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

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Available from:

Young Lives

Department of International Development

University of Oxford

3 Mansfield Road

Oxford OX1 3TB, UK

Tel: +44 (0)1865 281751

Fax: +44 (0)1865 281801

E-mail: younglives@younglives.org.uk

Web: www.younglives.org.uk

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Abstract

A great deal of attention is now paid to the ethics of social research. Research governance has expanded, and a burgeoning literature is emerging that describes the processes, practices and questions that arise in social research with children, families and communities. This paper outlines the approach taken to research ethics within Young Lives, a long-term study of childhood poverty in four developing countries. It describes some of the practical difficulties that Young Lives faces, and emphasises the importance of understanding local contexts in undertaking research with children and families in environments that are dynamic and may change rapidly from one year to the next, economically, environmentally and politically. The paper aims to contribute to current debates about research practices, the ethics of longitudinal research with children and research with communities in majority world contexts, in the spirit of shared enquiry and learning.

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The Author

Virginia Morrow is Reader in Childhood Studies at the Institute of Education, University of London. She is also Course Organiser of the MA Childhood Studies (sociology of childhood and children's rights). She has published widely on methods and ethics of social research with children; sociology of childhood and children's rights; social capital in relation to children and young people; child labour and children's work; children's understandings of family and other social environments. She is an editor of *Childhood: A Global Journal of Child Research*. As Child Research Associate for Young Lives, she is advising the qualitative research team on conceptual and theoretical frameworks, qualitative research methods with children and social research ethics.

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1. Introduction

Research ethics exist to ensure that the principles of justice, respect and avoiding doing harm are upheld, by using agreed standards. These basic principles are universal, though there are of course many subtleties and diversities, and the contingent aspects of how principles are understood, interpreted and practised can vary from place to place (Ulrich 2003). However, all variations tend to revolve around the question of how to balance the interests of the individual with those of the community/society/family and the goals of research studies. A great deal of attention is now paid to the ethics of social research in general (ESRC Research Ethics Framework 2005), and with children in particular. Research governance has expanded and a burgeoning literature is emerging that describes the processes, practices and difficulties that arise in social research in developed and developing countries (see, for example, Dyer and Demeritt 2009; Ulrich 2003). In Europe and the USA, medical research has developed standards over several decades and social researchers also agree to observe high ethical standards. Young Lives takes a positive view of ethics as enabling high-quality research, respecting the key principles of justice, respect and avoiding harm.

Much can be gained by drawing on examples from medical research ethics, because these show direct links between research, risks, and health and social effects (see, for example, McGregor (2006) in relation to a meningitis drug trial with children in Nigeria). The effects of social and educational research may not be traced so clearly, but may just as seriously damage people's lives, futures, reputations and relationships, through public reports and influence on policies and practices (or lack of positive influences where they are urgently needed). Although informed consent and the 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 harms occur. While social research like Young Lives does not pose the same kinds of physical risks as medical research, the study has to balance the potential for harm, and to avoid exploiting people in the majority world in research. This is a risk Young Lives attempts to reduce by use of local researchers, and focusing on local needs and interests.

About Young lives

Young Lives is an in-depth international research project funded by the UK Department for International Development (DFID). The study is longitudinal in nature, and involves following the lives of 12,000 children growing up in four developing countries over 15 years: Ethiopia, the state of Andhra Pradesh in India, Peru and Vietnam. Two cohorts of children – a younger cohort who were born in 2001-2 and an older cohort born in 1994-5 – are being followed, with the younger children being tracked from infancy to their mid-teens and the older children through into adulthood, when some will become parents themselves.

A variety of methods are used to collect both qualitative and quantitative data at the individual, household and community level. Regular questionnaire-based surveys of all the children and their carers are carried out every three years, together with more in-depth research using participatory methods with selected children. This is complemented by interviews, group work and case studies with the children, their parents, teachers, community representatives and others. The focus is not only on the children's material and social circumstances, but also their perspectives on their lives and aspirations for the futures, set against the environmental and social realities of their communities. The aim of the project is to gain a deeper understanding of the intergenerational transmission of poverty, how families on the margins move in and out of poverty, and the policies that can make a real difference to their lives. It also aims to inform the development and implementation of policies and practices that will reduce childhood poverty.

This paper aims to contribute to current debates about research practices, the ethics of longitudinal research with children, and research with communities in majority world contexts, in the spirit of shared enquiry and learning. It describes the approach that Young Lives has adopted, as a starting point for identifying more fundamental ethics questions that arise in managing and maintaining long-term relationships in research. The paper is structured as follows. The first section describes the Young Lives approach. The second section discusses some of the difficulties encountered in fieldwork and Young Lives' strategies for attempting to resolve these. It focuses on the following topics. Firstly, it describes the processes in seeking research ethics approval. The paper then describes some of the practical difficulties that Young Lives faces: first, in seeking informed consent; second, dealing with raised expectations in research with people in very poor communities; third, questions of compensating respondents for their time; fourth, child protection concerns and parents' fears; fifth, reciprocity in research; sixth, managing long-term relationships in research, including explaining archiving; seventh, the effects of the research on children and families; and finally, it makes some suggestions for future rounds of the survey. The paper 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. The paper does not discuss the use of translators.

Experiences relate to both the household and child surveys and the qualitative research. In the qualitative research, conversations with participants have been recorded, transcribed, translated and coded, so is a systematic part of the research documentation. Ethics questions can differ between the two research processes, in so far as qualitative research allows more time to build trust and learn about respondents' concerns, and so on. The wider implications for the quantitative survey research are discussed, because there is an important relationship between the two components, which from the point of view of families and children may not be obvious, especially as the survey round and qualitative research happen separately, with several months between them. We hope that Young Lives can offer useful examples of how we addressed these problems.

2. Seeking research ethics approval

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

- 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. (The Declaration of Helsinki was the first international code on research, written by doctors, following public concern about under-researched medical treatments (WMA 1964/2000).)
- Save the Children UK Child Protection Policy (Save the Children 2003).

Initially, ethics approaches in Young Lives were developed collaboratively 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 specific sections below). Following piloting of the qualitative research methods in 2007, a memorandum of understanding for fieldworkers was developed in collaboration with qualitative research teams, setting out some basic guidance about research procedures and respectful communication with research participants (see Appendix 1). This is now being used with the survey teams too. These processes mean that Young Lives has already collected a considerable amount of data relating to the ethics of the research that is available for analysis in data gathering reports (Ames 2009; Tafere et al. 2009; Truong 2009; and Vennam 2009). Young Lives qualitative data are all transcribed and coded using ATLAS-ti software, a qualitative data analysis tool. The qualitative data have been coded for 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 fieldnotes as they arise and discuss these with lead researchers. Survey enumerators also record ethics questions, and systematic analysis of these will take place in future survey rounds. All field teams received training that includes ethics. In Peru, for example, survey fieldworkers are all experienced enumerators, and are required to report any cases that give cause for concern to their supervisors immediately, who will try to resolve the situation with the fieldworker. The supervisors then also often bring questions to the attention of the lead researchers, who discuss what to do. In some cases direct help has been provided, but mostly people are directed to specific services or sources of advice relevant to the issue at hand. The ethics committee of IIN is also informed of these specific cases.

Research ethics have been discussed with the qualitative, quantitative and policy teams, with the aim of developing a shared understanding of research ethics within the whole study. This is a complex task, involving differing academic traditions and disciplines (economists, educationalists, social anthropologists, developmental psychologists, epidemiologists, nutritionists, social workers, 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 it does not negate it altogether, as there may be stark social differences between researchers and respondents. In other words, there are important power dynamics between professionals of a higher social class interacting with very poor research participants, and further power dynamics reflecting social divisions along the lines of gender, ethnicity and caste. This is as well as the very obvious power differential of age, with research teams conducting research with children as young as 6 or 7 (this is the case, of course, with research everywhere). Ethnicity and caste are highly sensitive and political issues in some countries and sites. Furthermore, there are differing understandings of children in each country, reflecting cultural, religious, and historical constructions of childhood, which it is outside the remit of this paper to explore. It is important to note at the outset that Young Lives' attrition rates – or rate of loss of participants from the sample – are low, less than 2 per cent each survey round. They are generally due to people withdrawing or, more usually, to the death of children (see Outes-Leon and Dercon (2008) for a detailed analysis and comparison with other longitudinal studies in developing countries).

3. Consent: Informed and understood, freely given, process adapted in local contexts

Young Lives works on the principle of respect for informed consent. Researchers must obtain informed consent of parents or caregivers, and of children who have the capacity to consent, and this is requested at the outset of the interview. 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). At any rate, research teams are concerned to ensure that the purpose of the research is clearly explained, that children and adults understand what they are agreeing to, and that their expectations of being involved in the research are not raised or unrealistic. Fieldworkers are also clearly instructed that informed consent must be freely given and voluntary, and that people need time to think about participation. From the fieldworker manual for the survey Round 3:

No project staff should pressurise, coerce or deceive respondents in an effort to ensure their participation. Staff should also try to ensure that respondents are not pressurised by other family or community members. Staff should not make any promises they cannot or are unlikely to keep. 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. Whilst the study procedures are designed to ensure that consent is informed and voluntary, the only person who can really ensure that is you, the fieldworker. You must make every effort to make sure the participants understand the study and feel free not to take part or to withdraw if they wish to.

In relation to consent from children, the fieldworker manual emphasises the following:

It is vital to take extra 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 is also important to bear in mind that children are generally taught from a very young age that they must obey adults. This makes it very difficult for them to refuse you. So you must make every effort not to put any pressure on them to participate in the study and to make it clear that there will be no adverse consequences for them if they refuse to take part. Similarly, you should explain the concept of anonymity in words they can understand. They should know that their identity will be kept a secret and that the information will not be used to identify them or to describe their life in particular, but rather to explain the typical life of a child in their community.

There is discussion, for example, in India about whether to seek children's consent before parents' consent and out of earshot of the parents. As noted in a training session:

Children are much more likely to really say what they want than. Some fieldworkers might use this method, while others might feel it is not culturally appropriate to talk first to the child. This is suggested during the training. But whatever they choose, all fieldworkers will run through the entire consent procedure with all children. They also

explain consent in 'child friendly' terms, (and they practise beforehand with an experienced researcher).

Young Lives' fieldworkers are clear about the limitations of the research in terms of its ability to realistically bring about change in research participants' lives. For example, qualitative research teams use local translations/relevant versions of the following 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 2009b)

In many parts of the world, however, people do not necessarily have any experience or understanding of what research is. Further, it is well documented that differing cultures have very different views on and approaches to 'informed consent'. The ESRC Research Ethics Framework (2005) recognises 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).

However, there is a danger here of setting up a false dichotomy between 'developing' and 'developed' countries in relation to ethics. The emphasis on the individual may seem inappropriate in some cultural contexts, until something goes wrong, such as a drug trial, and the focus will rightly be drawn to the individual cases where children have been damaged. Secondly, in 'developed' countries, there remains uncertainty about when parents no longer need to be involved in consent processes, and children are also seldom seen as completely separate persons, being always connected to parents or 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 layers of 'gatekeepers' before children can be approached to be invited to participate in research (Alderson and Morrow 2004)). 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 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 have voice-recorded verbal consent with the digital recordings

being stored (but not transcribed). Young Lives has ethics approval for this. Other teams have found it inappropriate to use voice-recorders, but are recording their experiences of the consent process in their field notes.

The important point is that consent is understood to be an on-going process. As a fieldworker in Vietnam notes:

This is in fact very similar to our fieldwork practice during which 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. In our view, this practice is necessary to ensure mutual reflexivity and thus an inherent part of a community based or action research or indeed any anthropological research.

An example is given below to illustrate the consent process, from India, 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 project 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?

While attrition rates are very low, in Round 2 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' (Tefere 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 this was felt to be appropriate.

4. Research in very poor communities

Despite efforts at clear explanations, in some communities in some of the countries, research teams have found that there are widely differing conceptions about the purpose of the research, which the research team would see as misconceptions. These are usually locally specific, linked to a history of interventions, and difficult to modify through conventional ethical 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 that if you have something to help me for her education. Maybe if you have something to help me, especially the payment.

Interviewer: Do you recall at the beginning of the interview, you were told about the objective of the study?

Caregiver: Yes.

Interviewer: Its main objective is not to help children in their current situation. However, it is a study about their problems to get general solutions not only for this site, but for Ethiopia's children in general, by bringing about policy changes... It also tries to publicise the general results of the study to concerned bodies in order to know more about the lives of children. Thus, there will be changes in the future, but in the current situation we give exercise books for the time you spend with us. At the beginning we start the study telling you that we are not doing aid, rather we are conducting research. And it is to bring changes in the future.

This example suggests that Young Lives seems to be understood by some families as an intervention to provide individual children with a better life.

In Peru, parents very clearly associated Young Lives with various other programmes and interventions. Even though fieldworkers explain that there are no material benefits other than gifts for their children (i.e., 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 to him, 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 of Niños del Milenio told him that all children who participate in the study will directly become beneficiaries of the *Juntos* programme. Other families confused Niños del Milenio with NGOs, like *Intervida*, which sponsors children and communities.

In Ethiopia, too, a caregiver of a Younger Cohort girl challenged the researchers, recalling previous experiences of programmes and interventions in the locality:

You're coming from the government, right? We would inform you about the children's development and their work, not only the problems, and that will help you plan more things for our community. I remember one time some people gathered us to tell us about the equality of men and women and we spent too much time in the meeting and they gave us 15 birr [nearly a day's agricultural wage], and they sent us home. I had a lot of things to do at home the whole time I sat there. They just talk about things that are not practical. Many of us were angry because there was no visible change in the last 3 or 4 years they came to our community. The aid must be fundamental and generous because living expenses are getting high. Just giving some money doesn't do [much] good for long.

The researcher then explained that this is a research study and that he is not from the government. The parent replied:

I didn't mean to ask you for anything because you're not the government. It just sends you to make a study, and I understand.

Nonetheless, the idea that Young Lives is associated with the government remains. This perception is partly accurate in two countries – Vietnam and Ethiopia - as government departments are involved in data collection. Further explanations for this disjunction may also lie in the use of a clearly recognisable logo, and also the involvement of Save the Children UK (an international aid agency) in the study.

Considering the differing contexts in which the study is taking place is crucial to understanding how research ethics operate in practice. Young Lives is conducted across a very wide geographical spread within each country and in very poor locations. As such, many Young Lives' respondents are illiterate or semi-literate (in the case of parents) or have basic literacy (in the case of children). The situations in which Young Lives operates may cause difficulties and shape the research enterprise in general. Some of the ethical questions Young Lives contends with are specific to or more problematic in longitudinal research, as 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. Many of the difficulties Young Lives has experienced are also associated with general problems prevalent within the countries, and research ethics need to be understood in this context. Many of the study sites are recipients of a range of intervention projects, both governmental and non-governmental,¹ that offer services and may sometimes make unrealistic promises (see, for example, Mosse 2007 on how pro-poor interventions operate in India; see also Olivier de Sardan 2005).

Again, there are useful experiences from medical research to be drawn upon here. Fairhead et al. (2005), describing a clinical research vaccine trial in the Gambia, suggest that there may be a disjunction between research protocols and what happens in practice. In other words, what is supposed to happen, the procedures put in place to ensure that it does happen, the way these are actually implemented by fieldworkers, how fieldworkers describe this, and how people interpret interventions (Fairhead et al. 2005: 106). Although this disjunction occurs in all kinds of research, it seems particularly likely in a large, longitudinal, interdisciplinary, international study with vulnerable groups such as very disadvantaged children such as Young Lives. There may be a kind of 'therapeutic misconception' that has arisen as people expect some benefits to come from their involvement. The research teams are asking 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 use their very limited time and resources on activities that will bring them direct benefits. Furthermore, can, or should, we expect people to understand what 'research' is? In poor communities, it is likely that any outsiders who are not strictly government representatives providing government services become the objects of speculation, and in this process, it is difficult for people to distinguish research from intervention.

1 For example, one Young Lives study site, a community in Andhra Pradesh, Poompuhar (a pseudonym) has been the recipient of the following: the Indiramma scheme (Integrated Development in Rural Areas and Model Municipal Areas, a scheme to improve the standard of living in rural villages); PDS Antyodaya-Annayojana, Annapoorna, (national midday meal scheme); educational schemes (free text books); ICDS (Integrated Child Development Service); health, natural resource management and other social security programmes (such as food for work, widow/disabled pension, national family benefit scheme (NFBS); national maternity benefit scheme (NMBS); Girl Child Protection Scheme, which has a number of objectives to end discrimination against girls (see <http://www.aponline.gov.in>); Indira awaz yojana (IAY), a scheme to provide houses to members of Scheduled Castes/Scheduled Tribes, free bonded labourers in rural areas and also to non-Scheduled Caste/Scheduled Tribe rural poor below the poverty line, free of cost; national old age pension scheme (NOAP), and so on.

Further explanation for this may also lie in the over-use of the word 'project'. As a fieldworker notes, in one site in Vietnam:

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).

Again, this is not unique to *Young Lives*. Olivier de Sardan (2005) discusses what happens when 'development language comes into contact with a local language', and observes that 'projects have become privileged... as a language system' (de Sardan 2005: 179). He suggests that this is not so much a linguistic problem as a problem of translation. This may explain what is happening in *Young Lives* sites. It would be useful to see how this operates in the different languages used in the *Young Lives* sites, because it may go some way to explaining why people construct *Young Lives* as potentially providing aid. 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 investigation. The research teams emphasise 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. In Quecha, the word *proyectu* or *proyectupi* are borrowed from Spanish.

All of this is unsurprising, but is something that could usefully be explored in further qualitative research with communities. *Young Lives* tries to emphasise the word 'study' instead of 'project'. However, the examples from medical research suggest that the word 'study' can be equally loaded with negative connotations relating to 'experimentation'.

Parents' concerns can be allayed with careful explanations. Many of the transcripts show how the research team spend a great deal of time explaining the research in locally relevant ways. Parents are often concerned about why their children have been selected, so researchers explain the sampling process in a way parents and children will understand.

The following example comes from India:

Now, let me explain why we have selected [your child] for the research. While cooking rice, you will take some grains and test whether it's cooked or not. You will not check the whole rice. In the same way, we select some children to know how they are and to know about their lives, and to know how the lives of children are in [this community]. That's why [your child] has been chosen.

5. Compensation or rewards – how do these relate to understanding Young Lives?

The question of compensating or paying research participants raises ethical 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. It is important to note that payments should not be made to encourage people to take part 'as an incentive' because to do so is problematic, and contravenes Nuremberg standards that state no persuasion or pressure of any kind should be put on participants (Alderson and Morrow 2004).² In a useful review, Wendler et al. (2002) note four types of payment: reimbursement, compensation, appreciation and incentive. They suggest 11 safeguards that aim to reduce the chance that parents' and children's decisions to participate will be distorted by the offer of payment. These include the following: develop guidelines for all four types of payment; require an explicit justification for all incentives; ensure payment to subjects who withdraw; consider carefully any cases where there is concern that people are consenting because of payment and not because they wish to take part; and develop a general policy on describing payments in the consent process.

Within Young Lives, 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 are paying respondents, including children, for their participation in recognition of the fact that they might have missed the opportunity to do a day's paid labour to participate in the study. Others are given small gifts as a 'thank you'. Norms and patterns of reciprocity, notions of community, doing what the government tells you (for example, in Vietnam where government census enumerators are administering the survey) are likely to affect people's willingness to participate in research. However, paying respondents (adults and Older Cohort children) to compensate them for their time may be confusing. In Ethiopia, children are encouraged to use the money to buy school materials. During the first round of qualitative research, the Ethiopian research team noted:

Among the issues continually being raised in the fieldwork was people's understandings of *Young Lives* as an aid agency. As people are very poor, the money given is seen as aid... rather than an amount to compensate their time. That has brought some confusion between people being willing to participate and participating just for getting something out of it. Much effort has been exerted to tell people that *Young Lives* was a research project rather than an aid agency, but we feel that more energy is needed in future research. (Tefere et al. 2009).

² The Nuremberg Code (1947) was written following the Nuremberg war crimes trials at the end of World War II and forms the foundation for current medical and social research ethics.

This was improved for the recently completed second round of qualitative research. From the fieldworker notes:

We guided our field researchers to discuss with both the local officials and community members that *Young Lives* does not provide any aid to the community in general and to the research households in particular. The discussion with these groups were fruitful and, as a result, we managed to convince them that this is a research project studying childhood poverty to make suggestions about child-related policies to the government (Tefere et al 2009).

Other country research teams (Peru, for example) are giving small gifts as a 'thank you', as well as some supplies to the local school as a way of giving both individual and collective compensation. In India, research teams provide resources to schools (for example) as requested by local community leaders to benefit all children in the locality and to date has not been making direct payment to research participants.

Research literature discussing the ethics of paying research respondents is scanty. Head (2008), for example, discusses paying research participants in qualitative interviews (for research in the UK with lone mothers in a deprived area). She suggests that much more consideration needs to be given to the question of payment. In her study, monetary incentives had a positive impact on response rates, and some argue that omitting to make payments (or gift-giving) can be seen as unethical. On the other hand, paying people for interviews may be coercive, and may conflict with ideas of informed consent being freely given, especially in poor areas (Head 2008). Creed-Kanashiro et al. (2005) suggest that 'cultural context may limit truly independent consent and may also be distorted through the giving of incentives in populations in limited economic circumstances' (Creed-Kanashiro et al. 2005: 925). The Association of Social Anthropologists of UK and the Commonwealth guidelines (1999) recommend that 'There should be no economic exploitation of individual informants, translators and research participants; fair return should be made for their help and services'. The ESRC Research Ethics Framework guidance does not explicitly discuss payment to respondents, except to ask in an appended example of an ethics checklist: 'Will financial inducements (other than reasonable expenses and compensation for time) be offered to participants?', which suggests that paying reasonable expenses and compensation for time do not present a difficulty (ESRC Research Ethics Framework 2005: 34).

The question of remuneration to *Young Lives*' research respondents is becoming increasingly important as economies become more marketised. For example, in Andhra Pradesh, the National Rural Employment Guarantee Scheme, which pays household members at least Rs.60/- (approx US\$1.25) 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 respondents could carry out domestic chores or work on the farm while researchers talked to them, they are now becoming more and 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 rounds of the survey. 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 participate, so *Young Lives*' approach may need to be reconsidered.

6. Child protection and parents' fears

As noted, child protection protocols are adhered to (Save the Children 2003) and research teams are encouraged to discuss any concerns with the lead quantitative or qualitative researchers, whilst the research team based at Oxford provide guidance and support. There is also growing sensitivity as children mature about having gender-balanced field teams where possible, which is partly a child protection question as well as respect for local norms and values related to gender-appropriate behaviour (i.e., men and women being together).

In some sites, as noted, parents have very high expectations of the research, or have fears about what might happen to their children, and some of which relate to child protection. In Ethiopia, for example, qualitative research teams have found that parents believe their children might be taken abroad (to America) to be educated, and some felt worried about this. For instance, 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 consequently spend a great deal of time patiently explaining the study and reassuring parents and other adults in the community that children will not be taken away, and that Young Lives is a research study that is trying to find out about children's everyday lives and track changes over time.

In Peru, among some indigenous highland communities and other rural communities (located in the poorest regions), parents are also frightened that Young Lives children will be taken away by outsiders. These fears appear to relate to local myths about indigenous people being abducted, and murdered for their 'fat', which have a very long history, and are not related to Young Lives in particular, but to any outsiders. These myths can only be understood with reference to the earliest years of Spanish colonisation, and the long history of discrimination these communities have faced. *Pishtacos* were Spanish conquerors and missionaries who, it was rumoured, wanted the fat of native Indians for all kinds of purposes (Vasquez del Aguila 2007).

For example, as one of the fieldworkers noted: 'A few days after we interviewed the mothers who participated in the group discussion, one of them was worried because she thought that aim of Young Lives was to take (*llevarse*) the children away.' Newspapers in Peru have made much of child kidnapping in the context of hostility to inter-country adoptions. Parents and professionals appear to be reassured on hearing further explanations from fieldworkers. The following is an extract from group discussions with local authority workers in Peru, one of whom raises the question that there are rumours in the community that Young Lives are going to take children away, to which the fieldworker responds:

Fieldworker: It is good that you're mentioning this because, as the authorities, it is good that you're informed. As I say, this is a study that aims to learn from reality so that problems can be solved. Very often policies are made for adults and people forget to make programmes and projects for children. But this is the only goal. In this project, no one is going to take none of the children, no way are we taking them away from their homes. In fact, what we want is to see how they grow up in their homes, how some improve and others not, and the reasons why some make progress and other not. ... You can tell us any fear or worry that you have. In each visit we hand out a leaflet, a letter for the families with telephone numbers and address, and you can call and ask

anytime. We've also handed out a letter in the municipality, there you find our phone numbers and addresses. ...

Professional: Are you all Peruvians?

Fieldworker: Everyone, we are all as Peruvian as the yucca [cassava] and potatoes!

This is a positive reflection of the research relationship and it seems clear that people feel they can express their fears and concerns to fieldworkers. While these are very different versions of stranger-danger myths, underlying them may be similar ideas about powerful people coming into communities who will 'change our lives' for good or ill, all of which link to colonial histories, cultural myths and realities. As noted, Young Lives is not unique in experiencing raised expectations and alternative explanations from research participants.

Using websites as a way of informing people about the study can also lead to misconceptions. For example, in Peru, fieldnotes from the second round of qualitative research report that:

The use of photographs was explained again in one site, since some fears arose after a caregiver's older daughter living in Lima looked at the Niños del Milenio webpage, and told her pictures of the children are there, and probably people will take the children to other countries. It looked like a sort of catalogue of children available for adoption. We took the opportunity to remind them that the consent procedures only ask for academic use, not publicity, and thus photos on the website, as well as in leaflets, are not of *Young Lives* children. This eased the fears around the aims of the project towards children. Also, this round, we provided every family with some (3-5) photographs taken in [Round 1 of the qualitative research], so they have a sample of images we may use for academic purposes, thus trying to reinforce the informed consent the caregivers granted us. (Ames 2009)³

7. Reciprocity in research: What can Young Lives offer to parents, children and communities?

As the research progresses, Young Lives is developing ways to try to give something back to communities. Country teams are taking locally-relevant approaches to this. Some teams are making available small amounts of resources that will benefit the whole community, or all children in the community, for example by providing materials for schools in the communities. Preliminary findings are reported to the communities involved in the research at meetings in a manner that is intended to be relevant and accessible to them, and that highlights the

³ Visual images of Young Lives children or adults are not used in publications or printed material, and photographs or video-clips are only used illustratively at academic conferences and seminars. Copies of photographs of children and drawings created by them are returned to the children and families. A series of commissioned photographs of children who are not part of the Young Lives samples are used in communications work.

usefulness of the data they are providing. In some countries, as noted, this is accompanied by useful information, for example, about nutrition in Peru and local services in Ethiopia. Until now, the level and type of reciprocity has been decided by the country teams, but results have varied and Young Lives is now moving towards a more centralised strategy.

Attempts to report preliminary findings to communities are taking place, and research participants are very eager to know what happens to the information they provide. For example, in Peru, a leaflet has been produced summarising the research findings and this is presented at community meetings. (The Young Lives' 'community strategy' is currently under review, and will need to be appropriately targeted at the differing groups in age-appropriate language, etc.). Young Lives has been developing case study child profiles that highlight the complexities of children's everyday lives, going beyond poverty to show other difficulties that children confront, some of which parents may not be aware of (Young Lives 2009). Efforts are being made to ensure that feedback to communities explains how Young Lives is taking these messages to governments and is advocating with them for change. However, this is not straightforward and 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. Additionally, in some cases, research respondents do not see it as fair that they are giving up their time but everyone in the community is benefiting.

What can be given back to communities? Research teams could try to find out what information people would find useful, rather than (for example) 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 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. However, even this is tricky, as researchers promise children they will not tell others what they say, and with such small numbers in each community it might be difficult to mask identities. It will depend on the nature of the messages and their audience – what may seem obvious or 'common-sense' to local people may be of importance and value to others. 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 getting advice on this issue. Similarly, a group of community representatives also recommended that Young Lives should inform the community about its findings. However, research teams emphasise that children's confidentiality must be respected.

In Peru, the research teams have prepared general summaries of the main results in education and health, and these are given to families in brochures that are easy to read and attractive. However, some community representatives and professionals such as teachers had raised expectations about the research (also the case in Vietnam). For example, in one site in Peru, a group of teachers who participated in group sessions said that they would like Young Lives to explain to parents about the benefits of early childhood education, and motivate and convince them to bring their children to kindergarten. Other teachers asked about what fieldworkers observed in the classrooms; they wanted to know how the children in their class were doing and also get some advice. All of this needs careful consideration as there is a risk that Young Lives could inadvertently come to be seen as an 'intervention' or an 'evaluation', which has implications for further rounds of data collection. Further, there are risks of breaching confidentiality here too, so researchers avoid answering such requests.

8. Managing and maintaining long-term relationships in research: Explaining archiving

Archiving data is a relatively new requirement. Archiving any form of data presents difficulties for notions of informed consent, because the purpose of the research – the uses of secondary analysis – cannot be anticipated, and thus cannot be explained to people who produced the data in the first place (Alderson 1998). The Economic and Social Data Service (the UK data archive used by Young Lives) has guidance on how to seek consent from adults for their data to be archived. In relation to children, it recommends that 'storage of data should be explained in a way that children can understand. It should also be made clear who will have access to the information... information can be given about how data will be used' (ESDS n.d.) but does not provide examples of how to do this (see Goodenough et al. 2003, 2004; Helgesson 2005; Alderson 1998). Young Lives research teams explain what archiving is, and reassure participants about anonymity and disguising identifying features (of places, people, organisations) in preparing data for archiving. For example, in Peru, the term '*un archivo*' is understood, since almost all villages and communities own archives with documentation regarding the village, which is for public consultation. India suggested 'stored in a computer'. In Vietnam, researchers note:

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).

It is anticipated that rigorous controls will be placed on levels of access to data that are to be archived.⁴

4 There are other examples to draw on here. The 'Young Lives and Times' longitudinal study of children based at Leeds University is part of a wider UK-based study to develop an archive of qualitative material over the life-course. See www.timescapes.leeds.ac.uk.

9. 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 20, others until 15 years old. Other parents expressed their wish to keep in touch after the study was over (again, this can be interpreted as a sign of good relationships between the research team and participants).

Fieldworker: The project is supposed to last until children are 15, then 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 their Niños del Milenio? Where can they reach you?

Another caregiver had similar doubts about the end of the study. When the interview was over, the mother said to the fieldworker: 'All the best, and don't leave us behind, come visit us always.'

There are likely to be both short and long-term effects on children, their families and communities due to their involvement in the research because the study asks questions that encourage reflection, and might affect (for example) educational motivation. It is important that we follow this with children and their parents or caregivers over time. 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 is 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:

The children will be asked about what they do, their mobility, changes in the villages... while discussing all these, the children will come to know about theirs and their village's situation. ... Their elders are thinking that the madams are coming to our village, no-one has come until now, and they are working well.

Another boy reflected as follows:

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 for team members mingling with us. Earlier we never speak [up] before 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 come to know how to speak with elders.

10. Suggestions for future rounds of research

Young Lives will continue to develop the memorandum of understanding with research teams and fieldworkers, adapting it as we learn more about doing longitudinal research with children and families. This will continue to be used in training the qualitative research teams. Questions about informed consent and managing raised expectations clearly need constant reflection and development. The salience of the gender of fieldworkers is likely to increase as children get older and there may need to be gender-matching of fieldworkers and respondents. The effects on children and families of being involved in such detailed research also need to be followed over time. As noted, Young Lives attrition rates are very low, but the fact that some children are refusing should be seen positively.

In developing the Round 3 survey, certain sensitive and intrusive questions have been discussed in depth and dropped or refocused, in case they cause distress or difficulties. This depends on the country. For example, in Ethiopia, because of the political situation, it would be too sensitive to ask about participation in political protests. A great advantage of long-term research is that it provides time to learn from people and adapt methods and standards to fit their views more closely. Some of the research activities may be experienced as time consuming and difficult. For example, some of the questions in the household survey and child survey are complex, and children and adults may have difficulty answering them. Subsequent rounds of the survey have been adapted to minimise some of these difficulties, but there is a tension here because of the need for continuity of data and questions.

The importance of understanding context cannot be overemphasised, and while broad shared ethics practices are crucial, these need to be applied with some flexibility according to each situation that arises. This is very specific and dynamic and may change from one year to the next. For example, in two of the sites in recent qualitative research in Peru, levels of distrust seemed 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 organisations 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.

11. Conclusions

Young Lives has to balance a number of difficulties in walking the ethics tightrope (van den Hoonard 2002) and respecting the key principles of justice, respect and avoiding harm. Young Lives needs to retain a clear focus on ethics questions to address the concerns raised by parents, children and others and to respect parents' responsibilities for their children. A long-term study requires the building of trusting relationships with families and children over time. Young Lives is also attempting to generate a shared approach across the whole study to ethics questions and difficulties that arise. This needs to be a two-way learning process. There are also questions to be asked about how Young Lives might involve community members - parents, children and others – in constantly revisiting the ethics of what the study hopes to do. Young Lives' approach to reciprocity in research should not be simply about informing respondents about study findings; it should be used as an opportunity to learn what communities, parents and children think would be useful to them. However, not all families and communities will understand 'usefulness' in the same way, and this may be problematic if they see it as a promise Young Lives makes to them because they may request things that fall into the category of interventions. The project cannot do this and thus they will be disappointed again, whilst Young Lives falls yet again into the aid/intervention/project confusion. This is potentially a problem in research for both researched and researchers, wherever it takes place. Teams also need to be careful not to raise expectations about the type of broader public information that can be provided, so as not to then further raise expectations about the potential for Young Lives to bring about change or provide assistance. Young Lives needs to develop more responsive approaches, especially given 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, as has been noted in Peru: 'even then, 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).

This is, of course, a realistic assessment of what happens to research in practice, and it challenges Young Lives to provide good quality data that can genuinely inform policy-making, and to follow through in Young Lives policy work with some clearly workable suggestions and initiatives that can demonstrate potential change in children's lives. Otherwise, Young Lives will not be meeting its responsibilities to the children, families and communities. These broader ethics questions will be explored in a separate paper that will address in more depth the general ethics questions behind interconnections between research, government intervention projects, and INGO and NGO aid projects in the lives of people in majority world countries, drawing on the experiences of Young Lives. Some of the difficulties Young Lives contends with are specific to or more problematic in longitudinal research. However, many of the questions that have been explored in this paper are also associated with general problems prevalent within the countries, and the ethics of the research needs to be understood in this context.

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Appendix 1

Memorandum of Understanding for *Young Lives* Field Researchers

Key Points: Respecting Children in Research

Note: *the form of wording below is directed to children, and may need to be adapted for different respondent groups. This is a protocol, to be translated into relevant languages using locally relevant examples and forms of expression.*

1. **Introduce yourself.** Be sensitive to local concerns about children (parental fears of child abduction, for example. *Young Lives* aims to learn about the lives of children within their families, *Young Lives* will never take children away without consent.)

Consent

2. You must obtain informed consent from children, their parents or carers, and community members. To do this you must explain the following:
 - **Who you are:** For example, explain to children: *Young Lives is a study of children growing up in 4 countries (Ethiopia, India, Peru, Vietnam) 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/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.*
 - **Archiving:** *The information you give us will be stored on a computer. We are sharing the information that we collect now, and that we collected on our previous visits, with other trusted researchers (people like us) in Ethiopia/India/Peru/Vietnam and internationally.*
 - Take particular care not to raise expectations about the impact of the research. *We are here to learn from you, but we cannot promise to improve your life.*
 - **The details of our work:**
 - How long you will be in the community on this visit.
 - What you are asking them to do and how long this might take.
 - Why you are asking them to undertake activities (whether talking individually, in groups, drawing, body-mapping, etc).
 - How the data (including photos and videos) might be used.
 - If you are doing group activities, and other adults are present, politely suggest they leave (if appropriate). For individual interviews, explain that if a child wants another person to be there, such as a sibling, friend or parent/carer, this is OK, but emphasise that you are interested in the child's answers.

- **Anonymity:** Data will be anonymous *e.g. your name will not be used so we can describe what you think without anyone knowing that it is you. We will also disguise the name of the community where you live.* If children want to put their name on material they produce, let them, but disguise it before the materials are digitally photographed.
- **Confidentiality:** *e.g. I will treat what you tell me as 'confidential'. This means what you say will be shared with other members of the research team, but I am not going to tell your family or anybody in the community what you tell me. Your name will not be used when we tell people what we have found.*
- **Child protection:** *If you say something that makes me worried about your safety, I will talk to you about it first, then I may talk to my boss/supervisor.*
- Explain to children/caregivers that they may **opt out** at any time – i.e., they may ask for all the information they have given/data to be removed from the project/records destroyed at any point.

Respecting children's views and feelings

3. Emphasise that you are interested in children's descriptions in their own words and that there are no right or wrong answers. They can leave an activity if they don't want to carry on. They don't have to answer all the questions or participate in all the activities.
4. Be respectful that a child may be reluctant to speak about a sensitive topic. If you feel that children are unwilling to speak for any reasons, move on to the next question. This is especially important in a group so they don't feel embarrassed in front of other children. Be sensitive to children's body language and tone of voice. Do not put words into their mouths, though you may need to probe, in which case avoid leading questions. Some examples of leading questions are: *School is good, isn't it? Healthcare workers treat people in your community badly, don't they?* Use open questions, not closed questions that lead to yes/no answers. For example: *Tell me how you feel about school. How do healthcare workers treat people in your community?*
5. Ask children for permission to audio record, and explain why. (If they ask, let them hear themselves for a short while.) Ask children for permission to take photos or video, and for permission to photograph their drawings or other material they produce. Leave their drawings with them to keep.

Conduct in the field

6. Be punctual, organised and listen. Keep appointments, find the room, set out chairs and materials in advance. Turn off your mobile phone. Offer refreshments. Keep a flexible timetable and be prepared to have a break between activities, especially when children appear to be unmotivated or struggling to focus on certain tasks.
7. As a representative of Young Lives, under no circumstances should you hit/strike a child, even if this is acceptable within local practices. Do not speak to children in a rude or insulting way. Avoid raising your voice throughout the sessions. Try not to have a school-like atmosphere where discipline is valued, but a place where children can communicate freely and spontaneously. Avoid guiding or directing children, for example when drawing (e.g., by questioning their choice of colours, or shapes, etc.) or when discussing in groups (e.g. by contradicting them).

8. At the end of your visit, explain to the children what will happen next with the information they have produced. (i.e., it will be taken back to local HQ, typed up, and then sent to the main HQ in Oxford). Ask them if they have any questions, and allow them time to prepare questions before you leave. If appropriate (i.e., they seem comfortable and forthcoming), ask them how they experienced the activity, and include examples of this in your group report.
9. Thank the children for their participation. They do not need to thank you, nor should they be expected to. Let the children say goodbye to you, if they wish to.

Finally

10. After fieldwork, you must return all material (written, audio, visual) to the Lead Researcher. Be sensitive to the possibility of inadvertently revealing personal information in the community (e.g., don't recycle paper in the community/locally; after typing your reports, manually shred your notes if necessary). You must respect confidentiality at all times, i.e., not discussing data with people outside the team.
11. Young Lives (country office) and Oxford HQ retain full responsibility for the use of Young Lives material.

Young Lives is an innovative long-term international research project investigating the changing nature of childhood poverty.

The project seeks to:

- improve understanding of the causes and consequences of childhood poverty and to examine how policies affect children's well-being
- inform the development and implementation of future policies and practices that will reduce childhood poverty.

Young Lives is tracking the development of 12,000 children in Ethiopia, India (Andhra Pradesh), Peru and Vietnam through quantitative and qualitative research over a 15-year period.

Young Lives Partners

Young Lives is coordinated by a small team based at the University of Oxford, led by Jo Boyden.

Ethiopian Development Research Institute, Ethiopia

Centre for Economic and Social Sciences, Andhra Pradesh, India

Save the Children – Bal Raksha Bharat, India

Sri Padmavathi Mahila Visvavidyalayam (Women's University), Andhra Pradesh, India

Grupo de Análisis para el Desarrollo (Group for the Analysis of Development), Peru

Instituto de Investigación Nutricional (Institute for Nutritional Research), Peru

Centre for Analysis and Forecast, Vietnamese Academy of Social Sciences, Vietnam

General Statistics Office, Vietnam

The Institute of Education, University of London, UK

Child and Youth Studies Group (CREET), The Open University, UK

Department of International Development University of Oxford, UK

Statistical Services Centre, University of Reading, UK

Save the Children UK (staff from the Rights and Economic Justice team in London as well as staff in India, Ethiopia and Vietnam).



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An International Study of Childhood Poverty

Department of International Development
University of Oxford
3 Mansfield Road, Oxford OX1 3TB, UK
Tel: +44 (0)1865 281751
Fax: +44 (0)1865 281801
Email: younglives@younglives.org.uk

www.younglives.org.uk