Supporting community action on AIDS in India

The Future of Care & Support for Children Infected and Affected by HIV in India

Reflections on the experience of CHAHA

"Before joining CHAHA I faced difficulties in getting materials to go to school, but after joining CHAHA, such problems became fewer. The most significant change is that I can come out and talk to other people. I was scared to go out and play with others, but that fear is gone" Tracy, in a study using Most Significant Change methodology[1]

In March 2011, Alliance India's child centred care and support programme for families, CHAHA, supported through Round 6 of the Global Fund, will have reached its target of providing services to 64,000 children infected and affected by HIV, covering four of India's high prevalence states. After April 2011, if nothing changes between now and then in terms of funding, the programme will stop, and the children and families will receive no more care and support services.

The potential closure of the CHAHA programme roughly coincides with the ending of funding streams for India's other major care and support programmes for children supported by the Clinton Foundation and Family Health International. There is a need therefore to understand the impact of these programme closures on children and on the HIV response in India more generally.

[1] Stories of significance, understanding change through community voices and articulations, a report based on an evaluation of CHAHA by means of 'Most Significant Change" technique, Feb. 2010, www.aidsallianceindia.net

What is clear at the time of writing is that the National AIDS Control Programme is not yet able to absorb the care and support functions these programmes are providing. The political will is there and the government is investing time and resources into designing and piloting models for care and support, but these models will neither be fully tested nor rolled out in time to take over the children supported by CHAHA or partner programmes. Also, as this report will suggest, there are aspects of care and support that cannot be absorbed by health systems and sit better in civil society mandates.

As the care and support programmes draw to a close, it will be important for government, UN agencies and civil society organisations to learn collectively from the various experiences of delivering care and support to children over the last four years, and to determine what future support programmes should look like. This report is an attempt to contribute to these discussions through highlighting some of the lessons learnt, both positive and negative, from implementing the CHAHA programme.

The report is divided into two short sections. The first outlines lessons learned based on qualitative feedback from community representatives. The second discusses the data collected from Operational Research and the Midline Survey, and suggests tentative conclusions deriving from this data.

Lessons Learned: Community Voices

Feedback from the community pointed to four main lessons. The first is that care and support often has to begin with emergency support. We had not fully appreciated in the original programme design that we would be faced with women and children headed households who would require immediate stabilization interventions before we could open a dialogue about longer term support and health seeking behaviour. Neither the government's social welfare system nor its HIV programmes are designed to respond to such a challenge.

"….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."

…G. Manga, 25 year old widow from Andhra Pradesh

Children headed households, or children living with grandparents, or widows coping alone, are all particularly vulnerable to the social, economic and health pressures of living with HIV. Within the CHAHA programme our data shows that 35% of the households are headed by women and 8% by orphaned children. Widows experience particularly higher levels of stigma which deters them from working or accessing services. In CHAHA, our outreach workers have learned that it is offering to provide immediate assistance to address emergencies that allows for a long term relationship to be built, that can in turn lead to addressing issues of testing, disclosure and adherence.

"…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."

…Grand-mothers from Tamil Nadu and Andhra Pradesh who are caretakers for their grand children.

The second lesson is that even when people are informed of services and have potential access to them, stigma and discrimination continue to act as the most significant barriers to testing, disclosure and accessing ART[2]. Therefore priority has to be given to sensitisation of communities, their leaders and service providers. This requires a proactive campaign of "normalising" HIV that cannot be managed by health systems alone. Equally important, is the attention that needs to be given to children and their families in overcoming the self stigma that prevents children from feeling entitled and able to participate in school life, work, friendships etc. Again, this is a need that must be addressed by seeking out children and spending time with them, and not by waiting for them to turn up at health care centres.

"….for the success of CHAHA, we must create a situation where general community accepts PLHIV as one amongst them and extend their wholehearted support in improving their lives."

…Chadrashekharan, an outreach worker from Tamil Nadu

The third lesson is that child centred programmes need to consider the inter-relationship between a child's welfare and the welfare of their family, including siblings. The confidence to test a child and disclose status and the ability to care for a child and ensure sufficient nutrition both depend on the psychological wellbeing and economic viability of the household in which the child lives. Families of children infected or affected by HIV are often under considerable stress due to the loss of a parent and wage earner, and due to the stigma associated with HIV, and perhaps additional stigma associated with sex work or injecting drug use in the case of key populations. Even child centric programmes therefore need to be family centric and to look beyond the immediate health needs of the child, and to consider how to help the household in which the child is growing up sustain an environment in which treatment and social inclusion is encouraged.

[2] Facilitating HIV testing and disclosure with children and adolescents, A report on operations research conducted in CHAHA, June 2009

Finally, we should have paid more attention to sexual and reproductive health (SRH). Thanks to improved access to ART, we are now working with a generation of young people living with HIV and of a sexually active age. They will have partners and will get married. They may well be vulnerable to exploitation. They have a lot of special needs and fears around SRH that are not being adequately addressed in CHAHA or anywhere else.[4]

"….we do not get information about sex hence I feel that sex education should be provided through the organisation."
…Jeevan Bhanudas Jadhav, an 18 year old boy from Maharashtra

Operational Research and Midline Data

While the qualitative data suggests that care and support for children does add value, such data may appear less convincing to those primarily interested in understanding whether these programmes should be prioritised as part of a national response to HIV.

To answer this challenge, Alliance India has collected data to consider the relationship between care and support and the uptake of services.

1. Improvement in testing, ART registration and adherence to treatment

It is estimated that about half of the children born with HIV die before they are two years old.[3] There are two main, inter-related causes behind this shocking figure: firstly, the lack of timely diagnosis of HIV, and secondly and consequently, the lack of access to treatment.

Care and support programmes seek to address both of these issues. Table 1 shows the number of children accompanied for HIV testing within CHAHA. The high numbers of children who are tested positive demonstrates that the programme is identifying the children most vulnerable to HIV. Without this testing, their life expectancy would be much lower. Care and support then, would appear to increase the survival of children by facilitating early diagnosis.

Graph 1 compares a baseline and midline of a sample of children across four states where CHAHA is running. In two states, Andhra Pradesh and Manipur, the data does not point to a significant difference in ART adherence, but in two states and in total, an increase in adherence is evident. The programme has adapted to these figures by ensuring a thorough tracking of children according to national guidelines to promote adherence. It is hypothesized that children who are regularly contacted by outreach workers are less likely to be lost to follow up on ART and more likely to adhere to treatment. Graph 1 suggests support to this hypothesis but would need to be compared to data from non-CHAHA districts before attribution could be claimed.

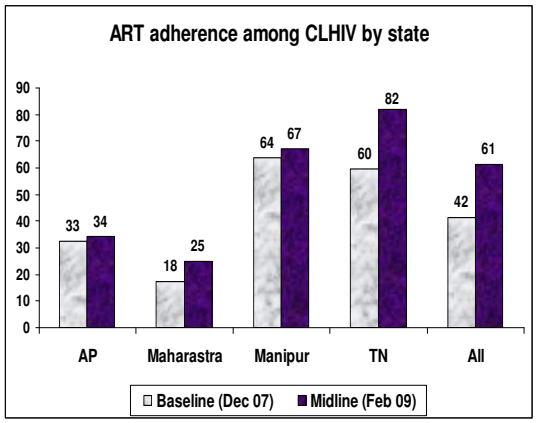
Table 1: CMIS data of CHAHA on children referred for testing (December 2009)

	Number of children tested	Number of children tested Positive	Number of children on ART
Manipur	233	33	285
Tamil Nadu	662	72	184
Andhra Pradesh	3871	434	790
Maharashtra	1916	417	1436
Total	**6682**	**956**	**2695**

[3] Guidelines for HIV Care and Treatment in Infants and Children, National AIDS Control Organisation, GOI. November 2006

[4] All quotes from Stories of significance, understanding change through community voices and articulations, a report based on an evaluation of CHAHA by means of 'Most Significant Change" technique, Feb. 2010

Graph 1: ART Adherence data from CHAHA Baseline and Midline



2. Support to parents and children for testing and disclosure

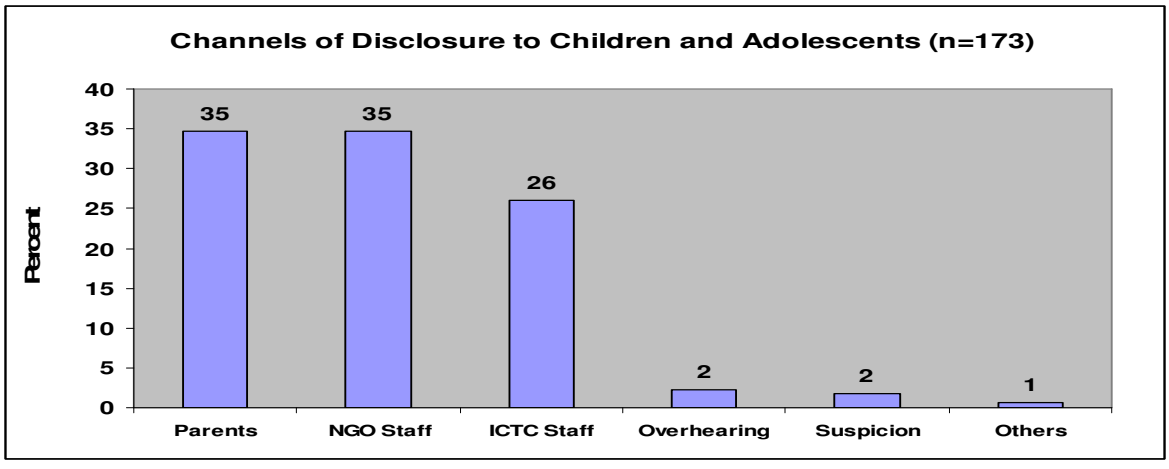
Parents experience deep reservations about disclosing their children's HIV status to their children, and once the status is disclosed, children need support in coming to terms with the news. Interviews with adolescents between 15 -18 years of age revealed that parents who disclosed HIV status to children were mainly those who had come in contact with CHAHA NGOs.

Graph 2 below also shows that it is NGOs, alongside parents, who play the most significant role in disclosure[5]. This would suggest that care and support programmes play a crucial role for both parents and children in coping with HIV status and planning for treatment and the future.

3. Increased access to long term government support and programmes

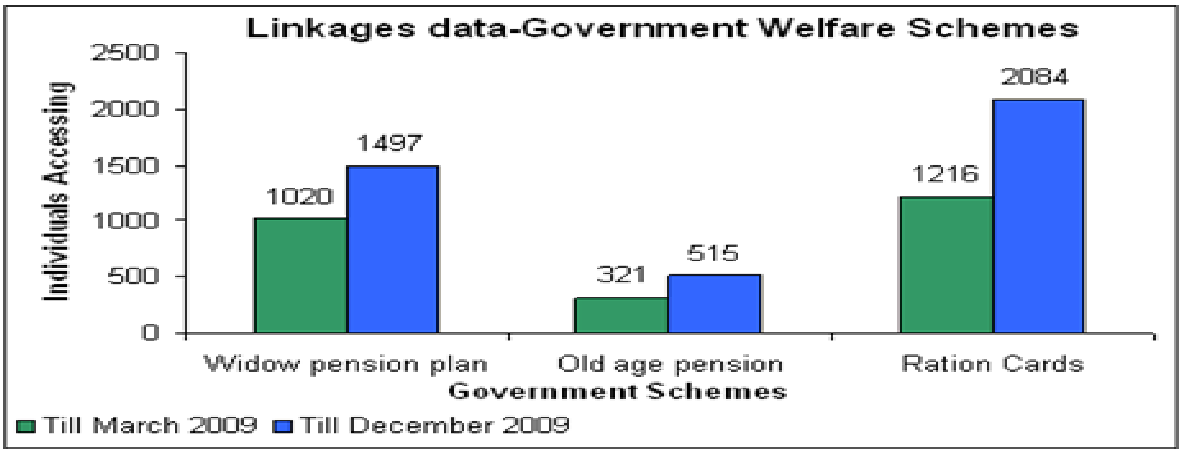
Care and support programmes seek to build bridges between people living with HIV and entitlements to government benefit schemes. This is a crucial part of facilitating sustainable support. For bureaucratic or logistic reasons, or due to stigma, entitlements can be difficult to access. Care and support programmes increase both the capacity of people to demand services but also the capacity of the service providers to provide them. The graphs 3 and 4 below show how uptake of government entitlements has increased for children who are part of the CHAHA programme over a period of 19 months (till December 2009). CHAHA is often the only initiative to help children and their families access these government services in the districts in which the programme operates.

Graph 2: Facilitating HIV Testing and Disclosure with Children and Adolescents, India HIV/AIDS Alliance, 2009

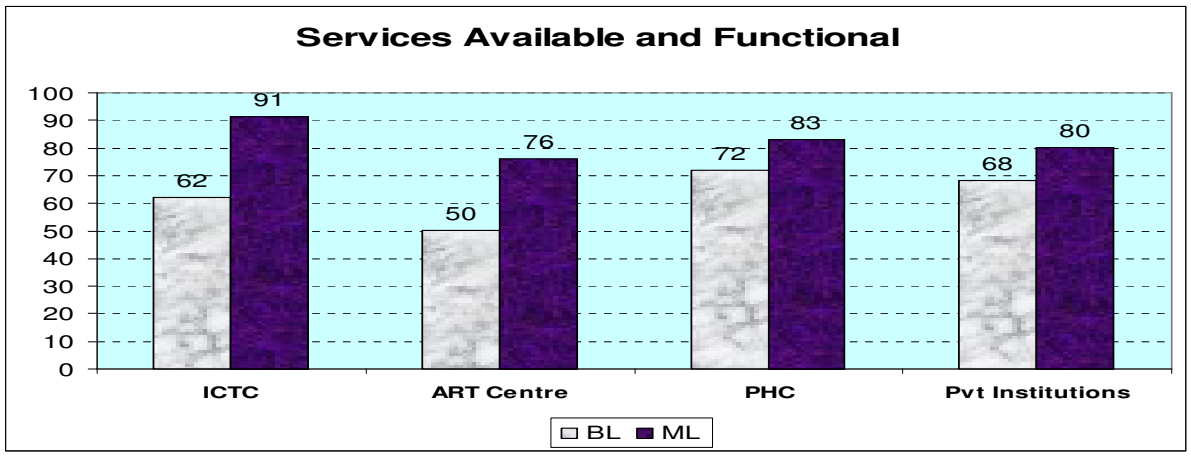


[5] Facilitating HIV testing and disclosure with children and adolescents, A report on operations research conducted in CHAHA, June 2009

Graph 3: CMIS data of CHAHA on linkages with Government Welfare Schemes (December 09)



Graph 4: Linkages to HIV and health services, CHAHA Baseline and Midline



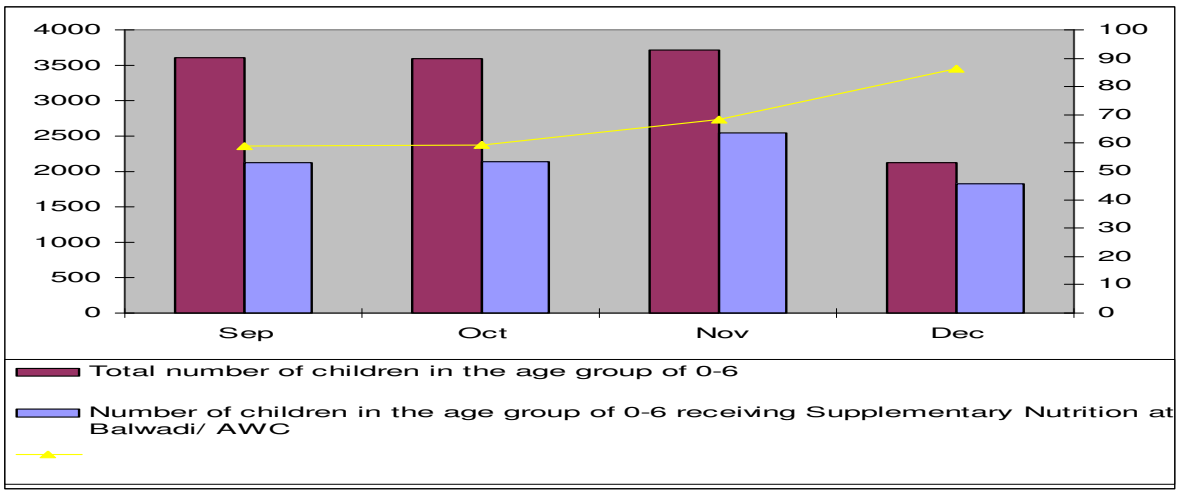
4 Reducing child mortality and morbidity

The lives of young children born with HIV can be saved if they have access to two crucial services - co-trimoxazole (CTX) prophylaxis and supplementary nutrition. Both are essential to strengthening a child's immunity. CHAHA has focused its advocacy in 2009 on ensuring that children do have access to these entitlements.[6]

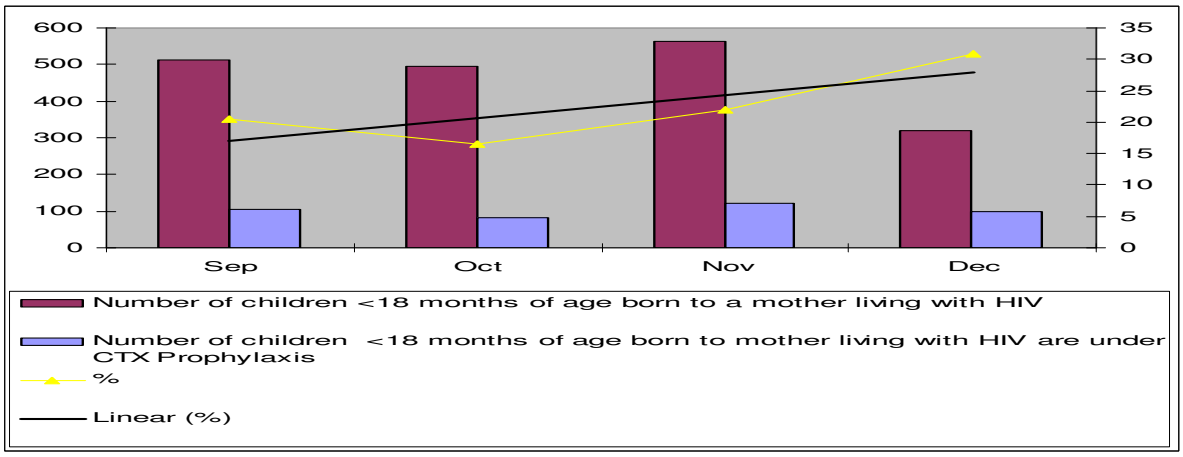
Initial data collection suggests that this focused advocacy is having a positive effect, as we can see from graphs 5-6. Again, this would suggest that in the absence of such care and support programmes, fewer children would access these entitlements and therefore fewer would survive.

[6] Advocacy in CHAHA-Annual Report 2009-10: India HIV/AIDS Alliance

Graph 5: Data collected on nutrition over four months in CHAHA project



Graph 6: Data collected on access to CTX over four months in CHAHA project



Conclusion

We think that this data points to a strong argument in favour of care and support programmes for children. Most evidently, it outlines that government and civil society have separate but mutually complementary roles to play. Civil society generates the demand for services, and the government ensures the supply. If civil society organisations stop their work within communities, especially marginalised communities, then we can expect the update of services to decline, thereby affecting the government's targets in the response.

This is part of a wider argument as to why not all HIV services can be mainstreamed. With widow and orphan headed households especially, there is still a need to reach out and support people in overcoming barriers to exclusion, including those of self stigma. This goes beyond the mandate of health systems and falls into the responsibility of those charged with community mobilisation.