



# STORIES OF SIGNIFICANCE

Understanding Change Through Community Voices and Articulations

A report based on an evaluation of the home  
and community-based care and support programme for children, CHAHA,  
by means of 'Most Significant Change' technique



# Stories of Significance

---

Understanding Change through  
Community Voices and Articulations

**A report based on an evaluation of the home  
and community-based care and support programme for children, CHAHA,  
by means of 'Most Significant Change' technique**



# About India HIV/AIDS Alliance

---

The International HIV/AIDS Alliance is a global partnership of nationally-based organisations, working to support community action on Acquired Immuno-deficiency Syndrome (AIDS) in developing countries. The national partners help local community groups and other Non-Governmental Organisations (NGOs) to take action on AIDS, supported by technical expertise, policy work and fundraising carried out across the Alliance.

The vision of the Alliance is of a world in which people do not die of AIDS. This means a world where communities have brought Human Immuno-deficiency Virus (HIV) under control by preventing its transmission, and where they enjoy better health and higher quality of life through access to comprehensive HIV prevention, care, support, and treatment services.

Established in 1999, the India HIV/AIDS Alliance (or Alliance India) comprises a Secretariat in New Delhi, five lead partner organisations (the Linking Organisations within the global Alliance) and their networks of over 100 community-based NGOs and Community-Based Organisations (CBOs) across Andhra Pradesh, Tamil Nadu, Maharashtra, Delhi and a state partner in Manipur.

Alliance India has supported over 120 community-based projects through its NGO and CBO partners to prevent HIV; improve access to HIV treatment, care and support; and lessen the impact of HIV, by reducing stigma and discrimination, particularly among the most vulnerable and marginalised communities key to the epidemic - sex workers, Men who have Sex with Men (MSM), Injecting Drug Users (IDUs), adults and children living with and affected by HIV.

Funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) was awarded to Alliance India in July 2007, whereby the partnership in India has been broadened to include three new project-based lead partner relationships with two external organisations and their networks of implementing NGO partners.

For more information, please visit our website on [www.aidsalliance.org](http://www.aidsalliance.org) or write to:

## **India HIV/AIDS Alliance**

Third Floor, Kushal House,  
39 Nehru Place

New Delhi 110 019, India

Tel. : +91 11 4163 3081

Fax: +91 11 4163 3085

SETU, Virtual Resource Centre: [www.aidsallianceindia.net](http://www.aidsallianceindia.net)

The text of this publication may be translated, printed and used for personal, educational and not-for-profit purposes only, provided at all times that the source indications are stated (to include, but not to be limited to, the India HIV/AIDS Alliance). We encourage the translation and adaptation of Alliance materials but we request prior written approval from the India HIV/AIDS Alliance. Under no circumstances can the India HIV/AIDS Alliance be held responsible for the content of any third party translation or adaptation. Failure to adhere to these conditions shall be considered a breach which may be actionable. It is strictly prohibited to sell any of the information or materials on to third parties or to use any of the information or materials for personal gain.

Design and Print: AB Impression Pvt. Ltd.

Email: [atul@impcom.in](mailto:atul@impcom.in)

Published: March 2010

© India HIV/AIDS Alliance, March 2010

For more details, please write to:

India HIV/AIDS Alliance

Third Floor, Kushal House

39 Nehru Place

New Delhi 110019, India

Tel: +91 11 41633081

Fax: +91 11 41633085

Email: [tchhabra@allianceindia.org](mailto:tchhabra@allianceindia.org), [vchaturvedi@allianceindia.org](mailto:vchaturvedi@allianceindia.org)

Website: [www.aidsalliance.org](http://www.aidsalliance.org)

SETU, Virtual Resource Centre – [www.aidsallianceindia.net](http://www.aidsallianceindia.net)

# Foreword

---

This is a report of stories. Stories in which children capture what HIV has meant for their lives. They talk of anger, of fear and of rejection, but also of defiance, of affection and of hope. Their experiences are told in the context of a Care and Support programme supported by the Global Fund: but this is no ordinary project report.

The methodology used, in which children talk freely about changes in their lives, is an attempt to understand and respect the people behind the numbers generated by project reports; because increasingly, development is being driven by numbers, by the need to reach ever larger percentages of target groups. Our goal is often to “saturate” districts or towns with services. There are a numerous drivers behind this trend: the influence of the private sector on development, the desire of donors to see quantifiable results for their money, the need to impress with the scale of our work and the wish to be sure that people are not being left out.

Yet there is a real risk in such an environment that numbers will become an end in themselves. It is too easy to assume that a person reached is a person better off, whereas in fact, as these stories tell, even well intended assistance can have mixed effects.

A visit to a child’s home to enquire after his or her welfare and offer assistance has in some cases been a turning point in a child’s life: opening up opportunities for schooling and health care. In other cases, it has aroused suspicion and hostility from neighbours, and thereby deepened a sense of exclusion and hopelessness.

It is by listening to these stories that we can learn to be better at what we do. There is genuine hope in hearing how kindness, attention and small investments of material support can change a child’s perspective on their future. But it is sobering to hear how for many children, HIV compounds an already deeply rooted structural vulnerability. There are no short and simple remedies.

Yet even having children remind us of that is a useful lesson, so that the numbers don’t make us complacent, and their silence doesn’t allow us to believe that the job is done.

This consultation with children was led primarily by three people—Navanita Bhattacharya, Tanu Chhabra Behl and Vaishakhi M. Chaturvedi, but it involved many more. I would like to thank all them, and all the children who participated.

**Alexander J. Matheou**

Country Director

India HIV/AIDS Alliance

[amatheou@allianceindia.org](mailto:amatheou@allianceindia.org)





# Acknowledgements

---

Alliance India expresses special gratitude to the community members, children and their caregivers, who gave their time and shared their rich experiences with the team. It goes without saying that without their individual and collective contributions, this study would have been incomplete.

Alliance India also acknowledges the significant contributions of its partner NGOs and its CHAHA programme team in the four states where the evaluation was conducted—Sneha Bhawan and Dedicated People's Union (Manipur); Kripa Foundation, Committed Communities Development Trust, Paramprasad Charitable Society (Maharashtra); Peoples Action for Creative Education, GUIDE and LODI Multipurpose Social Service Society (Andhra Pradesh); Madurai Multipurpose Social Service Society, Centre for Education and Empowerment of the Marginalised (Tamil Nadu). All the Outreach Workers are acknowledged for their relentless efforts for this process. These partner NGOs not only extended field support to this endeavour but also provided rich feedback and suggestions during the course of study.

The execution of this study was made possible because of the invaluable support provided by the nine Sub-Recipient (SR) organisations – Vasavya Mahila Mandali (VMM), Lepra Society, Plan India and Alliance for AIDS Action (AAA) from Andhra Pradesh; PWDS and TASOSS from Tamil Nadu; Social Awareness Service Organisation (SASO) from Manipur; and Plan India, NMP+ and MAMTA from Maharashtra. The study would not have been possible without their timely feedback, coordination and logistics support.

A special word of thanks is due to Vijaya Kumar, G.Rashmi, B. Keerthi from VMM; Uma Akula, Jayaram Parasa and Madhu Sagili from Lepra Society; Ajit Rao and Romee Hijam from Plan India; Basanta Moirangthem, Gilbert Chinir, and Ranjana. L from SASO; Sharad Shinde from MAMTA; Salim Shaikh from NMP+; Anil Kumar, Anand M., Clement from PWDS; Gayathri. J and K. Sugaraja from TASOSS; R. Shanthi Thumaty, Srinivas Goud and S.J. Prashanth Kumar from AAA for their support in facilitating smooth conduct of the study and providing their valuable inputs.

Alliance India would also like to acknowledge the efforts of the Consultant, Ms. Navanita Bhattacharya who designed and conducted the study and prepared this report.

The unbiased and speedy translation of stories into English language is attributed to Christina Nisha (Tamil), Srinivas Rao (Telugu), Babina Wahengbam (Manipuri) and Troikaa Translations (Marathi and Hindi).

Alliance India also thanks its staff who gave their valuable time in spending several hours at a stretch for selecting the MSC stories, which involved intensive discussion, analysis and debates – Pankaj Anand, Preeti Das, Umesh Chawla, Praween Agrawal, Kaushik Biswas, Deepa Shah, Amit Pandey, Manas Ranjan Rout, and Joydeep Sen.

Special gratitude is extended to the Senior Management Team at Alliance India, consisting of Alexander Matheou, Shaleen Rakesh, Rajan Mani and Sonal Mehta, for showing keen interest in the application of this technique and for providing their inputs from time to time.

Tanu Chhabra and Vaishakhi M. Chaturvedi are acknowledged for being an integral part of the entire process right from planning, coordination to facilitation of story collection and selection. The report in its final version with necessary review, editing and design is attributed to them.

This study and publication was made possible through the support of the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). The opinions expressed herein do not necessarily reflect the views of this donor.

## **Acknowledgement from the Consultant**

This study would not have been possible without the intimate revelations of women, men, girls and boys spread in 14 districts across four states of India, who readily participated in group discussions and exercises and shared their thoughts, opinions and ideas in settings marked by trust and mutuality. I am deeply touched by their readiness to participate in this exhaustive exercise selflessly.

I appreciate the enthusiasm with which the study team members owned the process from the beginning – from reaching the base on time to staying back late all days; from boosting each others' spirits to ensuring that the logistics are in place. I specially would like to acknowledge Vaishakhi M. Chaturvedi and Tanu Chhabra who showed exemplary leadership in ensuring that the study happened on time without too many constraints.

**Navanita Bhattacharya**

Development Consultant

# Contents

---

About India HIV/AIDS Alliance .....	3
Foreword .....	5
Acknowledgements .....	7
Abbreviations .....	10
Executive Summary .....	11
Study Methodology .....	15
Findings .....	21
Recommendations .....	49
<b>ANNEXURES</b>	
1. Story Collection Guide, Alliance India, CHAHA, July 2009 .....	51
2. Capacity Building, Story Collection Guide, Alliance India, CHAHA, July 2009 .....	52

# Abbreviations

---

AI	–	Alliance India
AIDS	–	Acquired Immuno Deficiency Syndrome
AP	–	Andhra Pradesh
APC	–	Assistant Project Coordinator
ART	–	Anti Retroviral Treatment
CBO	–	Community-Based Organisations
CLHIV	–	Children Living with HIV
CSG	–	Children Support Group
GFATM	–	Global Fund to fight AIDS, Tuberculosis and Malaria
GIPA	–	Greater Involvement of People living with HIV/AIDS
HCBCS	–	Home and Community Based Care & Support Programme
HIV	–	Human Immunodeficiency Virus
IDU	–	Injecting Drug Users
IGP	–	Income Generation Programme
LO	–	Linking Organisations
LOP	–	Level of Participation
LSE	–	Life Skills Education
M & E	–	Monitoring & Evaluation
MSC	–	Most Significant Change
MSM	–	Men who have Sex with Men
NACP	–	National AIDS Control Programme
NC	–	Negative Changes
NGO	–	Non Governmental Organisation
ORW	–	Outreach Worker
PC	–	Project Coordinator
PLHIV	–	People Living with HIV
PPTCT	–	Prevention of Parent to Child Transmission
PR	–	Principal Recipient
QOL	–	Quality of Life
SC	–	Significant Change
SD	–	Strategic Directions
SHG	–	Self Help Group
SR	–	Sub-Recipients
SSR	–	Sub- Sub Recipient
T.B.	–	Tuberculosis
TN	–	Tamil Nadu
UNCRC	–	United Nations Convention on the Rights of the Child

# Executive Summary

---

This report provides the findings and analysis of the experience of using 'Most Significant Change' (MSC) technique to evaluate CHAHA - a child-centred Home and Community Based Care and Support (HCBCS) programme. CHAHA (meaning 'a wish' in Hindi language), receives funding support from Round 6 of the Global Fund to Fight against AIDS, Tuberculosis and Malaria (GFATM). As a civil society Principal Recipient (PR), Alliance India has been implementing this project along with its consortium of 9 Sub-Recipients (SRs) in the states of Andhra Pradesh, Tamil Nadu, Maharashtra, and Manipur. This evaluation was done in 14 districts in the four operational states over a period of one month, mainly with the purpose of learning.

MSC is a participatory monitoring technique based on stories of important or significant changes—they give a rich picture of the impact of development work. MSC can be better understood through a metaphor of a newspaper, which picks out the most significant story from a wide range of events and background details that it could draw on. MSC does not replace other methods of monitoring and evaluation. In fact, it complements and works well in conjunction with other methods. MSC is best used to understand the unexpected outcomes as it is not based on indicators. It emphasises story-telling as a form of participatory monitoring, unique in its ability to capture direct views of target population, including unexpected and evolving outcomes. It is also unique in presenting a methodical, systematic way of collecting and analysing individual stories and selecting the most compelling one.

The MSC technique has been used essentially to learn from the first phase of CHAHA programme's implementation, specifically—what worked well and what needs to be done differently. The key objectives of this study were:

- To assess the intermediate outcomes, impact and potential for impact of the programme from the community and children's standpoint; and
- To understand the significant changes made in the quality of life of children and families registered in CHAHA

The key advantage of using MSC is its ability to capture and consolidate the different perspectives of key stakeholders—the community members, programme staff from SRs and Sub-Sub Recipients (SSRs) and Alliance India—to aid understanding and articulation of complex change, and to enhance organisational learning.

The important steps of conducting the study included – defining of domains, orientation and capacity building of key programme staff involved in the process, collection of Significant Change stories, selection of Most Significant Change stories at state level and subsequently at national level in Alliance India Secretariat.

Four domains of change were identified for the study in consultation with the partners. Domains were selected based on the kind of changes Alliance India and its partner

organisations wanted to measure. This was largely influenced by the programme objectives. The domains of change chosen for the study were:

1. Change in Quality of Peoples' Lives.
2. Change in Levels of People's Participation.
3. Negative Changes (because of the programme).
4. Changes in Staff's Capacity.

### **Key findings of the evaluation are:**

- The project has improved the quality of people's lives, especially where it is being implemented in conjunction with other ongoing programmes of the SSRs. For instance, CARE in Tamil Nadu integrated the programme with its longer term programmes on women empowerment, livelihood and micro-finance. Similarly, SASO in Manipur placed this programme in those areas where their Care and Support programme with IDUs was ongoing. As Manorama, an Outreach Worker (ORW) and a long-time worker with SASO succinctly said, *"Wherever SASO has been working for a long time, the children's support groups are more effective. This is because the need has been felt by the caregivers who requested SASO to include their children and keep them involved in group activities."*
- Many children and caregivers have reported increased level of confidence to challenge stereotypes and stigma and an enhanced ability to overcome fear of being deserted by family. Many have also reported a more positive outlook towards life. However, in general, change in power dynamics that may tilt the balance more equitably in favour of PLHIV whereby they feel confident to survive with dignity on their own do not feature in the stories. People, largely are reliant on the various support provided by the programme. In its two years of inception, the programme has been able to reach out to people. However, making them self-reliant and inter-dependent within their community structures is a long-term process requiring more focus on community led approaches.
- Most stories on change in levels of people's participation spoke of their increased capacity to cope – by securing household support for the family and nutritional and educational support for the children. Several stories also show the increased level of confidence in both children and caregivers, and a brighter disposition towards life. However, the aspect of community driven approaches of CHAHA did not get a prominent place in the collected stories in this domain. It shows the need for more strategic efforts at mobilising communities.
- The issue of stigma and discrimination which plagues PLHIV in many countries and contexts remains a significant area of concern in the four states in India too. It is learnt, through the stories, that largely children and caregivers are shunned and stigmatised by their communities. In some cases, ORWs visiting their houses has resulted in them being questioned and ridiculed by neighbours.
- All stories on changes in staff capacity reveal an increased level of awareness and confidence in field staff, especially the ORWs. All staff revealed that they have undergone a distinct change in their perspectives and mindsets. Stories from the communities corroborate the critical and significant role played by ORWs in increasing the programme's sphere of influence and acceptance within communities. This is especially true for those ORWs who live in the same geographical areas where the programme is being implemented and also those who have personal experiences of/with HIV/AIDS.

Using the MSC technique in evaluating the programme brought to light the existing organisational culture in the different organisations – SRs and SSRs. A vibrant, transparent and healthy work culture was evident during the story selection process where field staff openly challenged and debated with the project management team. In a few organisations though, field staff were reticent in the presence of senior management and project management teams, which was reflective of several dynamics – the interplay of power (hierarchy and authority) and gender.

At Alliance India, the staff felt that using a story-based approach was useful in helping them understand the capacity gaps at SR and SSR level. This study also reiterated the need for qualitative inquiry to gauge programme effects and also in creating safer, non-threatening and reflective spaces at all levels for staff to raise issues, voice concerns and find solutions in a way which is empowering. This evaluation has revealed that CHAHA, in its first phase of implementation, has had important effects in the lives of children and their families. Due to the support provided, children and caregivers are able to cope and have a positive outlook towards life. The programme has, through the counselling provided by field staff, given hope to a large number of people living with and affected by HIV. The stories also provide numerous lessons to learn from; the most significant being reviewing its strategy on working with communities in ways that encourage inter-dependence, empowerment and ownership.

## Key Findings: At a Glance

Domain of Change	Learning (s)
<b>Quality of life</b>	<ul style="list-style-type: none"> <li>• Children and caregivers have developed positive attitude and self-confidence</li> <li>• Children appreciate the support towards continuing their education</li> <li>• Improved well being, better health, being able to socialise, make friends and save money</li> </ul>
<b>Level of participation</b>	<ul style="list-style-type: none"> <li>• Children and caregivers have been able to disclose their status, interact with people and overcome feelings of being stigmatised by communities.</li> <li>• Several of them are volunteering to promote prevention, care &amp; treatment messages and becoming role models for others.</li> </ul>
<b>Negative change</b>	<ul style="list-style-type: none"> <li>• Fear of disclosure in the community with ORWs visiting their house</li> <li>• Multiple burdens being borne by women apart from taking care of husband and/or children. The stories highlight deep pain that children of such women feel for their mothers</li> <li>• Perceived inability to continue providing care by elderly caregivers, and a feeling of hopelessness by children (especially orphans)</li> <li>• Few stories in this domain show the disappointment experienced by children who were promised for certain favours by the SSRs but did not receive them</li> </ul>
<b>Gaps in the programme</b>	<ul style="list-style-type: none"> <li>• The doubts about the future, an unnamed fear, and the general poignancy in the stories are indicators</li> <li>• Most storytellers asked for more support - land, house, education support for children above 18 year, a job, a “business with a huge investment” amongst others.</li> </ul>



# Study Methodology

## Most Significant Change

Most Significant Change (MSC) is a participatory monitoring technique based on stories of important or significant changes, which give a rich picture of the impact of development work. MSC can be better understood through a metaphor – a newspaper, which picks out the most interesting or significant story from the wide range of events and background details that it could draw on.

Dynamic values inquiry is a central and critical part of MSC. When key stakeholders select stories of significant change, they participate in an ongoing process of deliberation about the value of individual outcome<sup>1</sup>. Designated groups of stakeholders continuously search for significant programme outcomes and then reflect on the value of these outcomes. This process contributes to both programme improvement and judgement. Rick Davies, the creator of MSC technique, reiterates how the emphasis on storytelling makes MSC different from formal monitoring techniques. Instead of introducing new professional skills, MSC takes advantage of everyday communication practices. *“Every language has an expression for ‘What’s new’.”*<sup>2</sup>

## MSC complements other M&E methods and looks for the unexpected

MSC does not substitute other methods of Monitoring and Evaluation (M&E). In fact, it complements and works well in conjunction with other methods. MSC is best used to understand the unexpected outcomes as it is not based on indicators. Conventional quantitative monitoring of predetermined indicators only tells us about what we want to know and think, we need to know. It does not drive us to explore beyond what is obvious – the indefinable, subtle and indirect consequences of our work. By getting this information on a regular basis, and taking time to reflect on what this means, organisations can adjust and modify their direction of effort so that they achieve more of the outcomes they value.

It emphasises story-telling as a form of participatory monitoring, unique in its ability to capture direct views of communities, including unexpected and evolving outcomes. It is also unique in presenting a methodical, systematic way of collecting and analysing individual stories and selecting the most compelling ones.

## MSC builds teams and encourages use of diversity of views

In many organisations, there are designated personnel involved in

<sup>1</sup>Dart, J. J. & Davies R.J, A Dialogical story based evaluation tool: Most Significant Change technique, America Journal of Evaluation

<sup>2</sup>Exchange, 2000-2005, London, UK



information collection, analysis and dissemination. Indicators are often identified by senior staff or M&E specialists. In contrast, MSC gives those closest to the events being monitored (e.g. the field staff and participant communities) the right to identify a variety of stories that they think are relevant and important. These are then summarised by selection when other participants choose the most significant of all the stories reported. By valuing diversity of views, it gives an opportunity for organisations to decide what direction it wants to go and how. This enables having a more shared vision.

### **MSC empowers and encourages reflection**

With predefined indicators, the nature of information and its meaning is largely defined from the beginning. With MSC, participants are encouraged to use their own best judgement in identifying stories and selecting stories collected by others. This involves the use of open-ended questions such as: *“From your point of view, what was the most significant change that took place concerning the quality of people’s lives?”* This freedom empowers participants involved in the process to think and analyse deeper the nature and impact of their actions – field staff and target population do not only collect information (or give information), they also evaluate that information according to their own perspective, understanding and experience.

### **MSC contextualises action or event**

MSC makes use of what has been called ‘thick description’ i.e., detailed accounts of events placed in their local context. Each MSC story has the storyteller’s interpretations of what is significant. This also enables a changing focus

on what is relevant and important as the MSC process is dynamic and is responsive to the context in which it is used. Participants choose what to report within specified domains.

In addition to its monitoring and evaluation functions, MSC can also help in:

- Fostering a more shared vision.
- Building staff capacity in monitoring and evaluation.
- Providing material for publicity and communications.
- Providing material for training staff.
- Celebrating success.

## **Using Most Significant Change Technique in CHAHA**

Alliance India initiated an expanded child-centred Home and Community Based Care and Support (HCBCS) programme in the year 2007, in line with the strategic priorities of NACP III. The programme named CHAHA (meaning ‘a

### **Strategic Directions**

- SD1:** To improve care and support services to children living with and/or affected by HIV and AIDS.
- SD2:** To create a supportive environment for reducing stigma and discrimination.
- SD3:** To create a supportive environment for strengthening of civil society and institutional capacity building.
- SD4:** Information systems and operational research.

wish' in Hindi language), receives funding support from Round 6 of the Global Fund to Fight against AIDS, Tuberculosis and Malaria (GFATM). As a civil society Principal Recipient (PR), Alliance India has been implementing this programme along with its consortium of nine Sub-Recipients (SRs), in the states of Andhra Pradesh, Tamil Nadu, Maharashtra and Manipur. CHAHA is working closely with different stakeholders and Government to find ways to help keep children with their parents or extended families. It would extend care and support to 64,000 children living with and/or affected by HIV and their families (especially women-headed households) by 2011.

The MSC technique has been used essentially to learn from the first phase of CHAHA programme's implementation, specifically—what worked well and what needs to be done differently. The key objectives of this study were:

- To assess the intermediate outcomes, impact and potential for impact of the programme from the community and children's standpoint; and
- To understand the significant changes made in the quality of life of children and families registered in CHAHA

The key advantage of using MSC was its ability to capture and consolidate the different perspectives of key stakeholders—the community members, programme staff from SRs and SSRs, and Alliance India—to aid understanding and articulation of complex change, and to enhance organisational learning.

The following steps were undertaken for the study.

### Step 1: Consultation with Alliance India's team

Consultation and discussions with Alliance India's team helped determine:

- Who will be the story-tellers?
- Should domains be established before or after collecting the stories and how?
- Should we keep a 'negative change' domain?
- What should the selection stages be?

It was also discussed that once the final report has been prepared, Alliance India will put in place a plan for ensuring feedback to its partners and through them to the communities. (Refer Table 1)

In consultation with Alliance India staff and SRs, the following sites were identified for the study.

Four domains of change were identified for the study in consultation with the partner organisations. Domains were selected based on the kind of changes through the CHAHA programme that Alliance India

Domains of change are loose categories of change used to distinguish different types of stories. Davies (1996) suggests that unlike performance indicators, the domains of change are not precisely defined but are left deliberately fuzzy; and it was initially up to field staff to interpret what they felt was a change belonging to any one of these categories.

**Table 1:** Data collection sites/districts per State

State	Districts
Andhra Pradesh	Vijayawada, Nagyalanka, Warrangal, Bhongir
Manipur	Imphal East, Imphal West, Chandel, Bishnupur
Tamil Nadu	Madurai, Theni, Dharamura, Erode
Maharashtra	Mumbai, Thane, Satara

and its partner organisations wanted to measure. This was largely influenced by the programme objectives.

The domains of change chosen for the study were:

1. Changes in Quality of Peoples' Lives.
2. Changes in Level of People's Participation.
3. Negative Changes (because of the programme).
4. Changes in Staff's Capacity.

The following table shows the number of stories collected per domain from each state.

## Step 2: Staff orientation and finalisation of domains

Staff from the Knowledge Management team of Alliance India oriented key staff from SRs and SSRs on MSC prior to commencement of the study. During the study, the Consultant spent half a day, in each site, reiterating key aspects of the MSC process. Emphasis was laid on the role of the facilitator and note takers, common mistakes that people in the respective roles make, and ways of minimising such errors. The importance

of asking open-ended questions, probing and documenting everything that a story-teller says, was highlighted. The need to maintain a respectful, confidential and non-threatening environment was explained to the staff.

Most importantly, it was emphasised that once a story was collected, it needed to be verified by reading out to the story-teller. This ensures correct recording of facts as well as gives the facilitator, time to identify gaps and ask additional questions to complete the story. Time was also spent in translating the questions in the local dialect.

## Step 3: Story collection and selection at community and state levels

The respondents (community members) were divided into two groups – children (9 -18 years) and caregivers (of children below 9 years). The children's groups were asked to draw what they considered as the most important/significant change for themselves because of CHAHA in a particular domain. Engaging the children in drawing helped them open up, relax and be more comfortable to share their stories.

**Table 2:** Sex-dissagregated data showing number of stories collected per domain per State

STATE	CHILDREN						CAREGIVERS					
	QOL		LOP		NC		QOL		LOP		NC	
	F	M	F	M	F	M	F	M	F	M	F	M
Manipur	5	8	9	10	11 <sup>3</sup>	4	11	4	11	4	12	1
Maharashtra	4	2	4	5	4	4	6	2	6	2	7	3
Tamil Nadu	15	14	19	11	17	11	24	8	25	5	27	6
Andhra Pradesh	60		10		10		32		10		7	
<b>TOTAL</b>	<b>108</b>		<b>68</b>		<b>81</b>		<b>87</b>		<b>63</b>		<b>74</b>	

QOL : Quality of Life

LOP : Level of Participation

NC : Negative Changes

<sup>3</sup> 4 Children, 2 each from Chandel and Bishnupur arrived late and were invited to share stories depicting any change that they experienced because of CHAHA.

Field staff collected stories from children and caregivers in separate groups by asking them the most significant change that occurred in a particular domain during the programme cycle. The question was asked with an emphasis on the reason that made the change so significant. An interview guide (Annexure 1) was prepared to collect Significant Change (SC) stories. Stories were collected through group discussions. With the children's groups, once they finished the drawing, the facilitator interviewed each child to explain the drawing and tell their story.

Groups were given the option of sharing their stories in groups or individually. Few groups of caregivers and children in Andhra Pradesh and Maharashtra decided to tell their stories individually. In such a scenario, there was no story selection at the community level. Those who were comfortable in groups selected one MSC story in their respective groups. However, the community level story selection was not possible in few places largely due to inconvenience to community members due to their other commitments.

On the final day in each State, a full day was scheduled for the state level

selection. Given the sheer volume of stories collected at each state, the state selectors were divided into two groups – one group being facilitated by the Consultant and the other by an Alliance India staff.

#### Step 4: Final selection at national level in Alliance India

A third and final level of selection of MSC stories per domain was held at Alliance India Secretariat in New Delhi. Eleven staff constituted the selectors' panel. The MSC story selected at State-level in each domain was considered for final selection.

### Limitations of the study

Some challenges were faced by the field staff in facilitation and collection of stories due to various reasons that led to a few gaps in documentation of the stories. However, such cases were few and far between and they did not significantly impact the MSC process.

- In Andhra Pradesh and Tamil Nadu, there was an increased attendance of children and caregivers than estimated that compromised the quality of data collected.

**Table 3:** Sex-dissagregated staff participating in story collection and selection per State

STATE	SR		SSR		TOTAL	
	F	M	F	M	F	M
Andhra Pradesh	3	6	24		33	
Manipur	1	1	20	8	21	9
Tamil Nadu	1	5	22	14	23	19
Maharashtra	0	2	11	11	11	13

**F** : Female

**M** : Male

**PC** : Project Coordinator

- The field work schedule was very packed due to the distance between districts especially in Andhra Pradesh and Tamil Nadu, which left little time to collate data in a systematic way in each state. Given the volume of data, this proved to be a critical limitation.
- A potential constraint of using MSC as an approach, as was highlighted during this study, lay in dealing with subjectivity and bias. Such biases could be seen in some stories as a result of prompting, asking leading questions and amending stories by the facilitators and note takers at the field level. Due to such challenges, in Tamil Nadu, few stories in the caregivers' group were disqualified from the selection process and all of them were sent to Alliance India for translation by external translators to minimise bias.
- In the 'Negative Change' domain, no story was selected at the State level in Maharashtra and Andhra Pradesh as the selectors felt that none of the stories qualified as a MSC in this domain.



# Findings

This section includes the stories selected at the national level (Alliance India level) and a thematic analysis of the findings from the stories collected. It is important

to mention here that common and recurrent themes from the stories have been highlighted and analysed.

## Domain 1: Change in Quality of People's Lives

A total of 108 stories from children and 87 from caregivers were collected from the four states. At the final selection level at Alliance India, 3 MSC stories (1 from the children's group and 2 from caregivers' group) were selected. Two stories from the caregivers' group were selected because the selectors at the national level could not reach consensus on one MSC story and therefore agreed to select two stories instead.

'Change in quality of peoples' lives' was identified as a domain as, amongst others, it also reflected the first strategic direction of CHAHA – to improve care and support services to children living with and/or affected by HIV.

Stories were collected from children and caregivers of children especially in the age group of 0 to 6 years. Given a choice between reporting on change which they experienced in their own lives or change that they experienced in their children's lives—majority of caregivers reported on changes experienced in their own lives. However, it is understood that this would have also included their children's lives as both cannot be treated as individual entities. The significant findings are:

### Regaining self-confidence

For **S. Samuel**, a child from Tamil Nadu, the most significant change is that he

is able to live with dignity and courage again. He says – *"I used to think low about myself when I was with my friends and felt embarrassed. Now I don't feel that anymore. When we had no problems everyone was connected with us, but now that we have problems they are keeping away from us. This troubled me a lot. Because of counselling I developed courage and self-confidence."*

A confident young girl, **S. Manju**, also from Tamil Nadu, was full of enthusiasm when she told her story: *"Before joining the project I used to fear going out, but after receiving training I am able to go out with confidence. The reason for this is the Kanyakumari Life-Skill training. I am a leader in the children's support group and that makes me happy. Before I used to hate my father, but now I relate well with him, and the reason for this is counselling. My health is also doing well. Before I used to have a nameless fear, but I have it no longer now. Now there is peace at home and the relationships are cordial. Before we used to fight for everything. I used to be very sad because of my family situation, but now I have the self-confidence that I can support my family even if the project is not there. The reason for this is the experience I got through the project like the trainings. I choose this change because I want to be a role model for others. Counselling should be given often."*



Manju's is not an isolated case. Several stories from all the states talk about the relationship that project staff forged with the target population, which has been a relief to most, especially the children. The programme has significantly improved the quality of children's lives by instilling confidence through trainings, children support groups and counselling. The stories also reflect that, unlike before, children have been able to develop positive attitude towards their HIV positive parents. This is a significant achievement for the programme. In addition, it is imperative to highlight that Manju and numerous other children are seeking planned professional counselling support, as they have experienced the benefit of psychosocial assistance.

**Priyanka Ramesh Kamble**, a 17-year old girl from rural Maharashtra works as a volunteer in the organisation and said, *"I have benefitted from the information on HIV. I explain it to people, I can talk with them. Earlier I did not speak in public. I was afraid. Madam [ORW] visited us regularly and explained to me every time, which helped to bring a change in me. I expect many more people should volunteer like this for the work. My confidence in public-speaking has increased. I go to fields for work along with other women and talk about it."*

**Madhuri Sanjay Dongare**, 12 year old from rural Maharashtra again, broke down in tears recollecting her experience *"...my father had HIV...We started ART treatment for him at Satara... We were concerned about him; mother provided him food, medicines on time. He developed stress and started taking alcohol. He drank continuously for four days and fell, and injured his face and was not able to take food. People from the village started abusing him that since he has HIV he has developed some illness in his mouth and hence he must leave and go away from the village. They said, an other people may also contract this dreaded disease because of you....one day he told my mother to look after the children. And without*

*informing anybody, when there was no one in the house, he added poison to alcohol and drank it...My grandmother started blaming my mother that she lost her son due to her....My mother and I got psychological support since we came in contact with the organisation. It has helped us in finding a new direction in our life. We are now able to live with pride in the society due to the help extended by the organisation. Girls in my school do not trouble me, do not discriminate against me, they talk with me nicely."*

Madhuri's story captures an important contribution of the programme—that of helping her and several others like her, in regaining self-confidence to lead life with a sense of pride. The story also highlights the supportive environment the programme has built to provide non-discriminatory education and strengthening peer support. A 17-year old boy from Manipur very poignantly said, *"The aunts and sisters of CHAHA project advised me to be brave and courageous. This has enlightened my life. The Most Significant Change is that I have the courage to live alone in the society even if my community people have no affection for me. For this reason, I succeeded in bringing a big change in my life."* On the same poignant note, a child while explaining his drawing said, *"My life was dry before but after getting in touch with CHAHA it has become lively"*.

For **Sathya Priya**, a young widow with a child – being able to live with confidence is the most important change. *"There have been lot of changes in my life after joining the CHAHA project. I have developed confidence. My child is studying in 3rd standard. Only after knowing the child was negative my in-laws were happy. I am living for my child. I am going for work. I am living as an example for others with self confidence."* 25-year old **Jamuna Devi**, a mother of 3 children, from Manipur, broke down while telling her tale: *"After meeting CHAHA I don't want to die. Before, I wanted to die. There is now a desire to live and my mind has*



changed. Now there is curry exchange [exchanging food] with my neighbours. Now people don't look down at us. People die without having the disease and also with it, so now we don't think about it and just live normally. I would have been happy if my child was not HIV positive. This thing really burns like fire in my heart." 28-year old **Ningkhan**, from Manipur, shared, "The reimbursement I get for the treatment makes a significant change. The change is that now even if my family members don't care for me, CHAHA supports me. Now, my thoughts have changed to a broader view."

For caregivers, too, the ability to overcome feelings of hopelessness and being able to interact with others has been a relief. The confidence that they have regained due to the support provided by the programme is indicative of CHAHA's success in its first phase of implementation.

### **Respite and reassurance in going back to school**

The second recurring theme in this domain, from the children, is the fact that they were able to go back to schools. A young boy from Maharashtra said, "The most important change for me is that now my mother can pay my school fees on time and I can attend my school properly. When I grow up and get a job I will build a house like this" (he pointed to his drawing of a house with flowers).

Another young girl from rural Maharashtra shared, "Due to CHAHA I get notebooks and other school materials, which saves money for my mother. The organisation and their programmes helped my mother become brave." **Thavamnai**, a grandmother in Tamil Nadu, who looks after her deceased daughter's three children, shared, "Providing education support for all three of my grandchildren is the significant change for me. If my eldest grand daughter does her studies well, she can then finish some technical training and go for work and look after my other two grandchildren. Therefore

this educational support is important for me. After my time there should be someone to take care of them. Therefore I consider the educational support for my eldest granddaughter to be the most significant."

**Babburi Hari**, a 14-year old from Andhra Pradesh said that to him the most important change is the fact that he is back to school. "Both my parents died of AIDS. I have a sister and we are living with our grandparents. They are very old and unable to do any work. After the death of our parents we were in crisis. Grandparents are very old and cannot work. I had to go for work and earn for the family and so had to discontinue my studies. It was very difficult to survive and so I decided that I will discontinue my studies and go for work. That time ORW Ravi uncle visited our house and explained about CHAHA programme. Since then I am happy going to school. If Ravi uncle did not help me, I would be working in a mechanic shop or doing some other work."

In all the stories told by children, they appreciated the support towards continuing their education. Adhering to the Right to Development component of the UNCRC, CHAHA has been able to ensure education for many children which is quite significant for the programme. In addition, this support has also reduced the vulnerability of many children against physical and sexual abuse because studies have revealed that schools are considered safer spaces for children as compared to children working on the streets, markets or outside home.

### **Improved well being: better health, being able to socialise and make friends, saving money**

**C. Sathya** studying in Class 8<sup>th</sup> said with a lot of pride and confidence that the most important change for him is developing new relationships. "Our old relatives and friends did not respect us, so I did not want to go and relate to them again. These new relations understand

*my situation and relate to me, therefore I have no hesitation. My old relations treated me badly but the new relations comfort me. That is the reason for choosing this change. Also they take care of my brother which makes me happy."* It was not clear from the story whether "new relations" mean living in foster care or not, the story, nevertheless, points to the fact that a safe environment for a child is imperative for her/his growth and development. Probing would have surely helped in constructing and contextualising the story and helped in understanding whether this is an exceptional case or a recurrent theme.

Being able to go out, mingle without fear, being able to overcome shyness, make friends and better health are important changes experienced by many children and caregivers from all the states. The following quotes are pointers towards this:

*"After joining CHAHA, I don't feel shy anymore and started going out. ...There was change in my education ...I started socialising among the people."*

*"When I came to CHAHA my health improved. Before that I used to be sick frequently but now I'm okay"*—was what a young girl had to say on being asked the most significant change she experienced in the quality of her life due to the programme. **N Tracy Chanu**, a young girl expressed in her drawing that the way the flower in her drawing is blooming fully, her life is also complete. She told her story—*"Before joining CHAHA I faced difficulties in getting materials for my school but after joining CHAHA I think my problem has become less. The most significant change is that I can come out and talk to other people. I was scared when I go out and play with others, but that fear is no more."*

**Gnanasekharan** from Tamil Nadu shared, *"My father used to get fever frequently because he had HIV. Our neighbours and relatives refused to share food with us and never come to our house or talk to us. I was very depressed*

*because of this. The CHAHA ORW came to our house and told me to be happy and not sulk. He understood our situation and spoke to our neighbours and my friends and explained our situation to them. Now I have a lot of friends who understand my family situation and provide support. The change for me is that I am able to play along with others and share my food with them."*

34-year old **H. Premila Devi** said, *"My child is not afraid of people anymore. Before when their friends played they didn't join but now they play together. Now without them the other children will not play. The most important change for me is that my child became a leader among his friends."* 45 year old **Kh. Premila** with two children, one of whom is living with HIV, recounted, *"Instead of using my money to buy clothes for my children, CHAHA always buys their clothes and because of this I could save some money and some of my burden is removed."*

**E. Vijayrani** from Tamil Nadu shared that her life took a turn for the better with support from the programme. *"Whenever I call Chellapandi [ORW] and tell him that my child is sick, he immediately comes and takes my child to the hospital. Even my own brothers will not help like this. CHAHA provides all help for education and food. Nowadays I don't think of committing suicide, I have completely left that thought. Now through IGP support they have got me a grinder, I will be grateful for that. Since I am doing my own business I am confident that I can bring up my son. It is the counselling that I received that has changed me so much. Everyone says that it is the doctor and God who saved me but the one who saved me is Chellapandi."*

**M. Sundara Pande**, a man from Tamil Nadu, with two children said, *"The most significant change is the improvement in the standard of living because of the household support that I have received. I get a salary of only Rs. 2000 per month."* For **Selvam**, another male from the same

state, *“This is second life for me. I used to drink continuously and became very ill. But now I have changed and my family members treat me well. They come and visit me often. I was 34 kg, now I am 64 kg.”* Such stories need no further analysis. The support provided by the programme has evidently been need-based for the families. Testimonies point to the fact that the programme has improved the well-being of children and their caregivers, who can now make friends, interact with dignity, save money and worry less about basic survival needs.

## Vulnerability of orphan children and young people

The stories from all domains, in fact, reflect the vulnerability of children and young people who have lost both their parents and are living especially with elderly relatives (mostly grandparents). The doubts about the future, an unnamed fear, and the general poignancy in the stories are indicators that organisations working in the field of HIV/AIDS should re-think their strategies of working with the orphans and most vulnerable children.

14-year old **Ashwini Arun Shinde** from rural Maharashtra shared, *“Madam [ORW] used to visit every month and explained that I need to take tablets daily. I was provided with all cereals and food. I was not feeling well some days before now I feel all right. I think that I should go to school but then what will happen to my grandmother and brother? If I go to any hostel through the organisation then what will happen to my grandmother and brother? There is nobody to support us. I learned how to live as a result of the programme. I also feel that I should work like madam.”* Ashwini Arun Shinde has acknowledged the programme’s support; his story also highlights his anxiety for his grandmother and brother. One can gauge the level of stress the young adolescent is experiencing, a reality for several others in similar situation.

A few stories revealed the emotional and physical abuse that the orphans experience—a finding that surprised the field staff. In their regular interactions with the children and their caregivers, they have seldom spoken fearlessly. Several ORWs said, *“During the course of our home-visits, we never got this kind of in-depth information, especially from those children who live with their relatives.”* One ORW from Tamil Nadu said how “deeply touched” she was and also very surprised to hear from many children whom she visited regularly, sharing about their daily experiences of living with their relatives. The ORW said, *“One child, Revathy, talked about how her grandmother abuses her, almost daily. I never knew about this!”*

**R.K. Jashima Devi**, an ORW from Manipur, confirmed, *“Most of the relatives keep the double orphan children as helpers in the house and as they start earning, they might even start testing different [injectible] drugs.”*

**Sanjit Singh**, a 13-year old school drop-out from Manipur drew a violent picture—a man with a gun and used the shade of black liberally. He explained that when he gets a little older he will kill one of his uncles who mistreats him by becoming an outlaw. Another adolescent had a similar drawing—again, a man with a gun. It is important to note here that several stories from children in Manipur highlighted the need for working with adolescent boys and girls. In the context of Manipur, various external factors such as peers, unstable climate, easy availability of drugs and alcohol, high incidence of HIV—may have disastrous influence on adolescents who are at their crossroads of becoming young adults. As one young boy said in his story— *“At first I used to make friends with all kind of people. Some people are good and some are bad. I was among the bad ones. I was roaming here and there and kept going for thabal chongba.”* While explaining his drawing, he said, *“In life don’t walk in the wrong path, take the right path”.* Another adolescent boy from



Bishnupur said, *“I don’t want the younger generations to take drugs. I don’t want the future generation to use weapons that can hurt other people.”*

An adolescent from Maharashtra, in his recommendation said, *“I want CHAHA to spread knowledge to the growing youth to take preventive measure against HIV/AIDS.”* Another adolescent from Maharashtra had to say this; *“Earlier I was ashamed that my father runs business of garland making. But now I help my Baba in his work. The major change is that my Baba understood the importance of taking tablets due to the programme and he abstained from the habit of tobacco and alcohol. If the people who participate in CHAHA are provided with employment then their need of money can be solved. Also they should be informed regarding the type of education their children should take in the future and the job they will get through it. Most of the children joining the programme are poor. They do not understand the importance of education. In short, we should guide them regarding vocations and education. Now education is of utmost importance.”*

Stories from adolescents especially from Manipur and Maharashtra highlighted the need for working more intensely with young people. As explained earlier, one state is riddled with political instability and conflict with a large military presence and the other is a melting pot of cultures and confluences, the economic epicentre of the country, where the divide between the rich and the poor is distinct. In contexts such as this, it is easy for young people, without proper guidance or counselling, to veer towards anti-social activities, thus rendering them more vulnerable to abuse, exploitation and infections. This undoubtedly calls for more specialised and skilled interventions with young people.

## **Issues related to Income Generation Programme (IGP) strategy**

Most storytellers from almost all the states in this domain, asked for more support from the programme in terms of land, house, continuous education support for children beyond 18 year, a job, and “a business with a huge investment” amongst others. The pointers to such demands were:

*“I have a provision shop. If you help buy things for it, it would be helpful. If CHAHA project can help us more it would be of great support.”*

*“I want to do business with a huge investment.”*

*“If you buy me a place it would be helpful to build a house and have a tea stall in it.”*

*“We need land, a house and all help for my son who is studying.”*

*“Continued support for higher education and you should help my son study to become a doctor”*

*“We want to go on a family tour”*

*“For going to school I want a bicycle.”*

*“It will be very good for me if tuition fee support is increased.”*

Apart from the abject poverty that most of the children and families are living in, it also indicates people have build high expectations on the programme. This reflects on the need for ensuring sustainability of any income-generating venture by a comprehensive value chain analysis. For example, if a family is being aided to start a shop at their village, the programme needs to help them assess its feasibility, viability and sustainability through a market analysis. Only then can a small business may be set up for success. At the same time, it is important to communicate well with the communities and counsel them on limiting their expectations from, and dependency on the programme.

## Selection of Stories:

Box number 1–3 have the stories selected at the national level, the final level of selection at Alliance India Secretariat in New Delhi. A total of 11 staff (4 female and 7 male) from Alliance India were part of this selection. They drew up the following criteria for selecting one MSC story in the domain of quality of life:

- A child is happy in terms of education, friends, and/or surroundings.
- Basic needs of child are met and being accessed.
- Future prospect (hope of better future), living with aspiration.
- To see life in a positive way.
- Secure environment, (family and external) i.e. little or no discrimination.

The selection criterion set by the prior state-level selectors from the 4 states included:

- Economic and emotional self-reliance.
- Being able to live a life free of stigma and the fear of being shunned, humiliated and isolated.
- Being aware of legal rights and being able to access it.
- Improved interpersonal relationships i.e. having friends, making friends, sharing, talking, empathising, helping, and seeking help.

It was observed that the selection criterion at national level was broader than state level criterion. This was largely due to the critical analysis of stories that took place during state level discussions. It was also observed that the selection criteria was not defined as per the four broad categories of child rights under UNCRC (development, survival, participation and protection) and in the best interest of the child, though an agreed criteria covered these issues.

All stories from children and caregivers in Maharashtra, Andhra Pradesh, Tamil Nadu and Manipur selected at the state levels show the significant effects that CHAHA has had in their lives. **Lavanya's** story from Andhra Pradesh shows she wanted to end her life. After CHAHA interventions, she wants to live and has now developed a positive outlook towards life. Her family has better livelihood opportunities now and she is able to go to school. Arun Shinde's story highlights that the programme has made progress in providing ART and counselling support but still it needs to go a long way in addressing vulnerable children's issues holistically. Suchitra's story from Manipur provides insights on how CHAHA has supported her through education and household aid and how that has benefitted her. At the national level, selectors chose **Kumaresh's** story (**Box-1**) as the most significant change story in this domain for children. Kumaresh said he has become more confident because of the counselling support provided by the programme. He had dropped out of school and was riddled with low self-esteem. He gave examples of how he built relationships with other members of his community because of CHAHA. A positive change in Kumaresh's attitude and a trusting relationship with his mother are clearly important effects of the programme.

A critical analysis of the five stories of caregivers selected at the state level highlight that inspite of high levels of stigma and discrimination faced by them, they have regained confidence in life and are in a better position to cope. **Memcha's** story reflects on the burden of HIV on old caregivers which is discussed in detail under domain 3 on negative change. Even in her sixties, Memcha from Manipur is determined to provide good life to her grandchildren. **Indubala's** story from the same state tells of her excellent leadership skills in reaching out to other people. **Sucheta** from Maharashtra told in her story that she attempted to commit suicide and had lost hope. The programme instilled hope

## Box: 1

### CHANGE IN QUALITY OF LIFE (Children)

MSC story selected at the National Level

**Name of the storyteller** : K. Kumaresh, Male  
**Location** : Erode, Tamil Nadu  
**Facilitator** : S.Babu Bhaskar  
**Note taker** : R. Krishnamoorthy  
**Date of recording** : 5, August, 2009

I know about this project for the past 8 months. I came to know about it from my mother. It was during Diwali last year that I took part in CHAHA for the first time. Before I knew nothing about this project, but now I get regular counselling and participate with interest in the project. Before I never used to share anything with my mother, now I share everything with her. Before I used to have inferiority complex, because I feared that people will keep me away, if they came to know of my mother's status. But now after attending counselling regularly I never think about it. I also dropped out of school as I got very low marks in the final exams, but now I am continuing my studies (ITI – Technical education) with the help of CHAHA staff. I have got a lot of friends through this project. Because of the problems, I dropped out of school. It was Joel annan (brother) who took efforts to get me back to school. Now I am able to continue my studies. If Joel annan had not been there I would have gone for some daily wage work.

What is most important to me is that I have got lots of new friends. Reason, before I never used to come out of my house. Therefore I never had friends. Now because all my friends are affected just like me, I am able to openly talk with them.

The fear that my neighbours will come to know of my family's HIV status and problems, discouraged me from having friends or sharing with anyone. But now I have dealt with those fears through counselling. I also have the opportunity to meet and make new friends. This makes me happy. This support should be given to every student who goes to work like me. If a tailoring centre is opened for girls it would be helpful. Everyone should love me all the time, like they do today. The staff in CHAHA project should visit our home often and take care of my mother and father.

and confidence. She now desires to live long and healthy.

For the caregivers' group, the national level selectors were unable to reach consensus and selected 2 stories (**Box 2 and 3**). Both the stories, Sujatha (Tamil Nadu) and Saraswathi (Andhra Pradesh) show improvement in the quality of their lives. Saraswathi faced strong stigma and discrimination from her father and neighbours. She had to move more than ten houses because of this. Now, she is a positive speaker. Sujatha's story is an excellent example of how a comprehensive HIV/AIDS programme can have positive impact on one's life. Reflecting on the principles of GIPA

(Greater Involvement of People living with HIV), her story tells us how she was able to use CHAHA's IGP support most effectively by becoming self-reliant and is, in turn, helping others by stitching clothes free of cost for CLHIV. The IGP support not only made her economically self-reliant, but empowered her in many ways. She talks openly, helps others and reaches out to others in distress. Her recommendation for the programme—facilitating the formation of adult peer support group—appears valid. According to the selectors, the rest of the stories show dependency on the programme, where the story-tellers asked for more support for themselves. Sujata's is a good example of how a programme,

## Box: 2

### CHANGE IN QUALITY OF LIFE (Caregiver)

MSC story selected at the National Level

**Name of the storyteller** : Sujatha, Female, 32 year  
**Location** : Theni, Tamil Nadu  
**Facilitator** : Vallermati, ORW  
**Note taker** : Ponnadi, ORW  
**Date of recording** : August 4, 2009

Before I came to CHAHA I had T.B. I suffered a lot and received no help from my brother or relatives. I was struggling to feed my two children. I could not go for work regularly. Because I took lot of leave, they sent me out of the job. A friend who is also affected by HIV helped us out. When I went to Chinnamanyur MMSSS clinic, the staff came and told me about CHAHA project. I had a lot of fear about HIV then. I asked the staff not to come home as I feared that my relatives will keep away from me. I managed to contact the CHAHA staff through phone, got the information, built trust and received support from CHAHA. I got provisions, rice, nutrimix, and education support. We were in a rented house and we could not pay the rent. CHAHA staff took a house from another stakeholder and put me there. I did not have pay any rent. They also got me widow pension and a tailoring machine from the government.

Now I am able to get a standard income. I am working as a social worker after CHAHA. Due to the continuous follow-up I have peace of mind, comfort and I have got the courage to speak openly because of CHAHA. My children are studying well as they receive nutrition and education support. Because of the help I received from Sasi Kumar, I have also got the eagerness to help others and now I stitch clothes free of cost for Children living with HIV.

Working as a social worker and helping people like me is the most significant change in my life. This is because I like providing comfort to people affected by HIV and providing support for awaiting medical help. I get peace of mind and satisfaction by helping people affected by HIV.

I recommend that higher education support for those who have completed standard 12 be provided by CHAHA. Also, once a month meeting for PLHIV and children from the same area should be organised. I also feel that taking children for excursions will bring them joy and comfort.

if implemented in the true spirit of participatory development, can sustain on its own.

Many children and caregivers from all the states became emotional and broke down while sharing their stories in groups. Many of them admitted how helpful it was for them to speak openly amongst those who shared similar experience. It also helped them draw strength from one another. Such group activity of story collection seemed quite therapeutic and empowering for children and their caregivers who are living within challenging contexts, as they were provided spaces that were safe,

non-judgemental, equal, and respectful. Having staff trained in the dynamics of HIV/AIDS and its interplay with gender, power, sexuality, and culture is important to facilitate such group endeavours, and in turn, train the community to do it on their own. It also throws light on how a (largely perceived by communities) service delivery programme can also include processes and interventions that are empowering and participatory.

This group-based process also allowed children to articulate their feelings and emotions through their drawings and by sharing their stories. As summarised by **Sujata**, an ORW in Nagyalanka in



Andhra Pradesh said, “I saw the power of articulation in the children today. I always asked the caregivers about the needs of the child before providing the support. I always thought the child will not be able to express what she/he needs. Today I was totally taken aback. I have learnt a

big lesson today. From tomorrow, I am going to talk to the child and hear her/his perspective and opinion.”

A total of 68 stories from children and 63 from caregivers were collected from all four states in this domain.

### Box:3

#### CHANGE IN QUALITY OF LIFE (Caregivers)

MSC story selected at the National Level

**Name of the storyteller** : Macherla Saraswathi, Female, 25 year  
**Location** : Fathimanagar, Warangal  
**Facilitator** : L. Veerabahu  
**Note taker** : Vijay  
**Date of Recording** : 22-07-2009

Ms. M. Saraswathi's husband was working in Surath in Mumbai, as a weaver. After few months he was continuously falling ill, unable to recover his health. Finally Mr. Swamy decided to go for a blood check up. Doctors found him to be HIV positive. He had also taken his family for HIV test. He and his elder son were found to be HIV positive. The others are HIV negative. Once he came to know of his HIV positive status, he left the family and went away. Till date, his where abouts are not known. His wife Saraswathi took the children and came to her parent's house. Her father came to know that her family is infected with HIV, so he refused her shelter in his house. She felt humiliated and took a room nearby her parent's house. Her mother and sister were helping her to buy food and other things for survival, without her father's knowledge. Once her father came to know that she is staying close to them, he told the landlord to make them vacate the room because her family is living with HIV. Repeatedly she was harassed to vacate the house. Within a short period of her stay she changed nearly ten houses. Through a friend, she came to know about LODI and its activities. Lodi's outreach worker, Bharathi visited her house. The outreach worker gave her counselling and supported her to balance her life psychologically. This happened a number of times in order to make her feel better and accept her life. She went through a lot of trauma, to educate, to feed her children and to pay her rent... she has undergone lot of psychological sufferings and felt discouraged to look after her children. She was fortunate that CHAHA programme was implemented by LODI. The coordinators of LODI enrolled her younger son in this programme. They began to provide household support to her. From then onwards she joined the PLHA support group. One of the PLHA members gave her a room on rent. She is attending the support group meetings regularly and gained a lot of knowledge by continuously attending the meetings on nutrition food and personal hygiene. Opportunistic Infections management, ART management, referrals and linkages, positive speaker knowledge etc. Based on this experience and knowledge, she is selected as a peer educator. She got her younger son tested for CD4 count. His CD4 count is 54. She went for ART. Meanwhile, she began to provide him nutritious food and took good care of him. With all these positive elements, he went for CD4 test and found an improvement. It increased to 1250 points. Now her two children are going to school. She thought that she will also get AIDS, so far she had begun to take precautions such as good food and hygiene. OI management, psychologically positive attitude, constant advice from ORWs and PLHA support group meetings have brought psychological balance in her life. She developed her self-confidence and began to believe to that she can prolong her life for 9/7 year living in good health. This is the most significant change in her life.



## Domain 2: Changes in Level of People's' Participation

This domain was chosen to reflect on Strategic Direction 2 (SD2) of CHAHA: 'To create a supportive environment for reducing stigma and discrimination'. It can be inferred that positive changes in the level of participation would also indicate better coping mechanisms to deal with stigma and discrimination. The stories in this domain largely show changes in level of people's confidence, improved well-being and also bring forth the vulnerability of orphans and adolescents. This section, apart from analysing the stories, also takes into account the perspective of staff that was shared by them during reflective sessions.

The stories from children and caregivers can be divided into two broad themes which are as follows:

### Leadership development:

Many stories show that children and caregivers have been able to disclose their status, interact with people and generally overcome feelings of being shunned and stigmatised by their neighbours or the communities they live in. The stories reflect that several storytellers are voluntarily spreading the message of prevention, care and treatment and becoming role models for others. Bhagyalaxmi's story shows how she took the initiative to approach CHAHA team to intervene when one school refused to admit her child. Such stories reflect that some of the Alliance India partners have worked effectively to build strong relationships to augment participation of children and caregivers.

In addition, **Gomathi's story** from Tamil Nadu shows the value children and also caregivers give to the fact they are able to interact freely with others. *"Before coming to CHAHA project, I was unhappy and did not know the importance of education. In CHAHA project they taught us to be united, and helped us understand the*

*importance of education and identify our talents. Expressing my sorrows through drawing and essay writing has helped reduce the burden and now I am happy. I used to be at home without talking to anyone. After coming to Children Support Groups I relate well and make friends easily. Life Skill Education helped me understand myself. Now I participate in school competitions without any fear."*

Another story from a young boy who did not want his name to be disclosed, points to the fact that 'being accepted' is of utmost importance. To not feel rejected anymore is empowering. The child from Andhra Pradesh shared, *"My father used to get fever frequently because he was living with HIV. Our neighbours and relatives refused to share food with us and never come to our house or spoke to us. I was very depressed because of this. The CHAHA ORW came to our house and told me to be happy. He understood our situation and spoke to our neighbours and my friends and explained our situation to them. Now I have a lot of friends who understand my family situation and provide support. The change for me is that I am able to play with other children and share my food with them."*

### Increased level of confidence:

This is similar to the theme of regaining self-confidence in the quality of life domain but is being highlighted again to reiterate the feeling of empowerment that people and children living with HIV experience when they inculcate a positive outlook, and are able to regain the courage to live with dignity and pride. Many stories from both caregivers and children show the confidence they got by being part of the programme – the confidence to essentially face the world with growing pride and confidence. Several stories tell about the feeling of hopelessness that the storytellers experienced earlier, some had recurring

suicidal thoughts. Ratnakumari from Andhra Pradesh said, *“...I studied up to 7<sup>th</sup> class and was searching for jobs when somebody told me that for doing job minimum 10th class education is needed. One day REEDS people came to our village and conducted sensitisation meeting for the positive people. I spoke in the programme about the issues of positive people. Initially I was very afraid to speak but due to support and counselling provided I got the confidence to speak and live. Through the support from REEDS I got confidence and they also helped me to get a job in PPTCT project. Not only I am confident but also helping and creating confidence among positive people like me. I am positive for 11 year now without any medication My CD4 count is 800 and I am confident that I can maintain this count in future also. I get tested every six months for CD4 count and T.B.”*

**Tamilarasi** from Tamil Nadu has a similar story to share. She said, *“I was very depressed about the loss of my parents. I did not concentrate on my studies. After coming in contact with CHAHA project I am studying well and getting good marks. I learnt good habits through the Life-Skill Education (LSE) group. The Children’s Support Group (CSG) helped me identify my talents and build on them and also get many friends. I participate happily in games and oratory competitions. I am getting over the worry of losing my parents. Through CHAHA project, I get what I want. Latha akka buys the things I need. In Children’s Support Group (CSG) I was the leader that helped me develop confidence. I am now participating in everything compared to before. I was not taking ART tablets regularly, now I am taking the tablets regularly heeding the advice of CHAHA. Since my parents and I had this infection, my schoolmates never used to play with me. Even children in my neighbourhood never played with me. Now we all play together. The reason for this is CHAHA project. Though there are still some children who don’t talk to me.”*

Both these stories clearly talk about the increase in level of confidence and the resultant decline in incidents of stigma and discrimination.

## Selection of stories:

Alliance India’s partners in Maharashtra (children and caregivers) and Andhra Pradesh (children’s groups) did not select any story because according to the state level selectors, none of the stories qualified as stories of participation. Instead, these sounded like stories belonging to the ‘quality of life’ domain. They arrived at the following criteria to define participation in CHAHA;

1. Involvement in programme cycle – needs assessment, design, implementation, monitoring, review.
2. Involvement in resource mobilisation – e.g. seeking help from community when needed; raising resources for survival needs.
3. Involved in community mobilisation – being part of sensitisation meetings; volunteering; leading SHG meetings; being part of advocacy (e.g. meeting the District Collector, along with NGO staff, for widow pension); positive people speaking in Panchayat meetings/Gram Sabha meetings/Self Help Groups.
4. Caregivers participating in assessing needs of the family along with the ORW.
5. Helping other positive people in developing and participating in referral networks.
6. Self-confidence—the ability to speak out.
7. Showing leadership qualities, such as being able to talk in large groups, being able to interact effectively with peers and taking initiatives.
8. Holding leaders accountable.

It is also important to note that the perspective of the state level selectors group included a 14 year old girl from

the community in Manipur. For her, sharing amongst friends, getting involved in sports and other extra-curricular activities, being able to express her feelings, taking decisions in the family (such as choosing which school to go to, which subjects to study), being able to enjoy festivals, being able to disclose her status are all indicative of participation in the programme. This provides interesting insights into what people closest to the 'field' understand as 'participation'.

After going through the stories selected at state-level, the national level selectors felt that the stories could be seen as overlapping with 'quality of life' domain

but they were still significantly different based on the following criteria:

- Being an active member of the children support group/adult group.
- Being motivated.
- Developing leadership skills and being a peer leader.

Based on these criteria, in the children's group, Ronald's story was selected in the domain **(Box 4)** as the selectors felt that this story reflected participation as he had started befriending other children, aspiring to come first in the class and sharing his viewpoints.

## Box: 4

### CHANGE IN LEVEL OF PEOPLE'S PARTICIPATION (Children)

MSC story selected at the National Level

<b>Name of the storyteller</b>	: Ronald, Male, Bishnupur, studies in Class VI, has 2 siblings
<b>Facilitator</b>	: Memthoi, ORW (supported by Elina, APC, SASO)
<b>Note taker</b>	: Jashima, ORW
<b>Date of recording</b>	: 29th July, 2009

Aunty Piyari came to our house and started giving support. Since then it has been a year that I have joined CHAHA. Before I joined CHAHA, I was a shy boy. I was unable to face the crowd and was too scared to talk to others. I was upset and lazy to do anything. But after I joined CHAHA, I started socialising with others and was able to talk to other people. I started participating in various school performances. I started having new friends and shared all the sad and happy moments. I came to know more about many diseases and started sharing the knowledge in school, at home and with others.

Being able to speak to others without fear and facing crowds are the most important/significant changes that I have experienced. When my friends stand first in class, I am also inspired to stand first. I want CHAHA to support me in achieving my goal.

#### Reasons for selection at community level:

- \* I like his confidence in speaking out his mind. This story reflects participation and his leadership qualities. He is not scared to share his viewpoint with adults and friends. He also educates peers about the disease. Confidence to speak with children and adults matches with my vision of participation.
- \* I myself came out after coming in touch with CHAHA and this story reflects my story.
- \* He is a small child and I never thought he would be able to express himself so well through his drawing. I feel that in most of the stories, facilitator and note taker have not been able to probe or think of various areas in which a child could participate.
- \* He was also able to expand his participation beyond CHAHA.

In the caregivers' group, selectors at the national level opined that out of all the stories in the domain, Rammanamma's story best depicted change in the level of her participation in the programme. **(Box 5)** According to most selectors, *"She is a leader and a role model. She is spreading awareness and by breaking barriers has shown tremendous courage"*. In fact, the reason why this story also got selected at the community level was because Ramanamma showed selfless courage in not committing suicide when she was almost on the verge of doing so. Instead, she educated herself on HIV/

AIDS and is now a community volunteer who helps others to access similar services.

Both at state and national level, there was a general level of dissatisfaction regarding the stories in terms of the details they captured. The facilitators shared they had difficulty translating the term 'participation' in local language and could not supplement it with examples as it was against the basic tenets of using the MSC approach where open ended questions have to be asked as examples could unduly colour the responses.

### Box: 5

#### CHANGE IN LEVEL OF PEOPLE'S PARTICIPATION (Caregivers)

MSC story selected at the National Level

**Name of the storyteller** : P. Rammanamma, Female, 30 year  
**Location** : Machilipatnam, Andhra Pradesh  
**Facilitator** : Kranthi  
**Note taker** : Sujatha, ORW  
**Date of recording** : July, 2009

My name is Ramannamaa and I am living in Machilipatnam. I lost my parents in my childhood. I was brought up by my grandparents. I got married to Ramana. Both of us were daily wage labour, and this was only the source of livelihood. We are living in Machilipatnam and we have two children. I came to know that my husband is living with HIV and he died of AIDS later. After his death, my children and I got tested for HIV and came to know that my daughter Sowmya and I are living with HIV. My In-laws threw me out of the house, when they came to know about our health status. I rented a house and started doing daily wage work and taking care my children. My health and Sowmya's health started to deteriorate slowly. Many times I thought of committing suicide and giving poison to Sowmya. But then I thought my other daughter will be left alone and will become an orphan. I dropped the idea of suicide because I know how difficult it is to live without parents as I have also gone through the same experience.

That time ORW Swarna from CHAHA project met me and she explained about HIV/AIDS and said that many people are living in India with HIV and I am not the only person suffering with the disease. She also explained about services in CHAHA and told me to forget that Sowmya and I are HIV positive. Her words motivated me a lot and are a reason for happiness in my life. Sowmya was taken for CD4 test at Vijayawada. As her count was very less, doctors recommended her for ART and she is taking her medicines regularly. Her health is recovering gradually and she is quite healthy now. We are receiving educational support, nutritional and household support and children are going to school regularly.

Recently I met with two PLHIV in village. I spoke to them and discussed all those issues which were being told to me by ORW. I also introduced them to CHAHA program and referred them to office. I usually enquire them about their health, whether they are taking medicine on time or not, about nutritious food etc. I also participate in sensitisation meetings and explain about the difficulties faced by PLHIV in the community. I have applied for six widow pensions from our village on behalf of women living with HIV. Wherever I go for work, I sensitise women on HIV related issues and provide them counselling and guidance and information on HIV/AIDS.



**Good practice, showing the possibility for innovation:**

PSU in Bishnupur, Manipur have cut down expenses on staff refreshment and other sundry office expenses and are utilising the surplus money to organise group meetings with caregivers. The response from the first meeting was such that they have decided to hold such get-togethers regularly.

In spite of the disappointment, all agreed that the exercise was immensely valuable in identifying the areas that need more attention by PR, SRs and SSRs.

Staff from all states also felt that since CHAHA is a performance-based grant as opposed to process based, they are not able to focus as much on community participation and mobilisation as they would want to. They spoke about the potential constraints that do not provide an enabling milieu for such a process.

Staff from SRs and SSRs in Manipur shared that *“areas where SASO has been working for a long time on HIV/AIDS, has greater community acceptance, home visits by field staff is higher and their general level of participation in programme activities is much more than those areas where interventions are fairly new. In fact, people have reported being able to tackle stigma with much more confidence in those areas where organisations have been working for a longer period of time.”* They further reiterated that more time is needed to build relationships of trust and seek allies in newer communities.

Several staff from different organisations expressed their doubts about whether children, especially the younger ones (below 8-9 years old) would be able to talk or express their feelings in a particular domain through drawing. All were pleasantly taken aback on hearing and seeing the children with whom they have been interacting regularly. They acknowledged that they had

been underestimating these children's creative energies and never thought they could draw such paintings and articulate their feelings so well. *“I was so surprised to hear from young children when they asked us to work with young people on the issue of drug use and sex education”,* was a rejoinder from a Project Coordinator in Manipur. *“I was not comfortable with mixing up children in groups (having ‘children living with HIV’ and ‘children affected by HIV’ in the same group). My perspective got changed as I thought they will be uncomfortable, hesitant and not articulate well. In fact they wanted to be in mixed groups”,* was the honest reflection of an Assistant Project Coordinator (APC) in Manipur. A counsellor from Andhra Pradesh, while reflecting shared, *“the MSC process with the children's group started with asking them to draw. I was surprised to see how they progress from drawing to asking each other about their treatment, duration, medicine and adherence. In group exercise such as this, they came together without inhibitions.”* An ORW from AP owned up saying, *“I used to identify needs by talking to the child's parents or caregivers. I never thought of asking the child. But after this process (MSC study) I have decided to directly ask the child.”*

The point here is that working with children requires the staff to be receptive, non-judgmental and see them as equals. A significant premise of participation in development programme is the belief that communities know and they know more (about community level dynamics that affect participation). In the context of children's participation, this is equally important to keep in mind. However, in cultures where the adage, ‘children must be seen not heard’, what has been noticed and documented in studies the world over, is the protective, paternalistic, patronising attitude which development workers immediately wear while working with children. There is a lot of assumption about whether a child of a certain age would be able to “participate”, “understand”, “articulate”, and generally talk about what is in her/his

mind. It became evident in the study, that the attitude and behaviour of many staff, from across hierarchies, is the single most important factor that can alienate or bring communities together. In the context of children, this is especially true. Children's participation may challenge fundamental relationships of power

between adults and children, and such power relations need to be negotiated if children's greater involvement is to be realised. It is important to recognise the diverse realities of children's experiences and to involve them in deciding what they want to change about their lives and how they can best go about it.

## Domain 3: Any Negative Changes

This domain was selected to essentially understand the gaps in the programme. A total of 81 stories from children and 74 from caregivers were collected from all 4 states.

### The significant findings include:

#### Fear and effect of disclosure

Story-tellers, both children and caregivers, said they feel threatened and isolated by community members and families once they become aware of their HIV status. It was also reported that CHAHA programme staff visiting them are compounding this issue. As 55-year old **Vemula Samrajyam** from Andhra Pradesh, a grandmother who takes care of her three orphaned grandchildren narrated her story of isolation, *"Five days after the death of my daughter Jhansi, the ORW came to our house and everyone came to know that my daughter died of HIV/AIDS. I had a petty shop and also sold tiffins in the morning. After the death of my daughter, my elder daughter suggested me to stop selling tiffins as no one will buy because a family member died of HIV. But I did not listen to her. However, after a few days I had to close the shop as no one was coming to buy from us."*

**L.Venkateshwaramma**, a 32-year old woman, from Andhra Pradesh, was deserted by her husband as he suspected her of having "loose character" and therefore being responsible for infecting their second child. She said that though she appreciates the help from CHAHA, the fact that the ORW visits her regularly is a matter of great

concern. *"As she (ORW) is coming to our house regularly, I have problems with my neighbours. They suspect me and I am scared of my positive status being revealed."* **Murugeshwari**, who along with her two children is living with HIV in Tamil Nadu, is appreciative of the help from the programme. She, however, shared that *"Once the project staff came in a van to my house and that attracted a lot of people. It would be good if they call before coming for a visit. We fear that others will come to know that we have AIDS."* **Backiam**, a woman from Tamil Nadu shared her pain, *"My children and I have HIV. We participate in project activities with full involvement. First my neighbours stopped their children from playing with mine fearing that they would get HIV. Now the entire village has kept us away saying that we are people living with AIDS. I feel hurt when they refer to me as 'The one with AIDS'. Now everyone will come to know that my children have HIV and it will affect their future."*

It is worth mentioning here that several stories in this domain from Tamil Nadu depict the fear that the storytellers are surrounded with the fear of rejection, isolation and humiliation. A woman in Tamil Nadu, who did not want to be named, shared, *"I never go to my mother's place as I am not accepted there. My brother comes and visits my children. But I want to go to my mother's house. My neighbours look at me with suspicion as I am living alone. I am worried that if my HIV status is known outside I would not even get a house for rent. I struggled a lot after my husband's death. Being discriminated by my own*

parents is painful to me. Whenever I receive the services I fear that my status will be revealed. If my status is known, they will not allow me even to enter the temple. The most significant change is that I fear that they may speak ill of me when I go home alone after attending meetings in office. I choose this because attending these meetings could reveal my status.” On being asked for her recommendations, she said, “I want to participate in all social functions without being discriminated.”

Children had similar stories of pain, fear and shame to share. 17-year old **Someshwar Rao** from Andhra Pradesh rued the fact that his family has been isolated by everyone. “No one is calling us for family functions or for marriage. My mother’s relatives totally isolated us and my father’s relatives are not talking to us. My mother and brother always stay at home. They do not talk to anyone. We are not living with rest of the family and we are living alone due to stigma showed by them”, he says. **Allakunta Sarala**, a 17- year old from Warangal in Andhra Pradesh candidly said, “Help in the programme is good but when my mother’s status of HIV positive was known, every one insulted me at work place, isolated me a lot. I felt very bad.”

**Anuradha Suresh Sutar**, a 13 year old girl from Maharashtra felt uncomfortable recounting the fact that it was staff members of the SSR who caused a lot of pain in her family. “The organisation members told something about my father to my mother so she went back to village (left the home). My father now does not meet the organisation members. My mother was ill. Due to medication, she is better now. Still the organisation people come to visit us. As the organisation members are visiting us often our neighbours enquire about it. We tell them that these people are from the organisation. Still they should visit only once in a month.” She suggested that meetings should not be organised during school hours as she misses school; this

was echoed by many children from all states.

**Shalini**, an 11 year old girl from Tamil Nadu had to say this, “My grandfather beats my mother and grandmother after getting drunk. I was studying in nursery class in a convent. After a week they asked me to sit alone, I came and told this to my mother. My neighbour had gone and told the sister in school that I had HIV. They sent me out of school and told me never to come back. So I joined a school in our village....I felt bad when my neighbours revealed our status to everyone in the village. They said that I got it from my mother.”

The stories in this domain highlight the need for supporting all staff on better understanding community mobilisation aimed at reducing stigma and discrimination. Evidently, families’ stigmatisation by neighbours, and disclosure of HIV status due to the frequent visit of the programme staff, highlights the need for doing things differently. Although it did not come out explicitly in the stories, yet a possibility is that this fear of disclosure may also affect medical adherence. In another story, **Jayanti**, a widow with children living in Tamil Nadu poignantly talked about her fear of disclosing her status to her children, “My children do not know that I have HIV. It hurts me to lie to them. I have AIDS. If I die, who will take care of my family in my absence. There is no help from anyone – my family or from outside.”

## Increased vulnerability of children and single women

Several stories from all four states and from both groups, of children and caregivers, reflect the multiple burden being borne by women—burden of blame, shame, earning a livelihood, staying alive, and taking care of husband and/or children. The stories also highlight the deep pain that children of such women feel for their mothers.



**G. Manga**, a 25 year old widow from Andhra Pradesh lamented, *"Whenever I go to medical shop for medicines, the shop keeper usually shouts at me and tells to me stay away from people in the shop. I feel very bad. Whenever staff from the NGO visits me, neighbours are very curious to know why they had visited me. My children are not allowed to play and talk with other children in the community. Neighbours used to ask me why my children are sick always, why they have fever all the time, why they are very lean not healthy etc. I felt very bad whenever such questions were asked. As I am a young widow, everyone in the village wanted to take advantage of me. I was very much afraid to talk to men. They were very rude towards me and insulted me verbally."* In fact, the vulnerability of being a young single woman was expressed by another woman in the same group in Warangal, Andhra Pradesh. **Polipaka Sarita**, a 30 year old widow, with two children sells vegetables to earn money. She narrated, *"When I go to attend meetings at office, neighbour suspect with wrong attitude. Whenever I take my sick children to hospital, people enquire about all details, like which hospital did I take the children, what did the doctor said etc. This interference I did not like at all. I am healthy now, but if I fall sick, I will be abused, blamed of wrong behaviour, then what will happen to my children. Before the death of my husband, all relatives were close to us, visited us during festivals. But now they have completely isolated us. Whenever I attend marriages or functions, people stare at me like a stranger. Neighbours say that HIV positive people will die soon. All this abuse hurts me a lot and I do not like this at all."*

Apart from feeling humiliated, the stories from the children point towards the undue stress experienced by them, especially those who are living under very difficult circumstances. **Pukhrambam Sushma Devi**, an 11 year old from Manipur, who lost her father due to AIDS, and whose mother

is positive, broke down while telling her story, *"The pipeline for the supply-water is located far away from my place. The one which is near my house has stopped giving water. My mother sometimes falls ill fetching water from far away. I feel exhausted taking care of my mother when she is sick. She has backache and joint pains and I had to massage her. I feel sad when mother is hospitalised. Aunt goes to hospital to look after mother. I feel sad for not being able to have meals together; everyday I eat with mother."*

14-year old **Selvanayagi** who lives with her grandparents (her mother is a widow with two daughters), expressed her feelings of deep distress in her drawing, *"We live in a tiled house. I have drawn the things at home. My problems, no one goes for work, my grandfather scolds my mother when she goes out. My neighbour used to tease me saying, 'your father is not with you'. My father fought with my mother asking for dowry and left us and went. We gave a complaint in the police station and they asked us to go to the women's police station, but we did not go there'.* The same girl, while verbally telling her story, shared—*"It hurts me when my grandfather fights with my mother after getting drunk. I feel sad when my mother beats me and my little sister and tells me 'You go die'. My father is not with us. I miss him a lot. When I am in school I think about him and feel bad."*

These stories, and few others with similar themes, show the importance of regular psycho-social support for such children who are living under stressful circumstances.

### **Perceived inability to continue providing care by elderly caregivers, and a feeling of hopelessness by children, especially orphans**

**Nadhya**, a child (age not documented) from Tamil Nadu poignantly ended his story saying, *"An old lady in our village said that our family was unlucky, that's*



*why my father is lame. I like the support being given. Wish my life is free of problems. I am seeing problems right from the day I was born. My father and mother should get well soon."*

Many grandmothers from Tamil Nadu and Andhra Pradesh, who have been forced by circumstances to look after their orphaned grandchildren asked, "(we) just want to know if our grandmother will still be treated for free when they grow up...We are afraid when they grow up, they will no longer be given treatment. Will the organisation continue to look after them? What will happen to them when we die. They are so young and we may die any day now." Their primary concern was related to their perceived inability to continue providing care for their children until they become self-reliant. Stigma and ostracism towards HIV positive individuals make it difficult to find someone they can trust who would be willing and able to provide care for their children.

This theme stresses the importance of early consideration of a child's future, child guardianship, or future placement plan for those who are under the care of elderly relative or HIV positive parent(s). This requires involvement of the appropriate referral services for succession planning.

### **Unkept promises and its effects on children**

Few stories in this domain show the disappointment experienced by children who were somewhat assured for certain services by the programme staff but did not receive them. As **P. Nandhini**, an 11<sup>th</sup> standard student from Tamil Nadu mentioned, *"When my mother went to the hospital, XXX madam told us about the CHAHA project. They told us that through this project we will get education and other support. After we joined the project, they brought rice and provisions for us. They told my mother 'don't send your daughter to work'. They stopped me*

*from going to work and admitted me in school and helped me take computer science group. I was hurt by the project. They asked me to join school. They said that after you join, we will help you by providing provisions for your family. I was disappointed because they did not help as promised. We did not have money for admission in school. In school they asked for medical certificate as I had missed a year. We needed Rs. 500/- for getting the certificate, we expected this support from the project but did not get it. That disappointed me. The significant point is that when I needed Rs. 500/- the project couldn't help me and they failed to support when I needed it the most. My mother is sick. I used to get Rs. 500/- by going to work but I stopped going because the NGO asked my mother not to send me to work."* Few more girls from this group in Erode (Tamil Nadu) had similar stories of unkept promises and shared their disappointment. These stories further emphasize on the need for managing expectations, through improved community participation.

### **Working with adolescents: special skills and interventions**

A 15-year old girl from Maharashtra, who did not want to be named, and when reassured of confidentiality, said, *"I first came to know from the organisation only that I am on ART. I was shocked to hear that and fell ill. They should explain such things to girls like me instead of telling it directly. Members of the organisation visit us on a number of occasions hence we and the neighbours face problems. They should visit once in a month."* She recommended that girls her age *"should be given more information regarding health, menstruation cycle; they should be provided with more nutrition."* Part of her experience was also recounted by **Jeevan Bhanudas Jadhav**, an 18-year old male from Maharashtra, *"As the organisation members visited us often, I was frightened, felt insecure....We do not get information about sex hence I feel that sex education should be provided through the organisation."*

A 17-year old adolescent girl (did not want to be named) from Maharashtra broke down while recounting her story, *"I had to bunk college as I was called in the organisation often. My study was lost. Household chores remained incomplete and hence the family members scolded me. As the organisation members visit us often the neighbours look at us suspiciously and doubt our character. They often ask as to whom I go to meet."* She suggests that she be invited to participate after college hours. She also suggested that the organisation members should not wear I-cards. Repeated visits, to the organisation as well as from the organisation, should be minimised.

Though the stories highlighted here are reflective of the effect of staff visiting the families, as has been described earlier, they also point towards the need for a different approach to working with young people. Working on gender and sexuality is imperative with young people, especially as they are at the cross roads of adulthood and go through different emotions and experiences.

## Selection of stories:

At the final national level selection at Alliance India, 5 MSC stories were reviewed in the children's group, but the selectors did not find any story as the MSC story in this domain.

In the caregivers' group, the national selectors selected 2 stories out of 3 as the MSC stories, as given in box numbers 6 & 7.

It is interesting to reflect on the reasons stated by the state-level selectors in Tamil Nadu for selecting **Chellavel's** story (**Box 6**) as the MSC story in this domain. They discussed, at length, how the support from CHAHA has been misunderstood by the community – thinking she is a sex worker – and has "illegal contacts" – hence getting all the household support. This, they said, highlights the need to strengthen community mobilisation. According to them, in contexts where stigma and discrimination is very high, family counselling is an important entry point, followed by counselling immediate neighbours. This should be an important

## Box: 6

### NEGATIVE CHANGES (Caregivers)

(MSC story selected at national level)

<b>Name of the storyteller</b>	: Chellavel, Female
<b>Location</b>	: Madurai
<b>Facilitator</b>	: Chadhrasekhar and Anand
<b>Note taker</b>	: Pannang
<b>Date of recording</b>	: August 3, 2009

Chellavel had a love marriage which was not accepted by her family. Her husband was HIV positive and she has a three months old baby girl. She shared her story thus-

When I go for ART and come late, they (neighbours) ask me where I have been and speak ill of me. During menstruation when I put aside the used cloth, other women speak ill of me. The people in my family keep me away, but the project staff comfort me. I received no help from my family. When project staff come I am accepted in the family. The village people think that I get the things (given in the project) in a wrong way by being with someone.

The fear I had in 2001, I don't have now. I go alone for CD4 testing. With this organisation(s) help, I am working now. When I go for work and see the suffering of other PLHIV, I find comfort. Through the project I learnt about healthy food and hygiene. I have understood that it is necessary to get an HIV test done before marriage.

As my daughter is living with HIV, I will get her married only to a boy living with HIV.

pre-condition for providing material support and making home visits. While in the current practice, they admitted, material support is provided immediately after identification of children, with no or limited time spent on building relationship of trust with the family and/or outside. The other pertinent point made by them was that the programme needs to look at not just the 'visible' needs of a family (e.g. nutrition, education, household etc.) but also the 'invisible' needs (e.g. emotional support, cultural and societal

acceptance). This, they agreed, requires more patience and better understanding on the part of the programme staff.

Selectors at the national level agreed with the arguments or analysis made by state selectors and added that there is a need for addressing gender and power dynamics in the programme. As women and girls are rendered more vulnerable because of their gender practical needs, this needs to be understood and interventions need to be designed accordingly.

## Box: 7

### NEGATIVE CHANGES (Caregivers)

(MSC story selected at national level)

**Name of the storyteller** : Amita, female 35 year, separated from husband, with one child  
**Location** : Manipur  
**Facilitator** : Gilbert  
**Note taker** : Manorama  
**Date of recording** : July 27, 2009

I joined CHAHA after meeting one of its staff. Because of the social stigma, I don't feel like going to other houses. Joining CHAHA when the children were small is fine but after they grew up, friends started saying that you got admission in CHAHA because you are HIV positive. So the children feel sad and embarrassed. As for me, I don't care because it's my fault.

The other thing is that before taking any support from them, they are asked to get the receipt from the school. I feel sad to ask receipt from the school and I don't want the school to know about taking support from CHAHA. I feel sad thinking that her friends will look down on her. Some even say that they take help from CHAHA and send the child to school because she's HIV positive.

It's very difficult to get receipt from schools as we can't afford to pay school fees when CHAHA asked for it. If the school barred the child from appearing in exams due to non-clearance of fees, project CHAHA should also give some relaxation regarding the receipt. When asked to for the receipt first, the clerk says, he need to tell the principal first and keep asking the reason for cutting the receipt. When I said that, I need the receipt for taking help from NGO, he suspects that we are HIV positive. So I feel sad and think that if I were not positive, I wouldn't have gone to them for help. Now that I stay separate from my husband with my sister-in-laws, I feel sad when they think about me as HIV positive and hearing what the localities think about me.

I have good relations with CHAHA so I visit the local people with the staff. Since it is difficult for them to enter a Muslim family, I have to accompany quite often.

I want CHAHA project to keep our trust and address the school about the project in detail. One thing I feel bad about is the existence of difference between those who get household support and nutritional support. Another is, the IGP receiver being very happy. I feel bad about the differences among them.

What I want the CHAHA project to take up is to spread awareness among the HIV positive people and help them get jobs no matter literate or illiterate. I want CHAHA to spread awareness amongst the drug users and sexually active people and make them aware.

There's nothing to cut in project CHAHA instead we can add more activities. Organising picnics for children, more creative activities, organizing drawing competitions, recitation and telling them more about HIV awareness are some of the activities.

The second story, that of **Amita**, (**Box 7**) selected at the national level showed, according to the selectors, how strategies like advocacy and community mobilisation are being implemented. Some steps taken by few staff of the programme may further marginalise the community. Amita's story shows how her pride was affected when the ORW, before giving money for her child's school fee, asked for a receipt. The story raises question about the strategic way advocacy may be done.

Staff in every state reflected on their attitude, behaviour, programme design and the way it is being implemented. The common rejoinder from most of them was, "...*(we) did not expect to hear such negative change stories. Thought we were doing it right. We are doing*

*a lot of sensitisation, awareness and meetings. But we are not doing it right. What is missing is facilitating reflection and providing space for people to ask questions, discuss, debate. We are lecturing, instead.*"

Stories from this domain showed significant gaps in programming in terms of issues like gender, power, sexuality, community participation and ownership. The findings in this domain suggest the importance of life-skills interventions and community mobilisation, especially for those who are subject to ostracism and discrimination. In addition, peer group support among children and caregivers, with sharing of experiences, especially from those who were able to successfully handle such issues, can be valuable.

## Domain 4: Changes in Staff's Capacity

This domain was chosen to reflect SD 3 of CHAHA: 'To create a supportive environment for civil society strengthening and institutional capacity building.' A total of 71 stories were collected in this domain from the staff working at SSR level as Programme Coordinators, Assistant Programme Coordinators, Counsellors and Outreach Workers.

### The significant findings in this domain are:

#### ORWs are reflective, powerful and backbone of the programme

Most stories, especially from ORWs show their deep level of reflection, a seriousness of purpose, and their tremendous contribution in making a significantly large programme like CHAHA work. The stories also reflect a great sense of pride which the ORWs feel. As **Tamil Selvi**, an ORW from Tamil Nadu said, "*In the beginning I worked for salary. After seeing the condition of the children and supporting them, now I really wish to help them wholeheartedly so as to improve the quality of their life.*"

**G. Valarmathi**, an ORW who joined the programme in Tamil Nadu in September 2007 said, "*In the beginning, I was afraid of doing this job, eating at their houses, as it is to do with the deadly disease of HIV/AIDS. I also got my blood tested. But after several trainings on this issue, it helped me to remove my fears. I started interacting more easily and without fear. I am happy that I am a part of making their future brighter*".

**F. Siraj Nisha**, an ORW from Tamil Nadu was equally honest in her reflections, "*When I joined the programme, I knew very little about HIV/AIDS. I was confused about my role; I had lot of questions about how I needed to implement my work. When I start working with children, will I be able to guide them? Will the children like me? Now I am a proud mother of 70 children*".

It is interesting to mention here that most ORWs have suggested that the support delivery strategy be reviewed – "*we should not provide the same amount to every one as all their conditions are not the same. For example, a family of*



**Table 4:** Sex-disaggregated data showing number of stories from domain on ‘changes in staff capacity’

STATE	Female	Male
Manipur	18	04
Maharashtra	09	03
Tamilnadu	15	12
Andhrapradesh	09	01
<b>TOTAL</b>	<b>51</b>	<b>20</b>

*four children will surely need more than a family with only one or two children. Hence, the amount for each support can be fixed either according to their needs or else according to their monthly income”* said **Tamil Selvi**, an ORW from Tamil Nadu.

Several ORWs reported about the change they experienced at personal level, which has directly impacted their work. **Khangembam Baby Devi** an ORW from Manipur very candidly said that the most significant change for her has been the fact that she is able to control her anger now. *“I used to be very short-tempered. When things don’t work out the way I want or find mistakes, I used to lose my temper easily. But after joining CHAHA as ORW and working with many caregivers and children, I’m now able to control my bad temper. I cannot get angry while dealing with the children and caregivers. They have so many problems of their own. So I learnt to control my anger... This has not only helped me in my work but has also earned me more respect in my family.”* **Peter Dilbung**, an Assistant Project Coordinator (APC) from Manipur stated that the most significant change for him has been the change in perspective about child participation. *“As a father of two children, my only dream was to raise them to what I want them to become in the future. Asking them their needs and desires was not my priority. Instead I only directed and forced them to do things. But today I have changed my thinking. I have learnt that parents must leave options for their children to make their own decisions.”* Peter, further in his story reflected on his own childhood and how that influenced his way of thinking – a childhood devoid

of guidance and space to voice his opinion.

**RK Jashima Devi** from Manipur felt confident enough to apply for the position of Project Coordinator (PC) when it was advertised but is still happy to be an ORW. Her story reflects her pride in the work she is doing, *“I think assessing the needs of the child as well as the family and ability to help them is the most significant change for me because even if I knew their problems before becoming CHAHA’s staff, I could not help them personally. But as I became a staff of CHAHA, I’m able to help them with the project’s fund and for this they gleefully hold CHAHA in their hearts. For example, one child lost both his parents. Out of the four brothers and sisters, two of them are in an orphan house and one of them stays with the relative. This child works in a butcher shop and is earning a living. There is no one for him. Seeing his problems, I helped him. He felt so happy with the support that he said, “I thought there is no one for me but now you are here, sister.”*

**Bharati Devi**, another ORW from Manipur, echoed the same pride as her counterparts in other districts and states. She says, *“The most significant change for me is the thought that community, children and their family members regard me as an important entity in their lives. For example, a Meira Paibi (name of an SHG) secretary who took part in one of the community sensitisation programmes took me to a child’s place who had lost both parents. The child was staying with his uncle and aunt. They kept the child aloof thinking that he is having HIV. In February 2008, I took the child for HIV test in RIMS (Government Hospital in Imphal,*

*Manipur) after talking to the child's aunt. The child was found non-reactive and in March 2008, he was registered in CHAHA. Then CHAHA took care of all his needs... Today, the child is living happily with the family members under proper care. This change is significant to me because people in the community respect me despite knowing that I am living with HIV. Instead of looking down upon me, they come to me to discuss about children in their neighbourhood who need support”.*

There are ORWs who have gone beyond the call of duty and helped people out of the belief that every effort they make helps the person in distress. **Uma Maheshwari**, an ORW from Andhra Pradesh writes in her story, *“Through this project I am able to help children and this is giving me job satisfaction. I always ensure that children should feel free to talk to me, share their feelings and sorrow. With this intention I had taken a child affected by AIDS, Versha who was having a lump on the upper lip. It was growing with her so I took her to Osmania hospital. Doctor suggested that for plastic surgery blood will be required immediately. I got motivated and donated my blood. I feel very happy that due to my help the child got rid of a major problem and is living happily.”*

Many SSRs have recruited ORWs who are living with HIV. This not only reflects their commitment to the issue but can also be seen as an effective way of mobilising communities, and providing an empathetic and safe environment for PLHIV to open up and garner confidence. **Gracy Nazareth**, who joined the programme in 2007 in Maharashtra, does not mince any words when she says, *“The important thing is since I am positive I felt good while working with others like me. I forgot my sorrows and difficulties when I listened to their stories and struggles. When I visited the home of one lady, she was in terrible grief. She used to ask why God has given her such a disease, why is he not giving her death instead. Then I disclosed my status to her and she was surprised to hear my story. She*

**Chandra was kept away from the village by the Panchayat leader and the village people. The village people felt that if Chandra and her family were in the village then the disease will spread to others also. When Chandra's husband died no one came to see or help them. Chandra and her kids took the husband's body to the burial ground and burnt it. This incident broke my heart. I resolved to make a change in that village. Likewise, we conducted awareness camps frequently in the village to get the message across to the people. But the Panchayat leader stopped us from conducting further awareness programmes. Later I participated in a bidding conducted by the panchayat leader and asked for a few minutes to speak. I was given time and I spoke for half an hour on how HIV spreads, doesn't spread, state of the affected people and the problems they face. As days went by there was a discernable change in their attitude. Now the panchayat leader and the village people are ready to do any emergency help for Chandra. This is what I consider the most significant change in the CHAHA project where I work.**

**(Excerpt from Bhuvaneswari's story  
PC, Tamil Nadu)**

*calmed down. She could not believe that I also live with HIV. We got solace after sharing our stories. We felt relieved and our confidence also increased. She left the thought of committing suicide after knowing about me.”*

### **Enhanced skills in several areas such as inter-personal communication, networking, knowledge on HIV/AIDS**

Almost all the stories show that staff members feel their skills in specific areas have improved significantly. Staff at PC and APC levels reported their most significant change has been their



enhanced programme management skills that encompass better communication with partners, ensuring timely implementation of activities and generally more enhanced interpersonal relationships skills.

**Longjam Elena Devi**, from SASO, who joined CHAHA in June 2008 (but has been with SASO since 1994) reported that her skills in facilitation have improved significantly. She says that with the introduction of the Life Skills module, she has seen herself becoming more confident in facilitation and in interacting with children using different methodologies.

Most stories talk about their significantly enhanced self-confidence, especially in meeting and networking with doctors and government officials. As **M. Shahjahan**, a PC from an SSR in Tamil Nadu stated, *"I have built my skills in interacting with people, mainly with the government. This change is very significant to me as it helps me in implementing activities effectively. For example, we have been able to establish such a relationship, if we write to a government office using the PACHE TRUST letter pad, they will provide immediate help to the person carrying that letter."* **Velladurai**, a Counsellor who joined the programme in September 2008 said that his skills in talking has increased, *"My capacity in preserving secrets has improved. I have learnt that only sweet and soft words can be the method of counselling!"* **Robita Devi**, an ORW echoed the opinion of several ORWs from other places too when she said, *"I am more confident now for example, in meeting doctors and technicians in the hospitals and creating linkages for the project."*

**L Shabana**, an ORW from Manipur proudly said, *"I learned to believe and trust myself better."* Preety from Maharashtra reported, *"I believe my self-confidence has increased. I feel this as an important change. I was under stress initially to go to people's place and give them the*

*information. Gradually as I started to work and attended trainings, it increased my self-confidence. I was able to arrange support group meetings in the community and put my point in front of the people. If I had no self-confidence then I would not have been able to work, especially with children on this subject. And I believe the self confidence helped me to grow and I moved from being an ORW to a Counsellor."*

## Need felt by staff to revise some of the current programme strategies

Four areas that need to be strengthened, as identified by staff from all the four states are:

- i. **Community Mobilisation:** Several staff, across hierarchies recommended that the community mobilisation strategy be strengthened. As **Chandrashekharan** from Tamil Nadu who joined the programme in July 2008 puts it, *"For the success of CHAHA, we must create a situation where general community accepts PLHIV and CLHIV as one amongst them and extend their wholehearted support in improving their lives."*
- ii. **Proactive engagement of children:** **K. Sugaraja** (a management level staff from Trichy) echoed the same view as most staff from all states, *"the project should give importance to the psychological aspects of children and provide necessary skills to staff members to strengthen the area of child counselling and support group."*

**A. Solairaj**, a Counsellor who joined the programme in August 2007 has several recommendations, including *"forming of district level Children Support Group by mobilising children at block levels; strengthening capacity of children to be able to go for treatment on their own, thus ensuring ART adherence; exposure visits to government offices so that they learn how it works and also provide interface between children and the government*

officials.” **Bharathi Devi**, an ORW from Manipur reiterates, “*Child counselling is needed to improve children’s quality of life.*” **Peter**, an APC in Manipur recommended that the programme should increasingly invest in advocacy at the national, state and district levels, focussing on children’s right to actively participate in development. He also recommended more training on child rights and child counselling for all CHAHA staff.

It is significant to note here that recommendations from several caregivers, especially single mothers echoes the need for more child-focused counselling and general programming. **Soibam Leikai**, a single mother from Manipur says, “*I want the project to organise counselling programmes for children in order to make them understand why they are taking ART. Before the children grow up and question us, I want the project to do frequent counselling. I want the children to know that they are going to take the medicine for their entire life. I have heard that sometimes children commit suicide when they come to know they have HIV and have to take life-long treatment. I am worried my children would kill themselves.*”

Many stories in this domain, from ORWs, recommended fun activities, like picnics, excursions, competitions, sporting events for children and reflecting on the need for investing in the holistic development of children living with HIV.

- iii. **Working with adolescents, especially girls:** The need to work with adolescents has come up in all the States. Several stories depict the vulnerability of the adolescents and the potential for them to get into a vicious cycle of exploitation, poverty, vulnerability to violence, addictions, infections and disease. **Anitha**, an ORW from Andhra Pradesh, based on her extensive interaction with adolescents in

the communities she works in recommends that adolescent girls and boys need training on sexual and reproductive health.

- iv. **Evidence based advocacy, including more cohesive coordination/linkage between national-state-district levels:** Several stories show the importance of evidence-based advocacy and the need for strengthening coordination efforts at district, state and national levels. **Roli** from Manipur points out, “*In states like Manipur where many government programmes are not functioning very well, the programme needs to look into it and review its strategy. For e.g. Integrated Child Development Scheme (ICDS) is not working well in the project but there are many church-based organisations that provide supplementary nutrition to children. We should be given merit for linking with them.*” **Raut Vijaya Laxman** from Maharashtra commented, “*Meetings should be held between SR/SSR, ICDS office, ART centre, and NGO.*” This point not only highlights the need for coordination mechanism at the district and state levels but also a strategic advocacy strategy encompassing all three levels (national, state, district) to raise issues of importance and take timely action.

It is interesting to mention here that few staff from Sneha Bhavan in Manipur, an implementing organisation, have shared the importance of “spiritual support” to PLHIV/CLHIV. As **Ayang**, an ORW from Manipur, says, “*Though the clients receive care and support, yet they always seem to be lacking something. But when they are consoled and are provided with spiritual succor, they are content.*”

## Story selection

Out of 71 stories received in this domain, Peter’s story was selected by national level selectors (**Box 8**). The reasons given by most of the

## Box: 8

### CHANGE IN STAFF'S CAPACITY

MSC story selected at the National Level

**Name of the storyteller** : Peter Dilbung  
**Location** : Chandel, Manipur  
**Organisation** : Sneha Bhavan  
**Note taker** : Self  
**Date of recording** : 29th July, 2009

I joined Sneha Bhavan as a volunteer in the month of March 2007. CHAHA project was launched in the month of June 2007 and I was offered the post of an outreach worker. After which, I was promoted to the post of a counsellor in the month of September 2007 and further I was given a chance to take up the post of an Assistant Project Coordinator.

Some of the changes in my capacity that has resulted from CHAHA, in the past 24 months are:

Communication Skills: both verbal and non-verbal have improved through field visits, contacts with various community leaders, sharing among staff and trainings organised under CHAHA.

Treatment knowledge: especially basics of HIV/AIDS which include HIV life cycle, testing and disclosure, OI treatment and the functions of ARV drugs.

Overcoming self-stigma: in the past, I thought HIV is a curse from God but now I understood it is like any other disease.

Child Participation/Child Rights: Dealing with children I learned through Children Support Group meetings, formal and informal child counselling sessions and LSE trainings and sessions.

Among the entire changes I have listed above, 'Child Participation' is the utmost change I have experienced in my entire life. As a father of two children, my only dream was to bring up my children to what I want them to become in the future. I always thought that achieving my dreams will be the only fruit of life that will bring me happiness. Asking their needs was not my priority instead I only wanted to direct them and forced them to do things. But today I have changed my dreams to the opposite and believe every child has his/her own rights and parents must help their children in choosing their needs and wants. Parents must leave options for their children to take their own decision.

I chose this change because the word 'participation' itself meant a lot to me because since childhood, I was never involved in the family meetings and any other meetings in the village. As a single orphan (my mother had died), I was left alone. No one was there to guide me or correct me when I did something wrong. I also never experienced any appreciation from anyone maybe because I was too naughty. Another reason could be that I didn't have proper place to stay as I was usually away to my uncle's or aunt's house. Thus, my life was like a piece of paper blown by the wind everywhere. Anyone could use it but I didn't know how to use it myself.

The reason child participation is significant to me is, even though I am a father of two kids I feel like I am regaining all the necessary skills I should have learned during my childhood days. I learned many skills which make me become a good parent and a good friend of my children. Whenever I see a child, I try to play and talk to them. This has become part of my daily activity at home and in the field which I never did before. Helping a child take his/her own decision by giving them options to choose is my only vision. This is what I love to do more than anything else with children.

My recommendations for CHAHA are that advocacy programmes to address the issues of children at the national, state and district level need to improve. More training on child counselling and child rights is required by the CHAHA staff. My only hope is that CHAHA project will surely be replaced by another scheme or project from some other source for the sustainability of the clients CLHIV/CAA and positive people as a whole.

**"May the CHAHA TREE stretch her branches like my loving mother's arms; underneath, may we enjoy her fruit of love".**

selectors at the national level was that the change depicted in this story is at an intrinsic level. The person has been able to utilise the learnings from trainings and his work in reaching a stage where he truly believes in child participation and child rights. It just does not pertain to becoming a better manager or champion of HIV/AIDS but is translated in his way of associating with his own children as well.

Peter's story also reflects the professional growth he has undergone and that his abilities were duly acknowledged to promote him from a volunteer to an ORW to a counsellor and now an Assistant Programme Coordinator. He is a key resource that the organisation would harness and communities would benefit from, even after the programme is over.

# Recommendations

## Strengthen the current community mobilisation strategy

As the stories in all domains reflect the persisting stigma and discrimination in communities, and the communities' dependency on the programme, there is a need to review the approaches of community mobilisation and participation in CHAHA.

The role of community leaders, family members and service providers should be enhanced as it is critical to sustaining changed behaviours. In addition, as communities and their members become more engaged, they can assume new and collective roles in decision-making

### **Inclusive community mobilisation is . . .**

- \* Working with the whole community - women and men, young people, and children
- \* Seeking to encourage individuals as well as the community to embark on a process of change.
- \* Using multiple strategies over time to build a critical mass of individuals supportive of an approach based on rights and responsibilities
- \* Inspiring and creating a sense of citizen action among a cross section of community members
- \* Comprehensive and dynamic

### **Community mobilisation is not . . .**

- \* Only raising awareness; Only training
- \* Ad hoc or sporadic
- \* A series of one-off activities being ticked off
- \* Pointing fingers, blaming, assigning fault
- \* Top down programme implementation by an NGO to a community
- \* Neat and completed within short timeframes

around allocating resources, planning programmes, defining policies, and ensuring their right to quality services – an approach that is based on rights and responsibilities.

It is recommended that religious leaders, once trained, can be proactive agents of change; and that community leaders, once sensitised, will be able to mobilise communities effectively.

Several examples and enough evidence from the world over, including India, highlight the significance of engagement of men and boys in health interventions with a gender perspective, which resultantly change attitudes and behaviour. Interventions with such target groups should include a systematic analysis and understanding that patriarchy, gender roles, and social norms, are the source of inequality and oppression and influence the behaviour of individual men and boys, and that such behaviour can be changed.

## **Innovation and skills required for working with young people and children**

The exercise of sharing Significant Change stories and drawings in groups of children, helped them share their feelings, fears and issues – a space they seldom get in their communities. There is need to review the current strategy of providing emotional support through children support groups and providing them a safe and enabling space within this set-up. As was seen in this study, when provided a safe and non-judgemental space, children blossomed in their expressions through their drawings and stories. Very poignant descriptions of drawings were found in the study, as seen from the examples below:

*“Due to over heat and sun light, flowers are crying and they are drying. No one*



*is coming forward to even fetch water for the flowers.”* (9-year old from Andhra Pradesh, who lives with her widowed mother in a hut which leaks in the monsoons).

*“The picture is expressing that a bird is waiting to go home. It expresses the fact about the stronger dominating the weak.”* (Oinam Rohit Meitei, 13 year).

It is recommended that the specific needs of children of different age groups should be recognised and accommodated in HIV and AIDS interventions. The different experiences of childhood with respect to HIV and AIDS, poverty, and of participation of girls and boys of different age groups need to be understood as the starting point for interventions with children. For instance, the study saw several children expressing their concern with drugs and war in Manipur; in other states the study saw how poverty is an unflinching reality in the lives of numerous children and even getting two square meals a day is a challenge, especially those without parents. Although such gaps have been addressed by CHAHA, however their sustainability remains the question.

Comprehensive sexuality education that promotes sexual and reproductive rights, gender equality and skill development for all children and youth is essential. Given the patriarchal contexts in most places where CHAHA is being implemented, children in general, especially girls, should have access to reproductive health information and appropriate services.

### **Integrate an understanding and analysis of gender, sexuality and power in CHAHA**

Reviewing CHAHA programme design from the perspective of gender norms, social construction of gender and sexuality, and how these influence the behaviour and attitude of men and women, girls and boys—is recommended. The Monitoring and Evaluation of CHAHA should measure changes in a sex-disaggregated manner. Reviewing current BCC messages, partnership

agreements, training schedules and modules, using a lens that includes an analysis of gender, sexuality and power, is also recommended. Building capacities of the programme staff across hierarchies in such area is also required. It is recommended to use participatory methodologies to get deeper insights into gender, sexuality and power and how these dynamics affect access to and control over resources – education, food, medical facilities and government schemes.

### **Strengthen coordination mechanisms at all levels**

As CHAHA moves towards greater degree of maturity and visibility, it is important to understand that coordination between various players – both government and non-government at all levels will help reduce duplication of efforts, garner improved support from various actors and to help build an overall climate of shared sense of purpose. Keeping these in mind, CHAHA would be required to play a key role in facilitating and strengthening a systematic approach for sharing of information and to create spaces for open and transparent communication. Being a forerunner in care and support programmes for children and families, improved coordination would also mean sharing of experiences and knowledge with range of stakeholders. It is understandable that due to variety of reasons, some coordination bodies in some areas have not reached their desired level of functioning. In some isolated instances, they are also non-functional. In certain other states/districts, reportedly, there are instances of exclusionary membership to such mechanisms/bodies. This does not bode well for the care and support-related efforts at district and sub-district level. Alliance India can work towards making all such spaces inclusive, transparent, responsive and participatory. Such efforts will require incremental efforts through strategic partnerships backed by mature negotiation by leaderships at different levels – state, district and sub-district.



# Annexures

## Annexures-1

### Story Collection Guide, Alliance India, CHAHA, July 2009

#### Introducing/Explaining to the Story Teller:

We are hoping to capture some stories about changes that may have resulted from the work we are doing. If you are happy with this, I will ask you 3-4 questions and write the answers down in my notebook. Is now a good time to begin? (If not when can we do this?). It should take 20-30 minutes.

We hope to use the stories and information collected from your interviews for a number of purposes including:

- \* to help us understand what participants think is good and not so good
- \* to make improvements to our work and learn from your experiences
- \* to tell our funders what has been achieved.

#### Confidentiality:

We may like to use your stories for reporting to our donors, or sharing with other participants and trainers:

Do you (the storyteller)

- |   |     |    |
|---|-----|----|
| 1. Want to have your name on the story            | Yes | No |
| 2. Consent to us using your story for publication | Yes | No |

#### Contact Details:

Name of the storyteller:

Name of person recording story:

Location:

Date of recording:

*\*(if they wish to remain anonymous, don't record their name or contact details – just write some description about them).*

#### Interview:

1. Tell me how you (the storyteller) first became involved with the project and your current involvement.
2. Please list the most important/significant changes:
  - Domain A: In the quality of your life
  - Domain B: In the level of your participation in the project
  - Domain C: Negative changes

that you feel have resulted from the project (you can list as many as you want to)

3. From your point of view, select the most significant/important change out of all the changes you listed above. Please try to describe this change in the form of a story (by giving examples).
4. Why did you choose this change in particular? (Why was it significant for you)
5. What recommendations do you have to make - what should the project be doing more or less of?

## Annexures-2

### Capacity Building, Story Collection Guide, Alliance India, CHAHA, July 2009

#### Introduction:

We are hoping to capture some stories about changes that may have resulted in your capacity as a result of being part of CHAHA. We want you to be **reflective, honest and critical in your response**. This will help us to learn and improve our work.

#### Confidentiality:

We may like to use your stories for reporting to our donors, or sharing with other participants and trainers:

Do you (the storyteller)

- |   |     |    |
|---|-----|----|
| 1. Want to have your name on the story            | Yes | No |
| 2. Consent to us using your story for publication | Yes | No |

#### Contact Details:

Name of the storyteller:

Location:

Date of recording:

#### Questions:

1. Tell me how you (the storyteller) first became involved with the project and your current involvement.

---

---

2. Please list the most important/significant changes in your capacity that you feel have resulted from the project (you can list as many as you want to)

---

---

---

3. From your point of view, select the most significant/important change out of all the changes you listed above. Be very clear and precise by giving examples to substantiate your opinion/view.

---

---

---

4. Why did you choose this change in particular? (Why was it significant for you)

---

---

---

5. What recommendations do you have to make - what should the project be doing more or less of?

---

---

---



A global partnership:

**International HIV/AIDS Alliance**

Supporting community action on AIDS in developing countries

For more details, please write to:

India HIV/AIDS Alliance

Third Floor, Kushal House

39 Nehru Place

New Delhi 110019, India

Tel: +91 11 41633081

Fax: +91 11 41633085

E-mail: [tchhabra@allianceindia.org](mailto:tchhabra@allianceindia.org)

Website: [www.aidsalliance.org](http://www.aidsalliance.org)

SETU, Virtual Resource Centre – [www.aidsallianceindia.net](http://www.aidsallianceindia.net)