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The Ethics of Social Research with Children and Families in Young Lives: Practical Experiences¹

[A] Introduction

Research ethics exist to ensure that the principles of justice, respect, and the avoidance of harm are upheld, by using agreed standards. These principles are universal, though there many subtleties and diversities, and how principles are understood, interpreted, and practised can vary from place to place (Ulrich 2003). Following controversies involving deception and political involvement by researchers in the social sciences, ethical codes building on these principles were developed. These codes built on earlier ones developed for medical research on humans in the Nuremburg Code (1947, following the war crimes trials) and the Declaration of Helsinki (1964). The governance of research has expanded and now includes ethical practices in social research in general (ESRC 2005, 2010) and with children in particular (Alderson and Morrow 2011; Schenk and Williamson 2005). A burgeoning literature describes the processes, practices, and difficulties that occur in social research (see, for example, Armbruster and Laerke 2008; Iphofen 2009; Mertens and Ginsberg 2009; van den Hoonard 2002).

In medical research, cases have been reported of drug companies exploiting desperate communities, without adequate attention to consent, communication, controls, and risks (see, for example, McGregor 2006). While social research, like

that of Young Lives, does not pose the same kinds of physical risks as medical research, it may seriously damage people's lives, futures, reputations, and relationships, through unwanted publicity and through influence (or lack of needed influence) on policies and practices. Although informed consent and Research Ethics Committee review may be vague and even alien concepts to many people, and burdensome to many researchers (Hammersley 2009; Dyer and Demeritt 2009), they gain clear meaning after harm occurs.

Young Lives values high-quality research, while respecting the key principles of justice, respect, and the avoidance of harm. Starting from approaches that Young Lives has adopted, this chapter identifies fundamental ethics questions and contributes to current debates about research practices, the ethics of longitudinal research with children, and research with communities in developing countries, in a spirit of shared enquiry and learning. It discusses some of the difficulties encountered in fieldwork and strategies for attempting to resolve these. The chapter concludes that an understanding of local context is central to explanations of how research participants respond to being involved in a longitudinal data-gathering exercise like Young Lives, and that some adaptation and fluidity is necessary at the local level.

[A] Seeking research ethics approval

The academic consortium that initiated Young Lives in 2000 was attentive to research ethics within the epidemiological/medical paradigm which is now broadly accepted in social research. For example, it developed an ethics committee in Vietnam, and obtained approval from the Research Ethics Committee at the Instituto de Investigación Nutricional (IIN) in Peru, which was established in 1971, as well as from the ethics committee of the Social Science Division at the University of Oxford in 2006, for the whole study. Young Lives has utilized

guidelines from the University of Oxford's Department of International Development, which are adapted from the ethical guidelines of the Association of Social Anthropologists of the Commonwealth, and are based on the Helsinki guidelines as well as the Child Protection Policy of Save the Children UK (Save the Children 2003).

Young Lives' qualitative, quantitative, and policy teams have discussed research ethics in order to develop a shared understanding within the whole study. This was a complex task, involving differing academic traditions and disciplines (economists, educationalists, social anthropologists, developmental psychologists, epidemiologists, nutritionists, social work specialists, sociologists, and political scientists), and differing power dynamics within and between research teams and communities studied. Working with in-country teams may reduce 'stranger involvement', but there may remain stark social differences between researchers and respondents: there are important power dynamics when professionals of a higher social class interact with very poor research participants, and further power dynamics reflecting social divisions along the lines of gender, ethnicity, and caste (the last two highly sensitive and political issues in some countries and sites). There is also the power differential of age when adult research teams work with children as young as six or seven. Furthermore, there are differing understandings of children in each country, reflecting the different cultural, religious, and historical constructions of childhood.

Approaches to ethics questions in Young Lives have been developed in collaboration with the country research teams. The survey and the qualitative research teams undergo training sessions at which ethics are discussed, and fieldwork manuals contain detailed ethics guidance (referred to in the section on consent below). Following piloting of the qualitative research methods in 2007, a memorandum of understanding for fieldworkers was developed in collaboration

with qualitative research teams, which set out some basic guidance about research procedures and respectful communication with research participants.² This is now being used with the survey teams too.

Experiences relate to both the household and child surveys and to the qualitative research. There is an important relationship between the two components, which from the point of view of participating families and children may not be obvious, especially as the survey round and qualitative research happen separately, with several months between them. Ethics questions can differ between the two research processes, in so far as qualitative research allows more time to build trust, learn about respondents' concerns, and so on. Young Lives qualitative data are all transcribed and coded, and include a category on participants' comments about 'relationship to Young Lives'. Thus all data from participants about their experiences of being involved in the Young Lives study, their views about the questions, and their questions to researchers can be analysed. Qualitative fieldworkers record ethics questions in their field notes as they arise and discuss these with lead researchers. These processes mean that Young Lives has already collected considerable data relating to the ethics of the research (Ames 2009; Tafere et al. 2009; Truong 2009; and Vennam 2009). Survey enumerators also record questions related to ethics, and systematic analysis of these will take place in future survey rounds. In Peru, for example, survey fieldworkers are all experienced enumerators, and are required to report any cases that give cause for concern – for example, relating to child protection or children's health/medical condition – to their supervisors immediately, who will try to resolve the situation with the fieldworker. The supervisors then also bring questions for discussion by the lead researchers. In some cases direct help has been provided, but mostly people are directed to specific services or sources of advice relevant to the question. The ethics committee of IIN is also informed of these specific cases.

[A] Consent: Informed and understood, freely given, adapted in local contexts

Researchers in Young Lives must obtain the informed consent of parents or caregivers, and of children who have the capacity to consent. In Peru, for example, the IIN ethics committee recommend that, in addition to parents' or caregivers consent, 'children aged seven and older give their assent to participate' (Creed-Kanashiro et al. 2005: 926). Research teams are concerned to ensure that the purpose of the research is clearly explained, and that children and adults understand what they are agreeing to. The fieldworker manual for the Round 3 survey states:

No project staff should pressurize, coerce or deceive respondents in an effort to ensure their participation. Staff should also try to ensure that respondents are not pressurized by other family or community members. ... The respondents will have at least 24 hours to consider whether they want to take part and will be free to withdraw from the study at any time.

In relation to consent from children, the manual emphasizes care 'to explain in ways that they can understand why you are there, why you are interviewing them and what the information is to be used for'. It points out that children are generally taught from a very young age that they must obey adults, making it difficult for them to refuse researchers. So it must be made clear that there will be no adverse consequences for them if they refuse to take part.

Young Lives fieldworkers are clear about the limitations of the research in terms of its capacity to bring about change in research participants' lives. For example, qualitative research teams use local translations and relevant versions of the following statement when explaining the research to children:

Young Lives is a study of children growing up in four countries – India,

Peru, Vietnam and Ethiopia – taking place over 15 years. We are trying to find out about children's everyday lives: the things you do, and the important people in your life, and how these things affect how you feel. Bits of what you say/write/draw will be used in reports that we write that we hope will be helpful to local and national governments when making plans or planning services for children in the future. Our research may not change things in the short term, because that depends on local and national governments. (Young Lives 2009)

In many parts of the world, however, people do not necessarily have any experience or understanding of what research is. Many Young Lives respondents are illiterate or semi-literate (in the case of parents) or have basic literacy (in the case of children). People who have minimal basic education and no exposure to formal manipulation of knowledge cannot be expected to fully understand the parameters of a research study of this kind.

Further, there may be differing understandings of and approaches to 'informed consent'. The ESRC Research Ethics Framework (2005) recognized that, in developing countries:

The conventional meaning of informed consent may be problematic because the conventional model of consent rests on 'the primacy of the individual'. The individual is seen as both the owner of rights and the bearer of reciprocal duties to the rights of others. This emphasis on the individual can seem inappropriate or meaningless in some cultural contexts, where the individual may take less precedence than broader notions of kin or community. (ESRC 2005: 24. See also Brown et al. 2004).

There is a danger here of a false dichotomy between 'developing' and 'developed' countries in relation to ethics. The emphasis on the individual may

seem inappropriate in some cultural contexts, but when something goes wrong and people are damaged, the focus will rightly be drawn to the interests of the individual. Second, in developed countries, children are also seldom seen as completely separate persons, since they are connected to parents/carers.

Young Lives attempts to ensure that reasonably equal minimum standards are met in relation to seeking informed consent. Research teams initially approached community leaders and then individual parents and children (similar practices operate in developed countries where negotiations take place with several ‘gatekeepers’ before children can be approached to be invited to participate in research; see Alderson and Morrow 2011). Informed consent is sought and recorded from parents and children by enumerators and fieldworkers at the beginning of each visit, again at the start of each session or activity, and ideally again at the end of the session in relation to how the data will be used, or regarding participation in future activities. Where appropriate, researchers provide contact details of the research teams and detailed leaflets that they can read out to ensure minimum standards of information.

Within the qualitative research, there is a constant process of attempting to check participants’ understandings. Some teams have found that signing a paper consent form is not acceptable for various reasons, mostly because people are wary of putting their signature on forms, and so they have voice-recorded verbal consent with the digital recordings being stored (but not transcribed). Other teams have found it inappropriate to use voice-recorders, but are recording their experiences of the consent process in their field notes. Consent is understood to be an on-going process. A fieldworker in Vietnam noted that ‘local people ask lots of questions about us as researchers and the research, and we always take time and interest not only to satisfy their curiosity but also to get their feedback about the research itself’.

The following example from India illustrates the consent process, with one of the qualitative research team explaining the study to an Older Cohort girl:

We are coming from *Young Lives*. We told you about this study in detail in the morning. While we were conducting the group activity, we told you why we came to your village, and what we wanted to know about you. Now the interview which we are going to do is totally about your personal information. [A list of examples follows.] We came here to know all these things. So now we are going to start our interview. If it is a long interview and if you feel like stopping it you can ask us to stop, we shall stop there, ... we shall continue tomorrow. You can also stop me if you don't understand any of the questions that I ask. OK! Shall we begin?

In the second round of the qualitative research in Ethiopia, an Older Cohort child declined to participate, despite his parents' willingness for him to do so. 'There was some speculation from the caregiver that the boy had heard a rumour from his friends that Young Lives has a mission to convert children to Protestantism' (Tafere et al. 2009). This demonstrates differences in views between parents and children, though of course parents may have had similar fears. That children's views about participation are respected must be understood positively as informed consent operating in practice. Further, this situation may change on the next visit, in which case, children's or adults' previous refusal could be explored with them if they were willing.

In Young Lives, research relationships have to be sustained over a long period of time, and informed consent has to be renewed, which is difficult if the research is not promising to improve people's lives. Notwithstanding the emphasis on continual consent, the loss of participants from the samples in Young Lives has been less than 2 per cent per annum, and is usually due to the death of children (see

Outes-Leon and Dercon 2008 for a detailed analysis and comparison with other longitudinal studies in developing countries).

[A] Research in very poor communities

As noted, it is inevitably difficult for people to understand the parameters of a complex study like Young Lives. Many of the study sites are recipients of a range of intervention projects, both governmental and non-governmental, that offer services and may sometimes make unrealistic promises (see, for example, Olivier de Sardan 2005). Frequently, participants assume that Young Lives is an intervention from which benefits can be extracted or expected (see also Nyambedha 2008). Requests for personal assistance from members of poor communities to visitors of all kinds are so common, despite constant explanations, that this is likely to be a generic situation. In some communities, research teams have found widely differing conceptions about the purpose of the research. These are usually locally specific, linked to a history of interventions, and difficult to modify through conventional ethics procedures. For example, in Ethiopia, the interviewer asked the caregiver of a Younger Cohort girl if she had any questions or suggestions:

Caregiver: What I want to request is if you have something to help me with her education. Maybe if you have something to help me, especially the payment ...³

In Peru, parents associated Young Lives with aid interventions. Even though fieldworkers explain that there are no material benefits other than gifts for their children (that is, books and crayons), parents remain hopeful: ‘Maybe one day you bring some help/benefit for us [laughter]’; ‘Maybe when he’s studying, you [Young Lives] can help me with it’ (Quechua-speaking caregiver).

Fieldworker: And your father approved of Niños del Milenio [Young Lives]?

Older Cohort boy: Yes, because he said it could bring some aid.

In another example from a group discussion in Peru, a professional asked the fieldworker about the purpose of the study. The fieldworker started to explain, but another professional interrupted and mentioned that there was a problem with the programme *Juntos* (a government-run conditional cash transfer programme). He claimed that fieldworkers from Young Lives had told him that all children who participated in the study would become direct beneficiaries of the *Juntos* programme. Other families confused Young Lives with NGOs like Intervida, which sponsors children and communities.

Despite explanations, the idea that Young Lives is associated with the government remains. This perception is partly accurate in Vietnam and Ethiopia, where government departments are involved in data collection. Further explanations for it may lie in the use of a clearly recognizable logo, and also the involvement of Save the Children UK (an international aid agency) in the study.

There are often gaps between what is supposed to happen, the procedures put in place to ensure that it does happen, the way these procedures are actually implemented by fieldworkers, how fieldworkers describe this, and how people interpret interventions (see Fairhead et al. 2005: 106, discussing a vaccine trial in The Gambia). Although these disjunctions occur in all kinds of research, they are particularly likely in a large, longitudinal, interdisciplinary, international study with vulnerable groups such as very disadvantaged children. There may be a ‘therapeutic misconception’ that arises when people expect some benefits to come from their involvement. The research teams ask detailed questions about household expenditure, and some people living in poverty may understandably take every opportunity to ask for help and money, especially when they want to spend their

limited time and resources on activities that will bring them direct benefits. In poor communities, it is likely that any outsiders who are not strictly government representatives providing government services will become the objects of speculation, and in this process, it is difficult for people to distinguish research from intervention.

A problem has sometimes arisen in translation, and particularly in the use of the term ‘project’ (see Olivier de Sardan 2005: 179). For example, a fieldworker in Vietnam noted:

both at provincial and local levels, the term ‘project’ has become loaded with expectations for material and financial benefits, sometimes an instant remuneration. A research project without direct material benefits like Young Lives requires significant efforts to explain itself against the grain. ... [We were warned] about this aspect quite early before the field research started. We later found [the] warning described the expectations of officials, teachers, education administrators and village cadres more closely than those of the ordinary people. (Truong 2009)

In Ethiopia, however, Young Lives is known as a *tinat*, which means ‘study’. In Peru, the word *estudio* is used, which also translates as study. The word for research is avoided, because it can be translated as *investigación*, which may be confused with the word the police use for an investigation. The research teams emphasize that Young Lives is not an intervention or a programme evaluation. Peru teams do also use the word *proyecto*, but this is followed by a description that explains that it is a study.

[A] Reciprocity in research: rewards, compensation, and giving something

back

Compensating or paying research participants raises ethics questions. Payments can be made to reimburse expenses; to compensate for time, inconvenience, and possible discomfort; to show appreciation for participants' help; or to pay for people's help. According to the ESRC Framework for Research Ethics 2010, a balance has to be struck between coercion and 'incentivization'.

There should be no coercion of research participants to take part in the research. Adult research participants, however, may be given small monetary reimbursement for their time and expenses involved. ...Where children are involved, it is often appropriate to acknowledge their help with gifts to participating schools and/or personal gifts. In short, incentives may be permissible, but anything which implies coercion is not. (ESRC 2010: 29–30)

This has implications for informed consent. As Creed-Kanashiro et al. (2005: 925) suggest, 'cultural context may limit truly independent consent and may also be distorted through the giving of incentives in populations in limited economic circumstances'. Payments to encourage people to take part may in such cases contravene Nuremberg standards against persuasion or pressure of any kind on participants (Alderson and Morrow 2011; see also Wendler et al. 2002). On the other hand, the Association of Social Anthropologists of the UK and Commonwealth guidelines (ASA 1999) recommend, 'There should be no economic exploitation of individual informants, translators and research participants; *fair return* should be made for their help and services' (emphasis added). Others may rightly challenge the differential treatment of children and adults advocated by the ESRC guidance, which suggests that children should not be paid.

Each country research team deals with this in locally specific ways, reflecting cultural contexts about the value of people's time, their willingness to undertake research activities 'for the common good', and the reality of poverty and not having the capacity to miss a day's wages to spend time talking with researchers. Some country teams pay respondents, including children, for their participation. Others give small gifts as a 'thank you'. Norms and patterns of reciprocity, notions of community, and/or doing what the government tells you (for example, in Vietnam where government census enumerators are administering the survey) are likely to affect people's participation. However, paying respondents (adults and Older Cohort children) to compensate them for their time may cause some confusion, as the following example shows.

In Ethiopia, children were encouraged to use the money they received for participating to buy school materials. During the first round of qualitative research, the Ethiopian research team noted that, in the situation of extreme poverty, people perceived Young Lives as an aid agency and money received as aid. In the second round, researchers paid more attention to explaining that Young Lives does not provide any aid to the community in general nor to the research households in particular (Tafere et al. 2009).

Other country research teams (Peru, for example) are giving small gifts as a 'thank you', as well as some supplies to local schools. In India, research teams provide some resources to schools (for example) as requested by local community leaders to benefit all children in the locality, and up to 2009, were not making direct payment to research participants. However, in some cases research respondents consider it unfair that they are giving up their time but benefits are for everyone in the community.

The question of remuneration to Young Lives' research respondents is becoming increasingly important as economies become more market-oriented. For

example, in Andhra Pradesh, the National Rural Employment Guarantee Scheme, which pays household members at least Rs80 (the equivalent of £1) for a morning's work, has recently been implemented. Whereas in the past, the opportunity cost of spending time talking to a researcher may have been zero, or negligible, since respondents could carry out domestic chores or work on the farm while researchers talked to them, they are now becoming more aware of the financial value of their time, and are more likely to expect monetary compensation. Thus the decision has been made to compensate respondents for their time in subsequent research rounds. Similar patterns might apply in the other countries. Young Lives may run a risk of people refusing to participate in future: fieldworkers report that, especially in urban areas, it is already difficult to persuade people to continue to be involved. This is not to suggest that people should not be paid when they most need it – after all, the duress on poor people to agree to participate for material gain is created by their poverty, not by the incentives. Rather, it is to suggest that care has to be exercised here, and awareness that it may be difficult for low-status people living in poverty to refuse requests to participate in the research.

As the research progresses, Young Lives is developing ways to give something back to communities, and people are eager to know what happens to the information they provide. Preliminary findings are reported to the communities involved in the research at meetings in a manner that is accessible to them and highlights the usefulness of the data they are providing. In some countries, this is accompanied by further useful information, about, for example, nutrition in Peru and local services in Ethiopia. However, there remains a need to produce research summaries or short reports in language appropriate to the differing groups, according to age or culture. Reports to communities also explain how Young Lives is taking messages to governments and is advocating for change. However, this raises questions about the likelihood of governments (or local policymakers) taking

notice of research findings, and in the case of longitudinal research, the time taken for research findings to work their way into the policy domain. It was noted in Peru that while families react positively to the explanation that Young Lives is a study to gather information to inform public policy targeted at all children, ‘they are distrustful of any real impact of the information Young Lives provides in improving the current situation of poverty, because they distrust the government and feel abandoned by it’ (Ames 2009).

Further work can reveal what information people would find useful, rather than presenting very general findings about the whole country. For example, in Peru, fieldworkers noted that parents said that they would like to learn more about their own children and, since they attended the group sessions and talked to the fieldworkers, perhaps they could get more information about their children’s behaviour and feelings, and so on. In one site in Peru, parents were worried about the presence of gangs and wanted to know about their children’s whereabouts. They saw Young Lives activities as a way of obtaining advice on this issue. However, even this poses problems since researchers promise children they will not tell others what they say and emphasize that children’s confidentiality must be respected: with such small numbers in each community it would be difficult to mask identities.

In some cases, community representatives and professionals such as teachers expressed expectations about the research. For example, in one site in Peru, a group of participating teachers said that they would like Young Lives to explain to parents about the benefits of early childhood education, and persuade them to bring their children to kindergarten. Other teachers asked about fieldworkers’ observations in the classrooms: they wanted to know how the children in their class were doing and also to receive some advice. All of this needs consideration against the risk that Young Lives could come to be seen as ‘intervention’ or ‘evaluation’,

which has implications for further rounds of data collection.

A further benefit to local communities from the research process may be the encouragement of reflection, mentioned in the section below on the effects of research. This is particularly relevant to children who are encouraged to speak about matters that affect them.

The need for reciprocity is acknowledged in Young Lives research, but the level and type of reciprocity is decided by the country teams. Results have varied and Young Lives is cataloguing each country's approach to enable local adaptation while respecting key principles.

[A] Child protection and parents' fears

Research teams are encouraged to discuss concerns with lead quantitative or qualitative researchers, whilst the research team based at Oxford provides guidance and support following internationally accepted protection policies. There is growing sensitivity as children mature about having gender-balanced field teams where possible, which is partly a child-protection question and partly an attempt to respect local norms related to gender-appropriate behaviour (that is, men and women being together).

In some sites, although parents have very high expectations of the research, they also have fears about what might happen to their children, some of which relate to child protection. In Ethiopia, for example, some parents believed their children might be taken abroad (to the USA) to be educated, and some felt worried about this. One mother preferred to stay with her child during the interview, and later revealed to the researcher that she was guarding her child because she feared that he might be taken abroad for adoption. Research teams are consequently careful to reassure parents and other adults in the community that children will not

be taken away.

In Peru also, among some indigenous highland communities and other rural communities located in the poorest regions, parents are frightened that Young Lives children will be taken away by outsiders. These fears relate to local myths about indigenous people being abducted, and murdered for their 'fat', which have a very long history and relate to any outsiders. The myths have arisen in the long history of discrimination from the earliest years of Spanish colonization: it was rumoured that Spanish conquerors and missionaries wanted the fat of native people for all kinds of purposes (Vasquez del Aguila 2007). Besides, newspapers in Peru have made much of child kidnapping in the context of hostility to inter-country adoptions. A local authority worker in a group discussion in Peru commented that there were rumours in the community that Young Lives were going to take children away. When the fieldworker reassured them, a questioner wanted further assurance that the field team were all Peruvians.

This is a positive reflection of the research relationship, suggesting that people feel they can express their fears and concerns to fieldworkers. While these are different versions of stranger-danger myths from those in Ethiopia, underlying them all may be similar ideas about powerful people coming into communities who will 'change our lives' for good or ill.

[A] Explaining archiving

Archiving data is a relatively new requirement. Although there are rigorous controls on access to archived data, archiving any form of data presents difficulties for notions of informed consent, because the later uses of the research data cannot be anticipated, and so cannot be explained to people (Alderson 1998). The

Economic and Social Data Service (the UK data archive organization) has guidance on how to seek consent from adults for their data to be archived, indicating who will have access to the information and how it will be used. In relation to children, it recommends that ‘storage of data should be explained in a way that children can understand’ (ESDS n.d.). But the document does not provide examples of how to do this (see Goodenough et al. 2003; Alderson 1998). Young Lives research teams explain what archiving is, and reassure participants that anonymity will be preserved and identifying features (of places, people, organizations) disguised when data are for archiving.

In Peru, the term *un archivo* is understood, since almost all villages and communities own publicly accessible archives with documentation regarding the village. In India, researchers suggested ‘stored in a computer’. In Vietnam, researchers noted:

We used the word ‘storage’ (pack and store away), pointing to a cupboard or wardrobe or trunk if any of those are available in the house, or simply a box or a bag. Since we brought our laptop to the field, children saw us typing notes. We showed them what we typed – excerpts of transcripts of what they said (even if some can’t read) – and pictures (of their house, no person). We also replayed a short part of the tape so that they could hear their voice. We then explained that all of these will be kept in Hanoi and England for many years but nobody will know that these words are theirs or go after them because of what they said. The children and their family members were quite excited, some were scared at first, then became very proud. (Truong 2009)

[A] The effects on children and families of being involved in the research:

Prolonged contact

In Peru, some parents were not sure about the length of the study. Some thought it was going to follow up children until they were 15, others until they were 20 years old. Other parents expressed their wish to keep in touch after the study was over.

Fieldworker: The project is supposed to last until children are 15, then it is over, and then we'll leave you in peace.

Caregiver: Hmm, and that's it then. And, what if one day they study and became professionals and remember they're Niños del Milenio? Where can they reach you?

There are likely to be both short- and long-term effects on children, their families, and their communities because of their involvement in the research since the study asks questions that encourage reflection, and might affect (for example) educational motivation. Some participants may continue to welcome the research, others may resent the continued involvement. As one Ethiopian caregiver (of an Older Cohort boy) reflects:

Your follow-up is good. In earlier times we didn't know if the support was going to start or not. ... You have identified the children who have lost parents and who have parents. And it is for the future of the lives of children. ... So I have positive comment on Young Lives, I am happy about it. The child also has been filled with hope because of this study. All I have is this and I thank you.

In the second round of qualitative data collection in India, at the end of a group discussion, Older Cohort boys reflected on the research:

I have not seen any time [before] children meeting together and discussing about their matters. Till now no one has discussed like this with children. We feel happy that [research] team members mingle with

us. Earlier we never spoke [up] in front of anybody. But now we are able to speak out in front of people like you without any fear, and this helped us in having courage, and now I know what I will become in my future. Within these two years, we have come to know how to speak with elders.

[A] Suggestions for future rounds of research

Young Lives will continue to develop its memorandum of understanding (Young Lives 2009; referred to above) with research teams and fieldworkers, adapting it as we learn more about doing longitudinal research with children and families.

Questions about informed consent and managing raised expectations clearly need constant reflection and development. The possible effects on children and families of being involved in such detailed research also need to be monitored over time.

A great advantage of long-term research is that it provides time to learn and adapt methods and standards to fit people's views more closely. Some of the research activities may be experienced as time-consuming and difficult. Some of the questions in the surveys are complex, (for example, asking people to recall very precise amounts of foodstuffs, or asking children to write about unfamiliar concepts) and children and adults may have difficulty answering them. In developing the Round 3 survey, certain sensitive and intrusive questions have been discussed in depth and dropped or refocused in particular country contexts, in case they cause distress or difficulties. For example, in Ethiopia, because of the political situation, it would be insensitive to ask about participation in political protests. Subsequent rounds of the survey have been adapted to minimize these difficulties, but there is a clash here with the need for continuity of data and questions.

Such factors may change from one year to the next. For example, in two of the sites in recent qualitative research in Peru, levels of distrust seem to be higher than

they were on the previous visit, despite the explanations provided. However, the fact that these fears were shared openly could arise from greater trust in the field team. In one site, there seemed to be a decline in trust in general within the community towards local organizations and services because of an unsettling incident involving the arrest of a local leader (Ames 2009). When research teams visit, they are not going into neutral situations – situations change very rapidly, and these changes themselves need careful research and documentation.

[A] Conclusion

This chapter has shown how Young Lives has paid attention to the general principles of research ethics. Matters like consent and reciprocity are not straightforward when people meet from different social and cultural backgrounds, with different class and educational status, and with unbalanced power relations (especially those relating to age). The principles of research ethics, therefore, have to be adapted and applied to particular situations and particular times. Locally appropriate codes of practice require input from all stakeholders. Moreover, they require careful communication of the nature of the research, and realistic expectations of what it can offer, to the people who provide information. This adaptation and communication in turn requires knowledge and experience of local situations.

This chapter has shown that attention to research ethics needs to be on-going, requiring continual learning at all levels. Long-term research poses difficulties in establishing relationships with communities that are both ethical and enable the research to continue. It also offers the opportunity to learn about relationships between researchers and researched, and how to fine-tune these according to sound ethical principles.

This process also requires learning on all sides. While researchers explain to

those being researched the nature and purpose of the research, researchers must also be learning from those they are researching. Ethical research must take into account the understanding and values in communities being studied. Reciprocity requires learning from them what they find useful. Lessons arising from the experiences in particular locations and attempts to solve problems may help researchers in other situations to improve their practices. This requires communication and learning at a further level: between country research teams, aided by the central co-ordinating team. The central team takes guidance from its own researchers as well as from a range of bodies outside the project, including academic bodies, international NGOs, and national and local bodies governing ethics. Ideally the lessons learned can be reported back to such bodies, and this can help research governance bodies to understand the possibilities of local adaptation based on specific conditions and cultures.

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² <http://www.younglives.org.uk/what-we-do/research-methods/ethics>

³ Interviews transcribed here are from the second round of in-depth interviews conducted in 2007/08 as part of the qualitative research within Young Lives.'