designing culturally and contextually respectful studies, case studies, and additional reference documents. It is not adolescent-specific.
Violence Against Children Survey	https://www.cdc.gov/violenceprevention/pdf/vacs/VACS-trainingwhitepaper.pdf	2017	This white paper focuses on research on violence against children and provides specific information about ethics-driven approaches to implementation and training. Considerations include the research team composition and responsibilities, comprehensive training, in-depth questionnaire review, discreet community entry protocol, the potential for experiencing vicarious trauma and how to manage it, and the handling of training material and electronic data entry.



Table 2 provides examples; however, INGOs often develop their own resources based on the existing guidance and best practices identified across the literature and their in-country experience resulting at times in conflicting or fragmented messaging that researchers and data collectors working directly with adolescents may receive.

Furthermore, it is not uncommon for there to be a tension between guidelines intended to safeguard the service or research organization and those intended explicitly to protect young people. Obviously, these two needs (organizational and child protection) are intertwined but those with whom we spoke made a distinction and specifically talked about the difference between child safeguarding and child protection protocols. When talking about *child safeguarding protocols* one operational definition used is: “the responsibility that organizations have to ensure that their staff, operations and programs ‘do no harm’ to children and that any concerns the organization has about children’s safety within the communities in which they work is reported to the appropriate authorities.”¹ *Child protection protocols*, on the other hand, are defined as “measures and structures to prevent and respond to abuse, neglect, exploitation and violence affecting children.”²

What we see is that the organizations with whom we spoke all reported having child safeguarding protocols while approximately half had child protection protocols as well. The ethical quandary that this presents is that organizations need to ensure that they do no harm because of their adolescent research or program in part to protect participants and concurrently to protect their organization. An example of how these two entities can be conflated is when the legal office at a US-based research university informed researchers there that according to state law all cases of abuse that meet the state’s definitions, regardless of where they occurred in the world, be reported to the IRB and in addition, must further be fully disclosed with identifiers to the university’s legal office. This is required, the researchers were informed, to meet state requirements even though neither the university nor any U.S. state official could do anything to protect the children involved.

¹ Save the Children. 2014.

https://resourcecentre.savethechildren.net/node/8560/pdf/kcs_understanding_2014.pdf

² Save the Children. 2010.

<https://resourcecentre.savethechildren.net/sites/default/files/documents/2779.pdf>

As is evident, there is much guidance that exists to assist organizations in working ethically with adolescents. However, with so many different guidelines there is yet to be an agreed upon approach that clearly protects young people in research and programs. Given the multiplicity of guidelines, organizations may choose to model staff guidance on existing standards of other organizations which may fail to take into consideration their unique work and ethical needs.

Best Ethical Practices in Working with Adolescents

Based on the on the Ethical Research Involving Children UNICEF has identified a set of best practices in working with minors across issues including: harms and benefits, informed consent, privacy and confidentiality, and payment and compensation. Best practices in balancing harms and benefits require that organizations:

- Justify the research being conducted, and the reasons for including or excluding children, which further means thoroughly considering the harms and benefits of research to them, families, and communities. Beyond this, groups should look to develop research plans and protocols by consulting local standards and practices.
 - Assure that children are not harmed by the research throughout the project. This includes having strategies minimizing distress as well as implementing protocols to safeguard children from abusive or incompetent researchers.
 - Develop plans for supporting children and after the research project. This includes having a response plan to handle child safety concerns. Also following on research, groups should make efforts to ensure that children during families, and communities are not harmed by the sharing of research findings.
- With informed consent, best practices require that organizations:**
- Obtain consent from child participants having ensured that they are fully informed to both the purpose of the research and extent of their involvement. Additionally, groups must respect youth decisions regarding their participation, including dissent or unwillingness to participate. During research, groups should ensure that participants understand that consent is renegotiable and can be revoked by the research subject at any time.
 - Recognize the obligation but also the limitations of obtaining parental consent, which requires assuring that parental interests are not prioritized over those of the adolescent.



- Craft the consent process to be appropriate recognizing children’s developmental capacities as well as the context of research. This may include consulting with local community representatives to determine whether their consent is additionally needed.

Considering privacy and confidentiality the best practices include:

- Respecting children’s right to privacy and work to ensure the confidentiality of their information. This includes the secure storage, protection, and disposal of collected data.
- Recognizing that assurances of confidentiality include explicit discussion of potential limits to such assurances. Further, that groups are prepared to respond to concerns raised by community stakeholders and young people themselves.

Finally, for payment and compensation the best practices are for organizations to:

- Avoid payments that risk being viewed as to bribes coercion, or pressure on individuals to either participate in a study or project or to influence their responses while participating.
- Consider the context and consult locally regarding appropriate payment for research. This includes working to see that payment does not create unrealistic expectations or leave participants disappointed.

The discussions summarized in this report illustrate the extent to which ethical issues continue to arise in research and programming with adolescents and, how guidance and standards may not always be translated into real world scenarios.

Primary Ethical Considerations and Challenges

There is a general, though not universal, acknowledgment that adolescence is a vulnerable developmental stage. However, protocols that view all under the age of 18 years as equally in need of the same protections fail to account for the dramatic developmental changes that occur in the second decade of life. As development progresses from childhood to young adulthood so too does autonomy and decision-making capacity evolve creating challenges for guidelines that are not necessarily applicable in either childhood or adulthood. Respondents with whom we spoke strongly suggested that there is a compelling need to have a developmental lens to policies and guidelines; and so too, there is need to involve young people themselves in the process of guideline and policy creation as they mature. What may be the needs of a young adolescent (those ages 10-14 years) are unlikely to be the same as for those aged 15-19 years, nearing the age of majority. This co-creation of guidance also recognizes the distinct challenges, opportunities and experiences that are unique to adolescents of different ages. Thus, it is important to acknowledge that adolescents have autonomy rights; and as such, it is critical to involve them explicitly in research, program and service development to assure that they fully understand the implications of their involvement.



Respondents also indicated that there is an increasing priority to train staff who are working directly with youth on the management of ethical issues and unique challenges that involve young people. Indeed, staff working directly with youth are the first line of action and their level of knowledge regarding ethical responses is paramount to protecting and safeguarding adolescents. While introductory training is essential to effective implementation of ethical work, discussants also explained that training must be revised and periodically repeated to reflect updated approaches. Indeed, it is important to understand that approaches that view ethics as a dynamic process rather than a static checklist require: flexibility, regular protocol updates, adaptations to the context in which young people live, balancing of power relationships between INGOs (often based in a high-income countries) and implementation partners based in the countries and communities where the work is undertaken (often low and middle income countries). Thus, there is a need to continually balance priorities of different entities while maintaining a focus on the best interests of the young people served.

This balance was discussed by several respondents who acknowledged that organizations' needs or capacities and the rights to safeguarding and protection of the young people themselves do not always align. Organizations often face constraints of time and finances, or are operating under a research or programming directive, that restricts the extent to which they are responsible or capable of pursuing the full extent of safeguarding and protection activities that would benefit adolescents the most. Overcoming this balancing issue requires that, to deliver ethically based programs and research, an acknowledgment of the tension between the two, identification of where the organization needs do not perfectly align with those of young people themselves and establishment of protocols that assure that young people are continuously at the forefront of everything that is done.

This is relatively easy to say but challenging to do. For example, how and when to make referrals for a young person in distress becomes an important decision often complicated by the lack of resources or funding for such referrals especially when activities are grant-based. Who makes those decisions within an organization? What is the frame of reference that those decision-makers use to guide decisions? How is financial responsibility determined? Further complications arise in the characteristics of the contexts where organizations are working and the relationships that exist between INGOs, their implementing partners and local service providers who may or may not exist in the community and have the capacity to respond to referrals.

For some organizations the inability to satisfactorily resolve these issues has resulted in a de facto moratorium on research or programming with adolescents. Because of the challenges of meeting the ethical requirements organizations may be disincentivized to including adolescents and especially young adolescents in their research with the result that vital information needed for programming and services may never be obtained. This is what respondents described as a “culture of silence” around engaging with adolescents. Additionally, some respondents indicated that for staff to raise the ethical conundrums around working with adolescents may also be perceived as an organizational threat. This may reinforce an organizational “culture of silence”.

Finally, respondents told us about numerous situations that are rarely considered or covered in organizational guidance. For example, adolescents under the age of 18 are generally considered minors incapable of making independent decisions; but as we have noted previously, there is a vast difference developmentally between 10 and 17-year-olds; and guidance tends not to reflect these developmental differences that should be taken into consideration when developing protection protocols.

Finally, there is often little consideration given to the unique needs of special adolescent populations including: those living away from home, living on the streets or living in institutions (e.g. orphanages, juvenile prisons); adolescents who are married; emancipated minors (where such concepts exist), refugee and immigrant adolescents, LGBTQ+ adolescents, those living with a disability, chronic condition or HIV/AIDS, those using illicit substances, or young people involved with commercial sex work. This becomes a central concern as INGOs generally focus on the most marginalized adolescents who may not one covered by extant ethical guidance.



The Current State of Addressing Ethical Issues: How does training and guidance work in practice?

All INGOs stressed the importance of their local implementation partner organizations (IPOs). They indicated that while the INGO role is to establish the protocols or ensure that the IPO has sufficient protocols in place in order to enter into a partnership, training of those at the community level tends to be left to the IPO with backstopping support provided from the international organization. At the same time, many INGOs do take responsibility for training more directly by being on-site whenever possible. Whether incidents that occur in the field are shared with the INGO appears to depend on IPO interpretation of *severity* which can vary between context and agency. Additionally, INGO response often depends not just on severity but on details of the situation such as the context, services available, timeliness for project or study completion and donor considerations. The characteristics of this IPO-INGO relationship speak to the efforts of these partnerships to strike a balance of power that recognizes the capacity and autonomy of IPOs.

For research-focused work, the Ethical Review Board (ERB) or Institutional Review Board (IRB) often has specific protections for children (usually defined as those under 18 years), but often do not distinguish capacities of adolescents at different developmental stages. Additionally, respondents indicated that often the IRB standards are insufficient to address some of the most complicated and nuanced issues faced by researchers at the community level. An example of this relates to decision-making regarding when to intervene on behalf of a young person. For example, a respondent shared a story of a young adolescent who was being compelled by family to marry against their wishes. While there are protocols in place and a research ethic of non-intervention, these often do not address the human costs where intervening could have a powerfully positive impact on the young person. The same is true for abuse experienced by young people which may not rise to the level that mandates reporting but may require interventions in the best interest of the young person involved, which the research organization may not be equipped and/or funded to handle.

What are the guidance and supports to deal with such situations or complexities that field researchers talk about? Even with its limitations, the ERB/IRB process was seen to be critical to ethical research and was viewed to offer a dedicated space where research organizations could fully consider the gamut of ethical issues that might be faced in the work as well as map the potential resources to use. That said, the IRB system is too often viewed as a series of hoops to clear before research can move forward. And as respondents indicated, too often IRB staff and panels have neither the time nor expertise to address these complex issues as they relate to adolescents. Additionally, respondents discussed the gap they saw between the approved protocol and its implementation. Having ethical standards documented for the work being conducted does not equate to the practices that will ensure ethical programming or research. The gap between IRB expectations and on-the-ground reality was frequently discussed. This is further complicated by resource limitations in many low-income settings where there is not the capacity to provide services or protection when such is deemed necessary. A final point to consider when working with ERBs/IRBs is the need to ensure a rigorous process for reporting ethical violations, and the process to make corrections. This feedback is essential to ensuring that high standards of research ethics are established and indeed maintained; however, field staff discussed reluctance to report their concerns out of fear of retribution.

An Example of Best Practices

A research model that was shared is the approach and processes that are used in the Violence Against Children Surveys (VACS). In this example, from the start of planning the study in a given site there is strong engagement with community constituents to adapt the survey so that it is sensitive to community considerations but still explores the central issues and questions. The VACS uses same-sex interviewers and develops separate enumeration areas for males and females. Given that the study uses household samples, they space the distance between households selected to assure confidentiality; and they also limit data collection to only one young person per household. The VACS has established primary, secondary, and tertiary levels of referral with special attention to special populations such as married youth. There is also involvement of health care specialists such as social workers in the research. While there was an initial reluctance by researchers to implementing this approach, organization representatives maintain that quality of data improved as a consequence and the protection of participants increased as well.

This level of effort requires that the research organization is sufficiently resourced, which is not always the case globally.

Recognizing Ethical Issues and Making Referrals

One of the critical issues discussed by respondents relates to how and when to make referrals; and while it was acknowledged that INGOs have obligations to follow through on referral processes, this is complicated and does not always happen. As one INGO respondent explained:

Before, you would refer to a partner and you would feel that you took action and would feel like it was resolved. But it's an issue because now we go back to households and then we can see that action was not taken. We follow a protocol and that's fine, but it is quite [disheartening]. How can we look these people in the eyes if this was the end result? In some cases where I felt that immediate action needed to be taken and then I see that nothing happened, that really doesn't build your trust in the process.

Respondents talked about multiple steps in the referral process some of which are aspirational and others in fact implemented:

Step #1. Before the study or program begins

Respondents indicated the importance of mapping the locally available services so that if and when issues arise referrals are seamless. They also stressed the importance of continuously updating the services available and maintaining relationships with service providers, for in many resource-poor settings services come and go. Further, they emphasized the power of developing trusted relationships with these community referral sources for the issues they confront are often sensitive and complicated. It was often discussed that, where relevant, it is most efficient and often effective for INGOs to rely largely on the expertise and context knowledge of IPOs through this mapping process. This is especially true where a mapping of structures already exists based on the knowledge of an IPO and there is less of a need to independently create a system of referrals. For these purposes several respondents emphasized the power and strength of long-term partnerships with IPOs and working in communities for several years to maintain an established presence.

Step #2. Training

Respondents who we interviewed stressed the importance of training those undertaking research or providing programs to understand adolescent unique issues, rights and needs. This includes the right to refuse services or referrals-- a dimension of "autonomy rights". What this means is that those who work with adolescents need to have the skills not only to know when to make a referral but how to encourage young people to get the services they need and the best ways to facilitate that process that increases the likelihood that adolescents will use the referral of their own free will rather than by coercion. As noted, field workers are the first line of protection in these cases; and their initial responses to the disclosure of issues can directly impact adolescent responses. Further, if the referral process is not handled with skill and sensitivity or the services are not high quality, respondents noted that there is a risk that the referral, while well-intentioned, may in fact do more harm than benefit.

Currently, training content for data collectors often covers a broad range of topics. Ethics training is nestled within this larger set of topics and often does not discuss specific concerns of the research around adolescents. Depending on the research or program adolescents may be discussed as a focal concern, or they may be included to a lesser degree as a vulnerable population requiring additional support and attention. Respondents suggested several adolescent specific training strategies including the use vignettes, role-play and discussions of specific scenarios as vehicles for discussing ethically troubling situations.

Training on the provision of referrals was noted to be highly dependent on the type of research or programming being conducted and the specific issue being disclosed. To prepare data collectors and programmers for the disclosure of safeguarding or protection issues some organizations train on the soft skills needed such as compassion and patience, empathy and sympathy, and strong communication skills. However, some respondents recognized that this was largely a space where additional training can be conducted more generically in all organizations working with adolescents.



Step #3. When doing research or providing services

When making referrals respondents suggested that to the extent possible there should be options that include a mix of child protection services provided by NGOs, local providers, and government agencies. They also stressed the importance that all project/study participants -- and not just those identified as having specific issues-- are given a list of potential referral sources if they self-identify needs for which a referral would be beneficial. The types of referrals provided vary across the world, but can expand beyond safety and protection against violence to encompass topics such as tutoring and education, legal or justice-based needs, medical support, and financial aid. Additionally, as we have previously emphasized, a developmental perspective is important when considering how best to respect the autonomy rights of adolescents while concurrently protecting them from harm; however, it appears that most referral policies do not account for the evolving developmental capacities of young people.

A critical element in making timely referrals is that of recognizing where and how ethical issues have arisen. The approach to eliciting issues from field staff indeed varies as well. Respondents discussed approaches such as regular team-based debriefs, individual check-ins between field staff and team leads, messaging groups dedicated to discussing issues in the field and how they are handled (allowing for more regular, or daily, contact), and even data reviews to scan for ethical concerns.

An Example of Following Up Outside of the Study

Working with tight deadlines and funding limitations can be particularly stressful on the level of involvement of organizations with a research population outside of the study. An example from the Global Early Adolescent Study arose a couple of years ago in one of the research sites where unanticipated deaths occurred among the adolescent participants. The protocol appropriately indicated that all such untoward events need to be reported to the IRB. In a situation such as this there was a compelling need to follow-up with each of the households involved to understand the causes of mortality. However, there were no financial resources to undertake this intensive home-based follow-up; and the costs were born primarily by in-country research partners who could ill-afford such expenditures. As it turned out, none of the deaths were related to the research study but that is not relevant for the costs required to make such a determination.

Legal Ramifications of Working Globally

Dealing with legal constraints to best ethical practices

Those with whom we spoke identified numerous constraints that impact their ability to deliver what they see as best ethical practices in working with adolescents. For example, some laws limit service provision by requiring parental notification or consent. Others mandate reporting when services are provided. A key example of this situation is seen in service provision for adolescent sexual and reproductive health needs. In some settings laws mandate the reporting of what are generally viewed as confidential behaviors where disclosure can be harmful to the young person involved. Examples given of this scenario include: substance use, gender based violence, same-sex relationships and being an undocumented immigrant. A particularly complex concern arises when there is a mandated referral issued without a child protection system in place. This may increase, not diminish, the ongoing risk to a young person. As one INGO representative said:

.. In a place where gender-based violence is highly stigmatized, [bringing attention to the issue by making a referral] could do more harm than good...



Further complicating this issue are the substantial barriers to following up on referrals once made, for confidentiality requirements may preclude the referring entity from sharing any information as to whether the individual was seen and/or what services were provided precluding any follow-up or assurance that established guidelines were indeed followed. Additionally, respondents indicated that follow-ups are difficult to achieve for two key reasons: a lack of clarity about an organization's ethical responsibility to follow up, and the degree to which an organization has the capacity and resources to follow up. Consequently, follow up is often not attempted. This is especially true in contexts of limited funding and timelines.

It is prudent to further the discussion regarding legal mandates for reporting of abuse and neglect. Some respondents indicated that they believe researchers are exempted from country-specific mandates, although this is not always the case for specific countries, research or service fields, and protocols. Others indicated that there is a tension between the requirements of the country in which the INGO is headquartered and the requirements of the country where the work is being done. This tension can make following a country's laws a more challenging for organizations and the staff who are working closely with adolescents. For example, if an adolescent girl is married at the legal age according to her country of residence, but an organization's country of origin would deem that an underage marriage, compelling staff to decide whether this is a reportable issue.

More generally, respondents discussed the constraints that arise from parental consent requirements (for participation in research or receipt of services), which limits the very extent to which organizations can even begin to engage with and learn from young people. There is a noted concern of biases in the selection of participants for research and programming given that adolescents who have parental consent may be experiencing fewer adversities relative to non-participating peers.

Respondents also noted that at times there is a thin line between violence that, in some Western countries, would be viewed as abuse and in other cultures would be defined as normative childrearing practices. So, for example, in Western countries hitting children is generally considered abuse while in others it is a normative disciplinary practice. Organizational staff may then be faced with the decision to bring unwanted attention to this issue by reporting it, or to take a less legalistic route by seeking services for the young person without filing a report. There is also a tension, we were told, between legal requirements and the assurances of confidentiality that are provided to young people. Finally, legal requirements may be at odds with the autonomy rights of young people to make decisions that govern their own lives.

Recommendations to Address Gaps and Strengthen Ethics



Respondents had numerous suggestions to improve ethical approaches in working with adolescents that relate to research and programming.

Research Recommendations

1. When developing a parental consent form, one should see research as a vehicle for establishing dialogue between parents and researchers, if that is something parents wish, rather than a one-off approval process. One INGO representative described the need to recognize the importance of this process:

One of the most important protections that we have is to get parental permission. But sometimes by adding that extra level of protection and depending on the type of research that we are conducting, you know that might pose an increased risk for an adolescent.

2. Study instruments and measures should be age and developmentally appropriate allowing for younger adolescents to avoid being asked more sensitive questions where that is applicable. Such approaches should also reflect contextual and cultural sensitivities.

3. Sampling should aim to be geographic as well as age and sex representative.

4. Ethical guidelines and protocols should not be viewed as impeding quality research but rather facilitating it.

General Recommendations

1. Increase meaningful engagement of adolescents in the planning of both services and research so that from the beginning the work reflects a youth perspective and addresses their issues and concerns. This approach also better reflects and respects the autonomy of adolescents. Nonetheless, one INGO respondent explained the realities that are faced when striving to meaningfully engage youth:

Ethics is often used as a reason not to include adolescents in the planning or decision-making. It also adds time. as an implementer if you're under pressure, you've got to deliver a report, you've got to do your field work... You can get quite easily disincentivized to include a group [of adolescents] that way.

2. There is a need to overcome the “culture of silence” regarding adult reluctance to include adolescents in research or develop programs and services specific to this unique population, and the research that can or cannot be conducted with adolescents. Overcoming this issue involves educating key stakeholders that asking young people questions does not in fact lead them to undertaking behaviors that adults are most concerned about. Research and programming cannot support adolescents’ development and work towards improving their lives if ethical guidelines and government policies deny access to the information critical to addressing adolescent health concerns. This will also require that researchers and programmers face fewer seemingly legal and institutional barriers in working with young people. Making a process to work with them more accessible will require that regulations and response mechanisms are more clearly defined and less fragmented. Organizations will continue to engage with this moratorium on working with adolescents unless the obstacles and opportunity costs are removed.

3. There is need to better reconcile protocols and ethical approaches with the contextual realities of the lives of young people in the settings where programs and research are being undertaken. This means reconciling laws with best practices, training researchers and program specialists in working with young people on context specific policies and practices as well as expanding their understanding of some of the limitations of those policies and to increase the supports for implementing partners in terms of these ethical issues. As one INGO representative said:

What's acceptable in one country might not be acceptable in another one. So, finding that middle ground so we can all work together and understand that we're all doing this to protect those who are most vulnerable... It would be good to have a standard set of guidance that everybody should follow.

4. Organizations may be well-served to consider providing support and referrals services through their own means to ensure that adolescents in need of support indeed receive it. For example, it may be prudent to involve psychosocial support staff as a part of the research and programming process throughout, and even after, the work is completed. For example, study protocols might be well advised to continue providing access to social and/or mental health services for a period of time after data collection has concluded. This would ideally be available after each round of data collection.

Organizational Recommendations

1. There is need to encourage internal conversations among staff and leadership of organizations that make talking about ethical challenges less difficult and taboo. An approach to operationalize this recommendation is to establish regular communication, such as through quarterly meetings, between staff, researchers, and leadership of organizations outside of specific project debriefs to discuss emerging ethical challenges, successful approaches, and decisions about adapting guidance and methods in practice. Having this discussion as a standing meeting rather than in response to a research or project can create a more open space for sharing and minimize the perceived threats of discussing things that go wrong, ultimately better preparing organizations to address ethical challenges as they arise in real time.



2. INGOs should provide confidential access to psychosocial support for field workers who grapple with the ethical challenges in working with adolescents.
3. Several respondents suggested that there would be value to having universal standards or guidance that would help field workers deal with ethical challenges so that approaches are not all viewed as being at individual or organizational discretion. Standardized guidance was also noted as potentially beneficial for organizations particularly those that are new to research and /or programming with adolescents. Priorities identified for ethical guidance include: defining key principles; understanding and integrating best practices and working with adolescents within ethical protocols; providing guiding principles for implementing partners; and modifying child protection protocols based on the skills and capacities of implementing partners. Moreover, guidance should provide for adaptations for specific issues such as remote data collection.
4. There was a call by those who were interviewed for a resource center that could provide information and guidance that is non-prescriptive but rather can serve as a point of information and potentially support in dealing with these complex issues (Note: UNICEF has such a resource center accessible at: <https://childethics.com/>).
5. Several respondents also indicated the need for donors and funding agencies to better understand the challenges faced in implementing protective protocols and adhering to IRB requirements. This would provide more time and greater flexibility for research and programming activities and in addition would lay a strong foundation for an effective referral and follow-up process. But as respondents noted, this would also require greater financial resources than is often available.

Donor Recommendations

1. Donors indicated that there is need for program officers to have training on ethical issues involved in research and service provision to adolescents.
2. There is a need for donors to actively support the capacity building of their grantees.
3. Importantly, donors did explain that their framing often emphasizes trust-building and limits micro-managing, so that when issues do arise grantees feel free to come forward and do not feel they are being punished. Donors should work to making this emphasis a standard throughout their organization from staff who are working directly with adolescents to the board of trustees and senior leadership.



4. Donor organizations generally view themselves as having the ultimate responsibility in monitoring and supporting the ethical conduct of research. However, this perspective is not reflected equally strongly by all donors that may instead view the responsibility as that of the grantee organization. There is a substantial need to bring donor organizations to a greater understanding of their responsibility for work being done with adolescents.

Conclusions

Conducting ethical research and programming with adolescents globally is challenged by complications and stumbling blocks with which organizations and the individuals who are undertaking the research must contend. Speaking with organizations across various areas of research and programming with different levels of resources and capacities demonstrated how and where issues arise, and what they mean for adolescents. Moving forward with the complexities identified and recommendations provided means paving a path to ensuring adolescents are indeed supported in research and programming, throughout the variety of ethical challenges organizations will undoubtedly face. To this end, this report comes to three conclusions:

1

There is need for organizations to clearly affirm their commitment assuring the highest ethical standards in programming and research and to value the training, capacity building and open dialogue among and between staff as well as with implementing partners around the world.

2

There is need to affirm both child safeguarding and child protection and to see that the interests of the organization are best served when the highest ethical standards are maintained for work with adolescents. This will require clearer definitions of the level of responsibility and accountability that organizations have.

3

Much like there is for research training (e.g. CITI) there would be value for standardized training of field workers implementing programs with adolescents internationally. Ensuring that any standardized training, for research and programming alike, reaches and is implemented by organizations is then essential and can be monitored.



Save the Children.

Ethics in Research and Programming with Adolescents: Capturing the Perspectives of International Organizations