
Supporting Community Action on AIDS in India

**Recommendations from the National
Workshop on Children Living with HIV**
3rd-4th May 2006

The India HIV/AIDS Alliance hosted a National Workshop on Working with Children Living with HIV/AIDS on 3rd and 4th May 2006 in New Delhi. The key objectives of this workshop were to enhance understanding about issues of children living with HIV/AIDS and to develop practical programme and policy recommendations for providing care, support and treatment to children living with HIV.

This workshop was well attended by over 70 participants from 6 states in India. The workshop had representatives from the National AIDS Control Organisation (NACO), WHO, UNICEF UNAIDS, DFID, EU and the Delhi State AIDS Control Society. Programme staff from over 38 NGOS, working in the field of HIV/AIDS, participated in the deliberations of the workshop.

The first day's programme comprised two plenary sessions which focused on providing an overview of the current situation facing HIV positive children in India, current government responses to the situation, and programming responses from civil society. Plenary presentations were made by WHO, UNICEF, Family Health International, the Clinton Foundation, NAZ Foundation India, MAMTA, SEARCH and the India HIV/AIDS Alliance. This was followed by case study discussions and group work on five thematic issues (health & nutrition, stigma & discrimination, education, protection, and psychosocial support), in which children also participated. The second day focused on policy issues relating to positive children. Presentations were made on the key recommendations arising from the group work and on findings from the Alliance's draft Children and HIV/AIDS Policy Review. A panel discussion comprising representatives of government, UN agencies, positive networks and NGOs, further discussed and refined the list of recommendations for practical action from the meeting.

RECOMMENDATIONS

Please note that, where relevant, the main target audience(s) are indicated in square brackets at the end of each recommendation.

General Recommendations

1. Use appropriate language – “children living with HIV”, or “HIV positive” children, never “infected” [all actors]
2. The term “children” covers ages 18 and under, and thus includes adolescents [all actors]
3. Develop monitoring systems and indicators to monitor progress on all the different elements of support for children – including disaggregated data for different age groups, for example 0-5 years, 6-12 years and 13-18 years [Government and UNICEF]
4. Child support groups are a key mechanism and should be extended further [NGOs]
5. Use evidence based approaches, not ideology-led approaches [UNICEF, Government, donors]
6. Avoid supporting vertical parallel programmes and interventions, but strengthen what exists already, using it to integrate new issues such as HIV [donors]
7. Improve mechanisms for sharing information on good practice, recognising differences according to context, between civil society and government [NGOs and Government]
8. SACS need to make sure various government structures are on board and be responsible for informing NGOs what should be done and then be held accountable for what they do. [SACS]
9. Ensure that resources intended for HIV positive children reach them e.g. school-feeding programmes, scholarships [national and state Government]

Recommendations - Psychosocial Support

1. NACP-III should include interventions for age-appropriate psychosocial support which takes into account the particular needs of children living with HIV [NACO]
2. When providing support for people living with HIV, make sure support is also provided to children in the family so they do not feel isolated [NGOs and state/district Government service providers]
3. Strengthen community-based psychosocial support, combined with a referral system to trained psychologists where needed [national/state/district Government]
4. Using existing family counselling structures at community level in India, incorporate psychosocial support for families affected by HIV and AIDS (donors should also not create parallel new structures but support existing ones) [NGOs]

Recommendations - Health and Nutrition

1. Scale up of ARV provision to children living with HIV should include availability of appropriate counselling and testing, diagnostics, paediatric formulations and treatment guidelines [Government, donors and NGOs]
2. Ensure child and adolescent-friendly health services [state/district Government service providers and NGOs]
3. Ensure provision of nutrition support for children living with HIV at anti-retroviral therapy centers and under the ICDS programme [state/district Government and NGOs]
4. Increase the number of health care providers trained in pediatric HIV/AIDS care [national/state Government]
5. Ensure availability of drugs for treating opportunistic infections [national/state Government]
6. Ensure co-trimoxazole prophylaxis guidelines are included in the National protocols [Government]
7. Mobilise local governments and at community level (panchayats), to provide nutritional support – and not be limited to HIV affected children only [state/district Government]
8. Ensure access to Vitamin A supplementation for HIV positive children [NGOs]

Recommendations - Stigma and Discrimination

1. Use appropriate language – “children living with HIV”, or “HIV positive” children, never “infected” [all actors]
2. Ensure communities are well informed about laws and policies that treat children equally and fairly [NGOs]
3. Facilitate advocacy at all levels on behalf of children and young people to ensure that communities address stigma and discrimination and support children’s rights to be treated equally. [NGOs]
4. Children and young people should be allowed to participate in activities and decision-making. They can then challenge stigma and discrimination themselves.
5. Policy on non-discriminatory environment in schools to be upheld by the government. NGOs should play advocacy role to push government at all levels to develop policies. [national/state Government and NGOs]

Recommendations - Protection

1. Train peer educators to identify children in need and to link them with available community resources [NGOs]
2. NGOs should integrate child protection issues in the design of interventions and training of staff, volunteers, and community [NGOs]
3. Develop and strictly enforce policy and practice to protect confidentiality of HIV serostatus [national/state Government]
4. Establish mechanisms to monitor the situation of children in households, including vulnerable families, extended families, foster families, etc [national/state/district Government]
5. Develop and enforce protection policies within institutions and within other types of organizations such as schools [national/state Government]
6. Ensure state Government mechanisms (Commission for Child Rights) address issues relating to children living with HIV [state Government]
7. Testament of will: Recognising the many diverse cultures and religions in India, NGOs should consider emphasis on succession planning instead of wills, especially when working with very poor communities. This approach will safeguard the child better than testament of will, with its emphasis on civil law [NGOs]

Recommendations – Education

1. Chapter on HIV/AIDS should be part of teachers' training (both pre-service and in-service) programme with a specific curriculum, which would include sensitisation of teachers towards children living with HIV and affected by AIDS [NACO, national Government]
2. Education system should be flexible and responsive. This means providing extra and supplementary education support, allowing children to write examination as per availability, not to restrict admission and examination procedures [national Government]
3. Mobilise resources from NGOs and communities to support the educational needs of children (particularly their food, uniforms, study materials etc) [NGOs]
4. Create a positive and supportive environment in schools and community to ensure enrollment and retention of children living with HIV and affected by AIDS. This means facilitating linkages with other government supported programs like mid-day meal, ICDS etc [national/state Government].
5. Focus on reaching children who have dropped out of schools, especially those in child-headed households, with education [national/state Government, NGOs]
6. Link National Open Schools into education system [national Government]
7. Training on HIV and AIDS to both formal and non-formal educators [national and state Government]
8. Non-formal education, vocational education, life-skills training should include HIV and AIDS (NGOs, madrasas, ashrams, street-based schools, Nehru Yuva Kendra Sangathan (NYKS), run by Ministry of Youth) [national/state Government and NGOs]
9. AEDP (adolescent education and development programme) within NACP-III should be linked to non-formal education structures [NACO and Ministry of Education]