

Abstract

Program managers and researchers promoting children's rights to health, education, and an adequate standard of living often gather data directly from children to assess their needs and develop responsive services. Gathering information within a participatory framework recognizing children's views contributes to protection of their rights. Extra precautions, however, are needed to protect children because of the vulnerabilities associated with their developmental needs. Using case studies of ethical challenges faced by program implementers and sociobehavioral researchers, this article explores ways in which data collection activities among children may affect their rights. We suggest ways in which rights-based principles may be used to derive safeguards to protect against unintentional harm and abuses, based on a multidisciplinary consultation with researchers and service providers.

Les responsables de programme et les chercheurs favorisant le droit des enfants à la santé, à l'éducation et à un niveau de vie adéquat obtiennent fréquemment leurs données directement des enfants, afin d'évaluer leurs besoins et de développer des services adaptés. La collecte d'informations, effectuée dans le cadre d'un processus participatif tenant compte de la perspective des enfants, contribue à la protection de leurs droits. Cependant, des précautions supplémentaires sont à prendre pour protéger les enfants, par suite des vulnérabilités associées à leurs besoins développementaux. Se fondant sur des études de cas explorant les dilemmes d'ordre éthique auxquels font face les responsables de la mise en œuvre des programmes et les chercheurs explorant le comportement social, cet article examine les manières selon lesquelles la collecte de données auprès des enfants serait susceptible d'affecter leurs droits. Nous suggérons des méthodes permettant d'utiliser des principes fondés sur le respect des droits pour dégager des mesures de sauvegarde permettant de protéger contre les abus ou mauvais traitements involontaires. Ces méthodes se basent sur la concertation multidisciplinaire entre chercheurs et dispensateurs de services.

Los investigadores y gerentes de programas que promueven los derechos de los niños a la salud, la educación así como un estándar de vida adecuado, a menudo recaban datos directamente de los niños para evaluar sus necesidades y crear servicios receptivos. La recolección de información dentro de un entorno de trabajo participativo en el que se reconocen los puntos de vista de los niños contribuye a proteger sus derechos. Sin embargo, se necesitan medidas adicionales para proteger a los niños debido a que sus necesidades de desarrollo presentan muchas vulnerabilidades. En este artículo, mediante el uso de casos de estudio sobre los desafíos éticos encarados por los ejecutores de programas y los investigadores del comportamiento social, se exploran las formas en que las actividades de recolección de datos entre niños podría afectar sus derechos. Se sugieren formas en las que se pueden usar los principios basados en los derechos para crear resguardos que los protejan contra abusos no intencionales.

PROTECTING CHILDREN'S RIGHTS IN THE COLLECTION OF HEALTH AND WELFARE DATA

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In this article, we explore the ways in which data collection activities affect children's rights and suggest ways in which rights-based principles may be used to derive safeguards that adults working with children should implement to prevent unintentional harm and abuse.¹ Through case studies, we outline some ethical challenges with which program implementers and socio-behavioral researchers working with children have been struggling. We have chosen these issues for their wide applicability to research and programmatic activities among children in a variety of contexts. Although the responses outlined may be context-specific, our aim is to propose a framework by which others facing similar challenges might seek solutions appropriate to their own setting.

Many difficult ethical dilemmas arise when collecting data among children. Despite experience, education, and good intentions, skilled professionals often find themselves questioning how to proceed with their research activities. Without meaning to, interviewers can create anxiety or trigger grief even when their ultimate aim is to work with children to improve their well-being. Methodologies used for the collection of health and welfare data may be intrusive or exploitative, treating children merely as sources of information. Participatory methodologies represent an opportunity for investigators aiming to collect information from children

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to work with them collaboratively and involve them throughout the design and development of activities.²

However, guidance for social and behavioral researchers collecting data among children is extremely limited. Clinicians and bioethicists have long been publicly grappling with ethical dilemmas in pediatric medical research, and a new and rapidly growing body of literature explores approaches to seeking informed consent for biomedical research among people in different settings facing developmental or educational barriers to comprehension.^{3,4} While some professional groups have developed specific guidance for their members collecting data among human subjects in the parallel body of work documenting the struggles of socio-behavioral researchers and programmatic evaluators, available guidance is still in its nascent stages.^{5,6} We propose that an approach to conducting socio-behavioral research among children derived from principles of rights will be consistent and complementary with approaches derived from principles of bioethics—for example, the principle of beneficence (see Case Study 1).

The issues we raise are not unique to working among children: similar issues arise when evaluating health and welfare interventions among adults, especially among vulnerable groups—for example, people who have recently been bereaved, women who have just given birth, individuals at risk of domestic violence. We believe, however, that children are vulnerable in different ways from adults and require additional safeguards that respond to the imbalance of power between children and adults. Children have special vulnerabilities that are associated with their level of educational development and their reduced access to information, funding, and other resources. Thus, we believe that data collection methodologies employed among adults cannot simply be transferred to children, and we propose using a children's rights framework to safeguard their rights and avoid jeopardizing their emotional and physical well-being.

We do not claim that there are easy or unique answers to any of the complex ethical issues raised here. However, by asking these questions and seeking a framework by which to review investigator responsibilities, we aim to increase awareness of the complexity of collecting data among children, pro-

mote discussion, and offer some guiding principles for decision-making based upon principles of the rights of children.⁷

Programming for Children and the Human Rights Theoretical Framework

Approaches to programming for children have historically taken a needs-based approach that prioritizes the fulfillment of children's basic needs, such as food, health, and shelter.⁸ According to this approach, once children's basic needs are met, their situations are assumed inevitably to improve.

Subsequent theoretical developments have questioned this assumption and with it the effectiveness of the needs-based approach, recommending instead an approach based on the rights of children.⁹ Rather than focusing on children's needs alone and treating them as passive recipients of aid, the rights-based approach presented here takes into account the full spectrum of children's rights based on their human rights in accordance with the Universal Declaration of Human Rights (UDHR) and more specifically the United Nations Convention on the Rights of the Child (CRC).¹⁰

While acknowledging the importance of providing children with basic services, this approach emphasizes that the process through which children's needs are met should not be disempowering to them. Thus, children are not mere objects of charity but active subjects contributing to making improvements in their own situation. Accordingly, children are claim-holders of rights from duty-bearers who include caregivers, communities, governments, international organizations, and other institutions.¹¹

The need to bring the issue of children's rights into the center of human rights discourse has led to the development of international frameworks, guidelines, and strategies for facilitating child-centered programming. In particular, the UNICEF framework, developed from the CRC guidelines and indicators for human rights programming for children, has become a blueprint for children's programming.¹²

According to the CRC, the four broad areas of children's rights that programmers must address in any context are the rights to survival, development, participation, and protection.¹³ The right to survival means that children should have

access to adequate basic services like food, water, and health facilities. Children's right to development refers to children's entitlement to education, as well as to psychosocial and emotional support. Participation means that children have a right to be actively consulted and meaningfully involved in the making of decisions and plans and the implementation of activities meant for them. The right to protection refers to the fact that children should be born, live, and develop in a safe environment, free from all forms of abuse and exploitation.

Many children's programs have focused on addressing children's rights to survival and development, for example, through projects that focus on providing food, immunization, shelter, or school fees. The provision of such basic services has the advantage of being tangible and thus appealing to donors, fairly easy to design and manage, and showing immediate and measurable impact on children's lives. Meanwhile, programs addressing children's rights to participation and protection are more difficult to define, implement, and measure. As a result, there are few models to draw from and less evidence of interventions focusing on these rights, which are traditionally seen as the "softer" side of rights-based programming.¹⁴ Since children are defined as legal minors without the same rights accorded to adults, addressing child participation and protection in human rights discourse and program implementation until recently received little attention. Because the subject of children's rights has different cultural meanings and applications, the development and management of programs that recognize the rights of the child are a challenge.

This article focuses on two aspects of child rights that are relevant to programming: the rights to participation and to protection in the context of data collection, which is intrinsically linked to program and policy development. We explore ethical implications for conducting data collection among children for the purposes of research and program implementation and base our conclusions on case studies from the field.¹⁵ First, we discuss why it is necessary to gather information from children and what we mean by data collection. Second, we examine three case studies of issues that have arisen in fieldwork in different contexts and illustrate how a human rights framework can indicate safe-

guards to be taken in such circumstances. Throughout these case studies, we recognize that poverty represents an important risk factor affecting children's ability to realize their rights to food, shelter, and health.

Why Collect Data on Children?

To improve the lives of children, it is necessary to find out about their circumstances. It is best to do so by involving children as active claim-holders of rights that they should be able to realize with the support of duty-bearers. Researchers and program implementers gather information directly from children in order to develop appropriate responses to children's situations. Motivations may be as diverse as evaluating a specific children's program, understanding the extent to which children's rights are being respected and realized, or gathering information for policy advocacy on behalf of children. Data may be sought from children regarding a variety of health and welfare topics such as nutrition, sexual behavior, and risks of abuse, within a variety of settings (within the home, within schools). Each setting poses different methodological and ethical challenges, requiring careful study design tailored to recognize the specific characteristics of each research activity.

Collecting accurate and geographically specific information from children, in ways that respect their rights, is important in order to learn more about their circumstances, to design interventions that will be useful and appropriate on the basis of this evidence, and thus ultimately to improve their quality of life (as shown in Figure 1). This is an ongoing process, whose results feed back into refining continuing activities on the basis of the evidence. While the participation of children themselves is critical, protection measures must be in place to ensure that the process does not exploit them.

Methodology

Data presented in this paper were collected as part of a process to develop ethical guidance for investigators conducting research and managing programs involving children.¹⁶ A multi-agency steering committee convened an international and interdisciplinary consultative meeting including specialists in psychology, child development, sociology, anthropology, ethics, pediatric medicine, HIV/AIDS

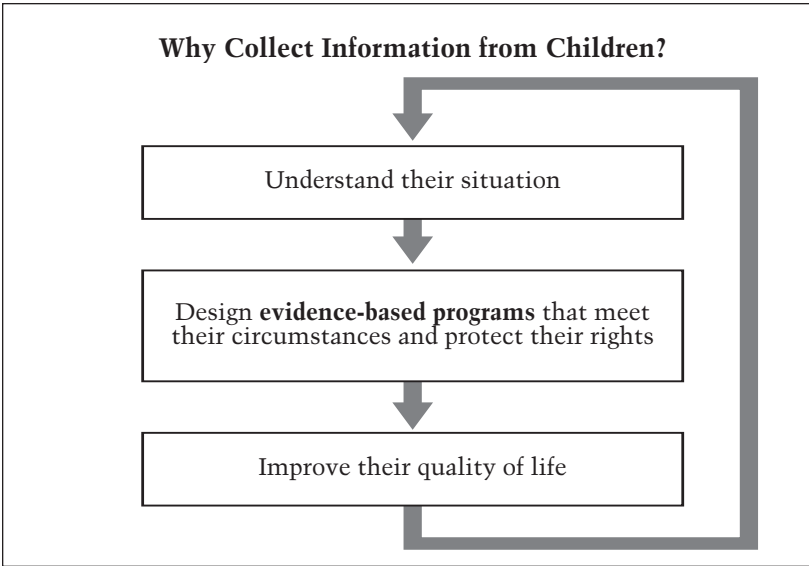


Figure 1. *Why Collect Information from Children?*

programs, and social work, to share lessons from their experiences.¹⁷ The case studies and recommendations that follow were gathered during the meeting and the dialogue that ensued, drawing on a wealth of experiences in different settings from a variety of perspectives.

In this article, we include exercises designed to gather health and welfare information about children, including those conducted by program staff to monitor and evaluate a particular intervention and those conducted by researchers for policy and program development. We examine three case studies of data collection among children, considering purposes, methods, and participation and information sources (Table 1), in order to highlight some of the ethical dilemmas that can arise when working with children to improve their health and welfare. We apply the principles of children's rights to protection and participation to highlight some practical safeguards that practitioners working with children should implement to promote the realization of children's rights.

Rights-based approaches advise the use of participatory methods promoting the inclusion of children's input throughout activity design, development, and implementation. Participatory approaches are based on the premise that children are active community members, who are knowl-

edgeable about their situations, can identify their problems, and have ideas on how to make a positive difference in their own lives.¹⁸ Participation can be empowering to children when they are involved in the assessment, analysis, and planning of programs meant for the realization of their rights.

Case Studies

The three case studies that follow are experiences of data collection among children in Uganda, Cambodia, and Zimbabwe. We use these case studies to examine ethical questions and apply an analysis based on principles derived from children’s rights.

Case Study 1 provides an example of a dilemma in operations research methodology. In order to test the effectiveness of a new program, researchers try to make a direct comparison between those who receive the program to members of a group without access to the new services, who use the standard, locally available services. If the characteristics of this group are equivalent in all other ways to the group receiving the program, managers have a powerful tool to demonstrate their program’s impact. In settings where health and social services infrastructures are overstretched, the best services locally available may not actually be functioning to

Purposes	Methods	Participants and Information Sources
• To identify and assess the realization of rights • To develop and implement programs that address identified rights • To monitor or evaluate programs • To provide information for advocacy for policy change • To test hypotheses as part of scientific research	• Questionnaires • In-depth interviews • Observations • Focus group discussions • Personal histories through storytelling or diaries • Rapid assessments • Participatory methods (e.g., mobility mapping, pile sorting) • Community meetings • Examination of case records • Testing of biological samples	• Children • Adult family members, caregivers • Community members • Peers • Case records (e.g., medical, school) • Adults working with children (e.g., teachers, health workers)

Table 1. *Data Collection Activities Among Children.*

"Our research team wanted to evaluate an innovative support program for orphans and vulnerable children and their families in Uganda being implemented by an international NGO with whom we collaborated. We planned to conduct three surveys over a two-year period, comparing a group of children receiving the support intervention to another group living in an area where the program was not yet available, but due to be phased in at a later date. We wanted to take advantage of the natural opportunity to compare these children to a different group who were not yet receiving services (although they soon would be), without standing in the way of the program roll-out.

But it turned out that the program implementers were eventually unable to offer the program to the second group, due to factors beyond the control of the research team. Some of the researchers were tempted to return to the community not receiving services to continue observations as originally planned because this information would provide powerful results. But our data collectors, who had already been in contact with the community during the first survey round, felt strongly that this would be inappropriate. It would raise expectations about the services that were not going to arrive, and the long and potentially intrusive interviews with children could no longer be ethically justified. At that point in the study, we knew that the original study design had become unethical, and we discontinued interviews in the area without services, while continuing in the areas where the program was active."¹⁹

Case Study 1. *Using Comparison Groups of Children (Uganda).*

provide children with adequate care, and researchers may question whether it is ethical to work with such children on the basis of their restricted access to services.

Wendler et al. argue that it remains important to develop research that compares innovative new program approaches to the best standard of care locally available, even if limited, in order to produce research results that will be relevant and applicable to such deprived contexts.²⁰ For example, when evaluating a program for vulnerable children, it would be unethical to deliberately deprive children of *all* support services in order to obtain direct comparison data on the new program. It may, however, be considered appropriate to design a research study comparing the new program to the best standard of care locally available, in accordance with children's right to protection and the ethical principle of beneficence. In other words, while the use of a true control group (such as may be used in a clinical trial) is precluded, ethical research design may favor the use

of a comparison group. When the question being investigated is not *whether* to offer services at all but *how* to offer services, using a control group with no access to services at all is unethical. Such ethical requirements must always supercede the scientific rigor of research methodology.²¹

Donors and program implementers alike must keep this ethical requirement in mind when they seek empirically proven best practices. Ethically less problematic, albeit potentially scientifically less rigorous, alternative approaches to strengthening the design or evaluation of children's programs include conducting a baseline survey before a children's program begins and comparing outcomes to later results; examining the program's performance in multiple settings; monitoring the program at different levels of intensity; and using multiple methods to assess program impact, such as combining quantitative and qualitative techniques.

If these alternatives are not feasible, the opportunity remains to keep evaluations rigorous without compromising children's rights by finding a natural comparison group that already exists. For example, program implementers may phase in their services, starting in one geographic region and gradually expanding and fine tuning services as more funds become available. This was the original approach intended in the Uganda case study, where researchers planned to work with a comparison group of children initially without access to the new services, who would later be receiving expanded and improved services in their area. However, once it became clear that these children would not be receiving the benefits of the new services, the research design could not ethically be continued, and halting the comparison arm of the study was necessary for the protection of the children.

Regardless of study design, researchers should be in contact with local health and welfare services to whom they can refer children requiring support services beyond the capacity of the research team—for example, to respond to the discovery of abuse.

Seeking consent on behalf of children under the age of majority typically requires investigators to obtain and document the child's active agreement and the informed consent of a parent or guardian. If other adults, such as teachers and social workers, interact with the child as part of the study setting,

their additional consent may also be required. To respect the child's right to autonomy and participation, their active agreement (called "assent"), not just a lack of refusal, is required — taking into account their age, education, and maturity.

While seeking consent from a child's parent or guardian before a data collection activity remains the ideal, sometimes children do not have parents or effective guardians who can provide informed consent or represent the best interests of their children. In addition to the example of children living on the street examined in Case Study 2, similar ethical dilemmas arise when working with children living in child-headed households following parental death or when there is doubt about whether a guardian's interests adequately reflect a child's interests (as, for example, children at risk of abuse within the home).

In such cases where a child's connection to a responsible adult is associated with risk, or when the connection does not exist at all, researchers may question whether a mature child, already taking adult responsibilities in other areas of their lives, can actively participate in the consent process. If this is not acceptable under local law or custom, or if younger children are involved, appointing an independent advocate to represent the child offers a practical safeguard to children's right to protection. Procedures for working with child advocates, as well as the documentation of consent procedures, should be determined in consultation with the community and will vary according to cultural and developmental considerations.

In Case Study 2, interviewers were seeking to work with children living on the streets without parents or guardians who could provide consent. In order to protect the children, child advocates were engaged to oversee all contact with the children. These advocates were experienced in working with children and independent of any other interests, including the data collection activity. The child advocates were present to make sure that adequate protection was given to children during the data collection process.

The research team members had the responsibility of explaining to the child the purpose of the activity and the procedures involved in a manner sensitive to their level of development and understanding. Child advocates had the

"We wanted to conduct interviews with street children in Cambodia in order to better understand their vulnerability to HIV and design appropriate intervention activities. The children, who were aged 11-18, were recruited from a drop-in center run by a local NGO. Parental consent could not be obtained because parents were either unavailable or would not act in the best interests of the children. We had to take special care to make sure that the children's rights were appropriately and independently represented, so we sought independent child advocates to oversee the process.

We recruited a team of child advocates whose role was to protect the children's interests throughout the study. They included male and female representatives of ministries, legal organizations, child rights groups, and NGOs working with street children, all independent of the study. They were unpaid and received training and supervision regarding child protection issues, confidentiality, and research ethics.

A child advocate was present in the room with the child during the entire recruitment and interview process. When possible, the advocate was the same sex as the child. The advocate could interrupt, overrule, or terminate the process at any stage if he or she felt that the child was feeling uncomfortable or pressured. The child advocate could also assist in explaining the study to the child or rewording questions if necessary. In some cases, when children appeared scared to speak about their involvement in illegal activities, such as theft, the child advocate was able to find the right words to increase the child's confidence in the confidentiality of the research.

The interviewer sat in front of the child, while the advocate sat at a distance from the child but within sight. The presence of the child advocate in the room did not generally appear to make the child feel uncomfortable; however, some children spoke less freely and openly than expected from informal chats. The advocate's effect on children's behavior was only to be expected from the presence of unfamiliar and upper-class adults, especially in Cambodia's hierarchical society where behaviors and language are strictly codified according to social status and age.

In general, the children appreciated the efforts that were made to respect them as individuals. They appreciated the fact that higher class adults, with whom they would otherwise have no relationship, sat down on the ground with them, shared tea and bananas, and listened to them. They were also interested in the concept of child rights, which was new to the great majority of them.

Some children misunderstood the role of the advocates and had very high expectations that the advocates could provide them with continued help after the interview. It was important to clarify the boundaries of the role with both advocates and children: the monitoring was limited to the research period. Additional follow-up services were available through the local NGO drop-in center, if required.

The advocates were initially shocked by some of the personal stories they heard. However, they made great efforts to relate to the street children. Their participation was a valuable experience for the future development of child rights advocacy and specialized legal services in Cambodia. Further work must be done to assess how their presence benefited the children during the interviews and to make sure that if such a process is used again children understand the role of the child advocates."²²

Case Study 2. *Seeking Informed Consent from Children Without Guardians (Cambodia).*

more nuanced task of looking out for the best interests of the child, anticipating the risks and benefits that might result from their participation, and making sure that they were not anxious, overwhelmed, or confused. Children were informed that they would be able to stop the interview or refuse to answer any question at any time. Child advocates were responsible for verifying whether children understood this concept, ensuring that their participation was truly voluntary, and monitoring their reactions.

Depending on the nature of the activity, a child advocate might be used to ensure the protection of an individual child or represent the interests of a broader group of children within a single activity. Permission to seek consent through a child advocate instead of a guardian may be required by an ethical review board. Procedures must be determined in consultation with community representatives and be consistent with local law and practice.

Case Study 3 concerns the provision of incentives to children. International guidelines warn against unfair inducement of individuals to participate, but provide little guidance on how to recognize it.²³ Incentives should be sufficiently high as to avoid participant exploitation, yet sufficiently low as to avoid being irresistible.

It is critical to understand the reasons that should and should not be used for providing incentives to participants of data collection activities. Incentives must not be used to manipulate potential participants into providing information or to relieve responsibility if there is the risk of harm to participants. Incentives should not be used as a way to coerce children to provide information or as payment for data. Incentives may, however, be used as compensation for participants' time, travel, and inconvenience to show appreciation and make sure that individuals and communities have not been disadvantaged by their participation in the activity. While it may be practical to use limited incentives to compensate participants, researchers should exercise caution and try to avoid setting a precedent whereby future potential participants will refuse to be actively involved in projects unless there is a promise of payment.

Among adults, researchers have explored diverse approaches to incentives, but there has been little attention to

incentives among children.²⁴ Children, especially those living in situations of extreme poverty, are especially vulnerable to coercion, exploitation, and bribery. If incentives are used among children, they must be handled with particular care in order to provide protection from inappropriate pressure and abuse. Their purpose should be explained clearly and in a manner appropriate to the child's developmental stage. They should be introduced sparingly to avoid raising expectations and causing later disappointment, and to avoid unduly influencing an individual child's decision to participate. In Case Study 3, the food was given after and not before the exercise. Incentives should be in line with local living standards and subject to the advice of local community members. Local refreshments, school supplies, or refunds for travel expenses may be appropriate. Where possible, incentives should serve the role of providing refreshment during the activity, especially if it is time-consuming, rather than being portrayed as payment for involvement.

"We were conducting research that explored how to provide psycho-social support to orphans and vulnerable children in Zimbabwe. Our ethical review boards in the United States and Zimbabwe set guidelines that prevented us from offering individual children any money or food as a reward for being interviewed. We found this a difficult approach to take because of the current economic crisis in Zimbabwe and the severe financial hardships facing many families today. We even had trouble with rumors spread by groups of children who would advise other children not to show up for the interview because they weren't going to receive anything.

In a couple of areas, children walked 8 km or more for an interview, often on an empty stomach. Due to the levels of extreme need we encountered in rural areas, just before the children were due to head home, we announced without forewarning that we were offering simple lunches or snacks to the children as a gesture of goodwill. Respondents and interviewers were able to sit together and enjoy a simple plate of rice and soup.

Another thing we were able to do was to go back to each community's Gogo (female elder) after the interviews and offer her a token of appreciation. We would give each Gogo bags of sugar beans and high-protein biscuits that she could keep for herself or distribute to the children in her community as she saw necessary. Going back to thank these women was the best part of my day!"²⁵

Case Study 3. *Providing Incentives to Children (Zimbabwe).*

Incentives may be administered to individual children or to groups. If individual incentives are used, investigators must be sensitive to the possibility of pressure from children's families or peers to get the incentive. Incentives may be linked to a child's effort to attend an interview or meeting but must be independent of their responses and behavior during the research to avoid pressuring them. This includes the decision to end the interview early or to not answer certain questions.

Sometimes, the use of community or group incentives may be preferable to the use of individual incentives to avoid pressure on individuals. Community incentives, like school supplies, may be given to families, schools, or trusted community leaders rather than to individual participants. Distribution options should be discussed with community members to ensure reasonable equity.

Researchers need to find ways to simultaneously protect children from being unfairly exploited, yet also provide them with a meaningful token of appreciation that will not constitute coercion.

Conclusions and Recommendations for Researchers and Programmers: Ethical Safeguards for the Involvement of Children in Data Collection

For research activities, most national legal regulations require the research institution, such as a university or non-profit research organization, to establish an independent ethical review board (also known as an ethics committee or internal review board) to review all research protocols. Program monitoring and evaluation activities often are not legally bound by the strict requirements of formal ethical review that apply to research, but the lack of a legal requirement does not relieve the program manager of the responsibility to ensure that information-gathering activities are carried out ethically. Program managers should strive to uphold the same high standards of formal ethical supervision that apply to research activities, especially when the protection of children and adolescents is at stake.

The child rights framework, in particular children's rights to participation and to protection, provides a powerful tool to guide decisions about designing data collection ac-

tivities among children that can complement the principles of research ethics and broaden their application to programmatic activities. Taken together, the lessons learned from these three case studies suggest several recommendations on ethical safeguards.

In order to assure children's right to protection, program managers and researchers are responsible for careful advance planning, anticipating the effect of the activity on children and their families and thinking through all possible intentional and unintentional consequences of the activity. Monitoring and ensuring adherence to ethical standards must be an ongoing process throughout the duration of the activity.

In the context of a research study, investigators must ensure that services are in place to address any possible negative consequences of the data collection or the discovery of a child at risk. Ideally, data collection should take place within the context of a service-provider offering relevant support to the children involved in the activity. For example, investigating the different ways in which children affected by HIV/AIDS require psycho-social support should take place within the setting of a local organization already offering services to children with qualified staff on hand to offer psycho-social support. If the activity is not associated with a service, investigators should research and distribute information about relevant local referral services. It is not advisable to conduct a data collection activity without the assurance of *functional* support systems in place.

An important theme that emerges in applying principles of children's rights to concrete examples of data collection involving children is the tension between the principles of children's participation and children's protection. When children participate in data collection, their right to protection can be threatened as a result of the research methodologies employed. The use of participatory approaches emphasizes the importance of listening to children's views and creating opportunities for their meaningful involvement in data collection. On the other hand, the children's right to protection requires that they be protected from exposure to harm if, for example, collecting information about their personal circumstances may be considered upsetting or intrusive. For example, asking a question about the difficulties faced during a

Summary Guidelines

1. Carefully plan in advance and anticipate all possible consequences on children and their families. If appropriate safeguards cannot be put into place, the activity should not proceed.
2. Only begin the activity if services and referral mechanisms are in place to address possible consequences.
3. Balance the need to maximize children's participation with the need to minimize their exposure to harm.
4. Hold discussions with local community members, including children, whenever possible, to review and interpret the activity.

parent's illness may be upsetting, even if the ultimate goal is to design a support service that may benefit the child. To protect children from harm, the use of intrusive research methods and questions should be kept to a minimum in accordance with the basic ethical principles of beneficence and "do no harm," and researchers should investigate complementary information sources, such as parents and caregivers.

In planning approaches to children's participation, program managers and researchers are responsible for discussing their activities with local community members, including children, whenever possible. Consultation among community members plays a crucial role in determining what approaches are appropriate when working with children.²⁶ Community meetings at different stages of the activity can serve a variety of purposes, including sensitization, review, and interpretation of data. These discussions can serve the dual purpose of improving adherence to ethical standards and improving the quality of the information gathered. Areas in which community input is particularly relevant include age limits and processes for seeking consent.

Thus, investigators should pay careful attention to balancing the two distinct roles that children may play in the data collection activities—as participants and as respondents. Giving children the maximum opportunity to express their views must be balanced with protecting their best in-

terests and safeguarding them from potential harm and abuse by minimizing intrusion. Investigators must manage children's exposure to risk and make sure that they have the opportunity to express their opinions without compromising their safety and well-being. Researchers working with children have a responsibility to ensure children's meaningful participation in assessments, analysis, and action-planning activities in their communities without violating their right to protection.

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1. Terminology: In this paper, we use the word “children” to denote any individual younger than age 18—that is to say, we include adolescents and infants. However, we note that operational definitions and interpretations may vary according to culture and custom.
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