Listening to smaller voices:
Using an innovative participatory tool for children affected by HIV and AIDS to assess a life skills programme

Sonal Zaveri, PhD
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Our friend’s father had died of HIV but no one in our families was willing to go to the home to offer condolences. They were afraid of HIV and the stigma. But our friend was sad and we felt we must go to support her. We used to meet every week and were learning about life skills in our children’s group. Well, all of us walked to our friend’s house to offer our sympathies. What could our parents do but follow us?

(Group discussion with 12-14 year olds in a village in South India)

Reviewers: Kate McKeeg
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Emerging evaluation need

In 2007, I was asked to review the Life Skills programme implemented by Family Health International (FHI, now known as FHI 360) India. The focus was on how the programme had changed (or not) the lives of children who were infected, orphaned, affected by HIV (because of a positive parent) or vulnerable to HIV – street children, children of sex workers, migrant children and working children.

In India, children who are infected, affected by and vulnerable to HIV face multiple problems: spiraling poverty, irregular school attendance and/or dropping out, and health and nutrition problems of themselves or their parents. When HIV positive mothers are thrown out of their own homes or children are orphaned, children may lose shelter, access to food and education. But the most pervasive and most difficult problems facing these children are stigma and discrimination, often compounded by the grief of losing a parent to AIDS and the overall hopelessness of their situation. Most programmes focus on material support and meeting children’s physical needs such as education, shelter, health and nutrition. Few programmes provide psychosocial support through counseling and life skills. Perhaps this is because they are poorly understood, difficult to implement and assess.

The need to address psychosocial life skills arose from earlier evaluations I had undertaken in 2002-04 for FHI, India for their USAID-funded IMPACT programme that addressed the needs of orphan and vulnerable children. The evaluations indicated a need for children to learn psychosocial life skills to help them ‘navigate’ their very vulnerable lives. The intent was prevention – to help children learn life skills before difficult circumstances arise, providing better chances of coping and preventing a slide into risky behavior.

Between 2000 and 2004, FHI India supported the development of one of the few indigenously developed Life Skills programmes that specifically responded to the different vulnerabilities of children in the context of India, helping to develop essential skills in children to manage and cope with risk situations for HIV prevention and to cope with difficult circumstances related to care and support, including loss. Drawing on my many years of experience in children’s participation and rights, I developed and field tested the Life Skills Toolkit and subsequently trained and mentored dedicated Life Skills staff to conduct sessions with the children.

From 2004, FHI worked with children in community-based LSE (Life Skills Education) interventions in six states (low and high HIV prevalence) of India through 34 partners. Trained field workers conducted one-hour LSE sessions weekly for 25 to 30 weeks with a group of around 15 children aged between 9-18 years. I was deeply involved in the LSE conception, resource development, training and mentoring.

Discussions with FHI for reviewing the LSE programme in 2007 led to a collaborative development of the TOR referring to the broad questions “What were the Lessons Learned? What have children learned? What difference, if any, has it made in their lives?”

Evaluation purposes

Different groups had specific reasons to learn lessons from the LSE programme. FHI itself had anecdotal evidence that LSE facilitators had, for the first time, learned to encourage children’s participation, have a non-judgmental attitude, respect children and be sensitive to children’s communication. Many of these skills were painstakingly developed through the programme since culturally, children are often ‘talked to’ and not expected to take active roles in their lives. Reviewing the programme would help FHI to build evidence regarding how ‘softer skills’ benefit children and advocate to the various state and central governments about how important it was to address the psycho-social behavior of HIV and AIDS affected children in order to prevent the spread of HIV, to mitigate its impact and to catalyse social protection for children.

1Life skills is defined as: the abilities for adaptive and positive behavior that enables individuals to deal effectively with the demands and challenges of everyday life.” (WHO, 1993). Core skills include problem-solving, critical thinking, communication skills, self-awareness, coping with stress, decision-making (including goal setting), creative thinking (including value clarification), interpersonal skills (including assertiveness), empathy and coping with emotions.

2The author would like to thank Dr. Bitra George, Country Director FHI (now known as FHI 360) India and acknowledge former and late Country Director, FHI India Kathleen Kay for their support and commitment for the life skills programme for children infected and affected by HIV and AIDS under USAID-funded IMPACT.


4In 1997, USAID awarded Family Health International (now known as FHI 360) a ten-year cooperative agreement (October 1997 – September 2007) for the global IMPACT project to implement an HIV/AIDS prevention and care programme. In India, under the USAID-funded IMPACT, the project strategy was to develop demonstration projects and learning sites in collaboration with implementing partners in underserved areas; and provide technical assistance through capacity building and conducting formative assessments and technical studies.

The assessment also needed to understand how well LSE was implemented and the potential for scaling up and sustainability. Implementing partners were encouraged to adapt the LSE in their own programme area but many had informally expanded the programme to schools, other communities, and with adult groups. The review would assess how well and under what conditions LSE ‘worked’. Furthermore, many LSE facilitators advocated the approach with local and state government agencies. These experiences needed to be captured systematically as the National AIDS Control Programme was interested in developing operational guidelines for children affected by HIV, inspired by LSE.

Methodologically, FHI India was particularly interested in ‘hearing children’s voices’ and to engage them in understanding lessons learned. In terms of evaluation practice, FHI had several interests:

• What interactive tools (not pencil and paper questionnaires) to use to elicit responses from children that helped understand changes in their perception, attitude and behavior (and not just knowledge);

• How to tap into multi-cultural, linguistic different communities where children resided;

• How to use tools that enable children to participate easily; and

• How to elicit responses from relatively young children (average age 12-14 years).

To document lessons learned, it was important for me to take on a facilitator-reviewer role. This meant engaging children in the process (following ethical guidelines) and understanding their vulnerabilities, as well as to assess realistically to what extent implementing partners were able to address psychosocial issues with children in very difficult circumstances.

**Developing the ToR**

The evaluation design and ToR (see Box 1) were collaboratively developed with FHI over a couple of months in 2007. Overall, the assessment sought to review what worked well and what did not, lessons learned with three years of LSE implementation (2004-07) and recommendations for scaling up.

The review was carried out by a single consultant (myself) over 40 days, in eight sites located in North, Central, West and South India. There were considerable time and resource constraints that influenced what was possible methodologically. We discussed my role as an internal-external evaluator: internal because I had designed the programme and external as I was also an evaluation specialist. In reviewing the LSE, I was conscious about my role as a reviewer and evaluator and the need to ensure validity and objectivity.

**Box 1. Review questions**

**On child participation**

• How has it changed in the one/two/three years of the programme? In selection of the Life Skills topic, in children finding out, implementing or reviewing the activities linked to the life skills topic?

• How do children link learning with life? Do they share learnings with others? Has participation changed in the school, at home, with friends, at the center, in the community?

**Lessons learned**

• To what extent is children’s participation feasible?

• What aspects of LSE implementation are difficult to achieve?

• What support is required to promote children’s participation in programmes?

**On outcomes**

• What changes have occurred in LSE children’s knowledge, attitude and behavior? Among those who did not participate? Can it be attributed to LSE? Why and how?

• Are there changes in perception of HIV and other risk behavior or any change in risk behavior?

• What new child initiated activities have occurred?

• What changes are available in the family and community as a result of LSE?

**Lessons learned**

• What behavior changes were easy and what were difficult?

• What further support is needed for sustaining behavior change?

**Overarching questions**

• What overall difference has LSE made in the lives of children?

• How does the LSE promote HIV prevention, care and support for orphans and vulnerable children? (Descriptive analysis through case study if possible: in the lives of children; in the family, school and community)
The evaluation focus and values

Clarifying focus

The Life Skills Toolkit had been developed based on a theory of change that linked insights that children had from the LSE sessions to daily living. The assumption was that if learning is linked to life, attitudinal and behavioral changes could occur. Therefore, the LSE assessment needed to trace this pathway: Did children experience change in themselves, with their families and friends, in their school and working places? Was there a change in attitude and behavior? And most importantly, had LSE contributed to this change?

Behavior change programmes in HIV prevention with adults have had to tackle the traditional hierarchical ‘positions’ of gender relationships, considering it to be one of the drivers of the epidemic. The LSE Toolkit had introduced gender issues in each and every activity, not just a gender module, based on the conviction that gender affects all life skills. Therefore, the LSE assessment also needed to ascertain whether there were gender-related changes, such as: Were boys less aggressive towards girls? Did they respect them more? Were girls able to articulate what they wanted and to believe that they too could achieve what they wished?

HIV prevention assessment commonly focuses on whether knowledge messages are accurate, retained and if there are any misconceptions. However, the LSE study needed to assess beyond knowledge - could children perceive risk, choose the most appropriate behavior in that situation and act on it?

Valuing inclusion

Besides the inherent challenges in assessing a programme such as the LSE, we faced other challenges. The LSE was for and by children so we needed to understand their perceptions of change in attitude and behavior. Most assessments in which children are involved depend on proxy indicators obtained from parents, teachers and other significant adults. If however, one of the aims of the LSE was to raise self-esteem and other psychosocial skills, children needed to contribute directly to the assessment.

The decision to seek information directly from children was also based on a set of professional values that believed that children’s voices should be respected, that children want to and are able to share, that they can articulate their experiences, and that the evaluative process through a dialogic, participatory approach can empower them through the expression of changes in attitudes and behavior.

Recognising multi-cultural diversity

Another challenge was to devise an evaluation method that could be used across language groups, urban and rural populations, different sub-cultural groups and variations in vulnerability (street children, children of sex workers, migrant children, children of jailed parents, children infected and affected by HIV). India has an oral tradition, making it difficult to administer many Western methods that rely on pencil and paper. Many people are scared to fill in a ‘form’ and are unaware of how to interpret or answer even an agree/disagree question, to name a few barriers. Besides children’s literacy levels differ considerably.

Conventional focus group discussion, while useful, has limitations. Children may be shy and not speak up, some may dominate the discussion, and they may not be able to analyse and articulate what changes have taken place.

We needed at least one evaluation method that could be used easily by children to provide information on how children’s attitude and behavior had changed.

No baseline

Another set of challenges related to the evaluation design. There was no baseline since this was an innovative project and the LSE programme was being implemented for the first time. Most efforts focused on implementation, such as addressing children’s psychosocial behavior, facilitators acquiring child facilitation skills and encouraging children’s participation – daunting tasks since the LSE facilitators only had basic training in social sciences or counseling. Also, as children came with different vulnerabilities, any baseline would have been difficult to develop.

In the absence of a baseline and a control group, it would have been difficult to attribute any change to the LSE programme. There was considerable anecdotal evidence of changes in children but capturing it and assessing whether it would have happened anyway needed to be addressed as well.

Methodological choices

These design parameters – focus, values, and context – led to a number of choices that shaped the final approach I used.
Multiple methods

The assessment methodology was qualitative. The intention was to understand behavioral and attitudinal changes among children and qualitative methods were considered the most appropriate for the inquiry. Methods used included interviews, focus group discussions and Milestones in Learning and Empowerment (MLE) Mapping that plotted critical implementation ‘signposts’ on a timeline from initiation to more advanced LSE programmes. We also used two participatory methods with children: Picture Talk and Before-After Analysis (see more details below for description of Picture Talk). The ‘Picture Talk’ method was developed in dialogue with one of the organisations implementing LSE and was field-tested.

For the LSE Assessment, problem scenarios were represented through simple line drawings called ‘Picture Talk’ so that language differences across sites would not be a barrier. In addition, children who had attended LSE undertook a ‘before – after’ analysis, comparing situations and themselves before and after LSE. Children discussed in groups and then documented on paper. In this way, they indicated changes that had occurred in knowledge, attitude and behavior as a result of LSE. Along with the focus group discussions and interviews with parents, staff and other adults, I triangulated all the findings from the different methods.

Ethics and biases

We adhered to ethical guidelines by informing children about the purpose of the assessment and giving them an option to be involved or not. None of the children opted out. Children were asked if they wanted to say something during the group discussions but their silence was also respected.

The LSE Coordinator and staff introduced the consultant, remained physically present but out of earshot and did not participate in the data collection process. A member of the team served as an interpreter but it did not affect children’s responses or create bias as they were not questioned regarding what they did or did not like about the programme. The purpose of the discussions was to assess their responses and learning regarding risk situations. The methods and questions themselves were ‘neutral’ in relation to FHI and the people involved. The reviewer was conscious of the fact that she had developed the toolkit (although the children were unaware of it) and to the extent possible, ensured an objective approach. As the goal of the review was to learn, the approach of the reviewer was one of collaboration with children.

A rolling baseline to assess trends

In the absence of baseline studies, we opted for a rolling baseline by selecting projects that had a basic LSE intervention and those with longer implementation. From the different LSE projects that were managed by NGOs, the reviewer selected a sample (see below) based on their duration: those with less than and those with more than three years of implementation of LSE activities. The rolling baseline also provided information regarding trends – what to expect at the beginning of the LSE, in its early stages and for advanced LSE implementation. Such information would be valuable for implementers in future phases.

Sample frame

Criteria for selection of LSE project sites were:

- Field sites where LSE implementation was recent (one year) and sites where it had been implemented for a longer period (three years) and/or (if possible) included a comparable group of children involved with the same NGO but not enrolled in the LSE, thus giving us the basis for ethical and practical comparisons of incremental effects of LSE participation;
- Availability of staff who had received LSE training and continued to work with the NGO, thus having experiential and historical perspectives about LSE; and
- Geographical and contextual diversity, including girls and boys, children at risk, as well as those infected by HIV and affected by HIV and AIDS.

Based on the above considerations, the NGOs were grouped into three categories (see Box 2). This made it possible to use the same tools with children from Tier One, Tier Two LSE programmes and with non-LSE children. This approach compensated for the lack of baseline studies.

The total sample of children for the ‘Picture Talk’ depicting problem scenarios was 60 children. Three groups of five each from Tier One and three groups of five each from Tier Two; in all, 30 children. These

*CCDT or Committed Communities Development Trust provided inputs for the development of Picture Talk. The NGO is located in Mumbai India and works with vulnerable children including children infected and affected by HIV.
were compared to the Non-LSE group consisting of six groups of five each for problem scenarios – in all, 30 children. Girls and boys representation was 50% and selected randomly in each of the subsamples. The sample size was what was feasible, given the time required to administer the tool and time available to the consultant.

Innovating for children with ‘Picture Talk’

One of the innovative tools used was ‘Picture Talk’ representing 12 problem scenarios. The situations were developed for the evaluation after group discussions with children and staff in one of the NGOs. The scenarios were piloted, revised and 12 were selected to show the most common risk or conflict situations children are likely to experience in daily life.

Each Picture Talk had a ‘scene’ (see Figure 1) and in the foreground a boy and girl, observing it. Instructions were simple – “Look at the picture, what would the boy or girl do if they saw this happening?” In this way, the children projected themselves on to a neutral ‘boy’ or ‘girl’ and responded to the different risk situations represented on the 12 cards.

As children responded to each Picture Talk, the group would begin by describing the picture and state what they would do. I encouraged each child to participate and add her or his views. The children had participated in the LSE in groups, were comfortable in group discussions and since the intention was to obtain a collective opinion, it was deemed appropriate to elicit answers in a group rather than individually. Individual responses would have also significantly reduced the number of children participating. I noted the children’s responses verbatim in a notebook through simultaneous translation.

Figure 1. Example of a Picture Talk scenario

Three groups from Tier One, three groups from Tier Two and six groups from Non-LSE were shown these twelve problem scenarios and their responses noted. Each group averaged 5 children, so 60 children responded to this method: 30 LSE children (Tier One + Tier Two) and 30 Non-LSE children. The unit of analysis was, therefore, a group (of five children).
The resulting quantitative data indicated patterns. One of the limitations was that no statistical analysis was created out of the data categorisation. However, for the purposes of the project, the differences between the three groups were stark and hence provided valuable lessons for future implementation.

**Findings as patterns**

Each problem scenario response was scored. Two people—myself and an assistant—scored each answer to reduce interpretation bias. The numbers on the x-axis of Figure 2 are the total number of responses.

The responses for each of the three groups in any one tier for each of the categories were enumerated and the mean across the three groups used to represent the tier. See below for the mean responses for each tier of each category. If there is no bar for a particular group, it indicates that there is no response in that category.

The findings clearly indicated that behavior change was evident for both Tier One and Two sites but that attitudinal changes, such as on gender and empathy, clearly took many sessions (30) and good facilitation, which had been available in Tier One sites.

Figure 2 shows how responses were spread across the three groups, with some clear differences between the Tier One, Tier Two and Non-LSE children. An overview of the three groups—Tier One, Tier Two and Non LSE—indicates consistent changes in each of the categories depending upon the incremental experience of LSE programmes.

One pattern is clear:

- **non-LSE children** do not indicate critical thinking (why a particular problem happens) and are more likely to immediately seek the help of authority figures to solve the problem;

- **LSE children** are more likely to state what they can do.

Tier Two children, like the non-LSE children, will turn to authority figures as the first response but also as a last resort, like the Tier One LSE children. Like the Non-LSE children, Tier Two children are likely to look for a simple cause-effect answer to decision making.

Patterns in Tier One, Two and Non-LSE children are also visible around being judgmental and having empathy.

**Figure 2: Picture Talk responses across three tiers**

- Percieves risk and consequences of behaviour
- Talks to authority figures as first resort
- Talks to authority figures like police and teachers as last resort
- Explains - alternatives and choices for decision making
- Directive - single reasoning and decision
- Critical thinking
- Judgmental
- Empathy
- What I can do - self efficacy

![Figure 2: Picture Talk responses across three tiers](image-url)
Tier One children clearly indicated that they had many alternatives and choices and provided clear evidence of critical thinking. They responded in ways that were less judgmental, more caring and more likely to seek authority figures only as the last resort.

Self-efficacy, or ‘what I can do’, was clearly evident in both Tier One and Tier Two children, suggesting that confidence in one’s ability is the first step towards other behavioral change.

Sample responses to a selection of problem Scenarios for Non LSE, Tier One and Tier Two children are available in Table 1 below. In the Picture Talk illustrated below, the instructions to the children were as follows:

1. A girl is crying while the others are playing. You (point to the heads of a boy and girl watching at the bottom left of the picture) are observing this, what will you say and do?
2. A girl is walking on the street at midnight. The boys are there, what will you say and do with the girl?
3. A boy is taking things from a room. What will you say to him and do?

Compared to non-LSE children, LSE children demonstrated a higher level of confidence in their abilities, higher HIV risk perception, better skills to manage difficult relationships and risk situations, and better critical thinking and problem solving skills. Changes in perception of gender roles were evident: boys and girls felt confident about interacting with each other, and girls reported feeling confident about handling sexual harassment. While parents reported more responsible behavior in their children, teachers reported improved attendance, communication and performance in school.

**Improving implementation and scaling up**

The LSE assessment showed that LSE was a powerful approach for improving knowledge, attitudes and behavior among children and relevant for both low and high HIV prevalence settings. Picture Talk enabled children to express the changes in their own ‘voice’ and ‘on their terms’. Triangulating those findings with information from the other methods resulted in rigorous findings. The evaluation established with certainty that only at 30 sessions, are behavior and attitudinal changes visible while 20 sessions resulted only in some behavior change. These findings have helped to structure implementation in many states.

It must be noted that findings such as those from Picture Talk provide general patterns that are, nonetheless, strong indicators of changes taking place in children’s perception and thinking. This qualitative tool can be complemented by other methods, such as focus group discussions, to confirm findings with children, as well as through interviews and discussions with adults who interact with children and are likely to perceive changes in children. Such tools can be used only if reviewers and evaluators also become facilitators and are willing to reserve adequate time for children’s discussion; have the openness to accept what children say; and are comfortable working with children.
### Table 1. Sample of responses

<table>
<thead>
<tr>
<th>Problem Scenario</th>
<th>Tier One</th>
<th>Tier Two</th>
<th>Non-LSE</th>
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<tbody>
<tr>
<td></td>
<td><strong>We will console the girl, identify the problem, ask why she is crying, try to sort out the problem.</strong>&lt;br&gt;<strong>Categories:</strong> Critical thinking (why is she crying?); Empathy (console her); self efficacy (try to sort out the problem)</td>
<td><strong>Why are you crying? You want to play – we will ask the boy and girl to play.</strong>&lt;br&gt;<strong>Categories:</strong> Critical thinking (why are you crying?); Single reasoning and decision (she wants to play – will ask others to play)</td>
<td><strong>Don’t cry, why are you crying</strong>&lt;br&gt;<strong>Categories:</strong> Single reasoning and decision (don’t cry)</td>
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<td></td>
<td><strong>As no one is helping her, we will tell her to go ahead fast and we will go with her. Also tell her don’t go out at midnight, ask her where she wants to go and drop her in a safe place. There will be no transport at night so we will tell her to stay in the place at night. We will call the police as well.</strong>&lt;br&gt;<strong>Categories:</strong> Critical thinking; Alternatives for choices for decision making; Self efficacy; talks to authority figures as last resort; perceives risks and consequences of behavior; empathy</td>
<td><strong>Counsel her, work early and don’t go at night; help her and drop her at night; tell her how to handle situation; tell those boys that you are the brothers, you also drop her.</strong>&lt;br&gt;<strong>Categories:</strong> Critical thinking; Alternatives for choices for decision making; Self efficacy; empathy</td>
<td><strong>Tell boys don’t make comment on girl. Elders will scold you. If she complains there will be police action and they will beat you. Let her go home. Why are you loitering, go home and study. She is your sister.</strong>&lt;br&gt;<strong>Categories:</strong> Judgmental; believes authority figures like police will handle</td>
</tr>
<tr>
<td></td>
<td><strong>We will tell him don’t do it; it is wrong, invite him to the group and support change in his thinking so he understands consequences; tell him don’t do this and spoil your future, if you do this as an adult the police will beat you.</strong>&lt;br&gt;<strong>Categories:</strong> Self efficacy, empathy, critical thinking, risks and consequences, choices for decision making</td>
<td><strong>Do you know the consequences of stealing? Why are you stealing? This is wrong; your life will be spoiled. If your teacher sees you, she will remove you from school.</strong>&lt;br&gt;<strong>Categories:</strong> Judgmental, single reasoning and decision</td>
<td><strong>If you start this habit now, it will not leave you and when you grow, you will steal and be caught by the police. You will feel bad</strong>&lt;br&gt;<strong>Categories:</strong> Judgmental, single reasoning and decision</td>
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