Greetings from the Tamil Nadu State AIDS Control Society

According to the National AIDS Control Organization, approximately 50,000 children below 15 years are infected by HIV every year. In addition to those infected, children are affected both directly and indirectly when one or both of the parents become HIV positive. To address this staggering need, the national plan to address HIV/AIDS in India as articulated by NACP-III seeks to strengthen family and community care through psycho-social support, counseling to adhere to the prescribed ART regimen and education against stigma and discrimination associated with the epidemic.

Understanding the need to address the epidemic through family and community support, NACP-III has developed comprehensive guidelines on HIV care for each level of the health system; linkages with social sector programmes for accessing social support for infected children and their families; outreach and transportation subsidy to facilitate ART and follow up, nutritional, educational, recreational and skill development support, and by establishing and enforcing minimum standards of care and protection in institutional, foster care and community-based care systems.

Beginning September 2005, Tamil Nadu State AIDS Control Society (TANSACS) through its Tamil Nadu Family Care Continuum Program (TNFCC) successfully piloted a continuum of care approach to care of HIV infected and affected children by addressing needs of children and parents / care givers, and promoting on-going linkages between clinical, community and home based services. This has led to improved client tracking, comprehensive and uninterrupted services to families; improved levels of adherence to antiretroviral drugs, especially women and children; and successful linkages of clients to government schemes, of which they would otherwise be unaware.

Since its inception, TNFCC has successfully identified and registered around 16,000 people from 12000 families in 10 districts of Tamil Nadu; around 6,000 adults and children were started on ART and the program caters to 1200 infected children and 12000 affected children. A unique feature of the program is provision of effective pre-ART care to delay disease progression and maintain non-ART status for a longer period, while ensuring timely initiation of ART when needed.

TANSACS acknowledges SAATHII for its technical assistance to the program, Duke University for monitoring and evaluation, The Children’s Investment Fund Foundation for funding support, and all the TNFCC-associated ART centers, field NGOs and hospital NGOs for effective implementation.

This home-based care mentorship report is a process document that describes how the Technical Assistance team of SAATHII and the core NGO team comprising of project coordinator, counsellor and community health nurse, has built the capacity of outreach workers to provide home-based care. This document is intended for the program managers and NGOs implementing care and support programs in the community and provides the information on how to offer mentorship to outreach workers so they may provide quality home-based care and ensure minimum standards of care.

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TNFCC Program Background

Tamil Nadu has pioneered several initiatives and been a step ahead in HIV/AIDS prevention, care, and support. It has the distinction of being the first state to respond aggressively to demands placed by HIV epidemic on both government and other structures. Owing to high degree of political and administration commitment to control the epidemic and improving quality of life for PLHIVs and their families, several initiatives such as ICTC, PPTCT, targeted interventions, care & support programs, Community Care Centers and ART services have been initiated in the state over the years.

Tamil Nadu Family Care Continuum Program [TNFCC] is one such initiative being implemented by TANSACS with funding support from The Children’s Investment Fund Foundation [CIFF], Technical Assistance from Solidarity and Action Against the HIV Infection in India [SAATHII] and Monitoring & Evaluation assistance from Duke University since September 2005. The program was conceptualized with the objective of accelerating access to treatment and providing care and support services through a comprehensive approach involving public private partnership. TNFCC is implemented through 3 government hospitals in collaboration with 12 NGOs, CBOs and Networks of People Living with HIV across ten districts of Tamil Nadu.

Program Goal:

The program goal is to reduce HIV related morbidity and mortality and to improve the quality of life among children infected and affected by HIV/AIDS and their families through an innovative model of integrated clinical, nutrition, psycho-social and home-based care program.

Program components:

The program involves hospital and field component which has a wide range of services to both infected, affected people and ensures universal access to care, support and treatment.

Hospital staff (TNFCC Centers) provide routine medical care including DOT for TB, VCTC and PPTCT services, treatment for STDs, treatment for Prevention of Parent to
Child Transmission, diagnosis and treatment of opportunistic infections, antiretroviral therapy, in-patient care, laboratory-monitoring services, CD4 cell counts analysis, referral to various medical services including gynaecological, mental health, dental and ophthalmologic services and pediatric specific care for children.

Hospital NGO staff who are based at all three TNFCC centers provide counseling, treatment preparedness, psycho-social support, nutrition assessment and counseling, adherence monitoring and counseling, treatment literacy, out reach services, infection control, nursing and pharmacy services integrated with the clinical services provided by the hospitals, hospital sensitization programs to integrate HIV care, and also provide referral to income generating activities, legal, housing services etc.

Field NGO staff based in 10 districts identify and refer patients from the districts to TNFCC center, ensure access to routine and emergency medical care within the proximity to their residence, conduct follow-up home visits for home visit consented family to educate the patient and care givers on HIV care, OI identification & management, follow-up on adherence to treatments and nutrition supplements, work towards reducing HIV associated stigma and discrimination, conduct support groups in the community, referral to various non clinical services, facilitate child focused intervention and involve the communities.

*Flow chart describing Hospital based services:*
Flow chart describing Field Based Services:

- Mapping and Linkages
- Clients' identification and
- Enrolment at the hospital and consent for home-based care
  - Home based care for consented clients
  - Child Focused Intervention
  - Support group for adult and children
  - Community sensitization and resource mobilization

Service Delivery at the field level

Client wise information sharing to
Flow chart describing TNFCC Program Structure:

- **TANSACS EXECUTIVE COMMITTEE**
- **Technical Assistance (SAATHII)**
- **PROJECT STEERING COMMITTEE**
- **Monitoring & Evaluation (Duke University)**

**Program Implementation**

**Hospital based services**
- Counseling
- Nutrition counseling
- OI screening and management
- CD4 testing
- ART preparedness and ART initiation
- Referrals to clinical services
- Linkages to field NGOs

**Local operational committee**

**Hospital and NGO coordination**

**Information sharing**

**NGO/CBO Partners**
- Home based care
- Support group
- Adherence monitoring
- Referrals and linkages
- Facilitating community ownership
- Child focused activities
Home-based care is one of the core components in TNFCC program which, ensures comprehensive service delivery to PLHIVs and their families, facilitates linkages to various services including medical, and community based resources. The primary goal of the home-based care is to improve the quality of life of PLHIVs & their families, create community structures and build family and community ownership in combating HIV.

**Progress of Home-Based Care in TNFCC program:**

<table>
<thead>
<tr>
<th>Year I [Sept’05 to Aug’06]</th>
<th>Year II [Sept’06 to Aug’07]</th>
<th>Year III [Sept’07 to Aug’08]</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Major focus areas</strong></td>
<td><strong>Major focus areas</strong></td>
<td><strong>Major focus areas</strong></td>
</tr>
<tr>
<td>Client identification</td>
<td>Focus shifted from home visit to home-based care</td>
<td>Comprehensive home-based care services ensured for all clients consented for home visit</td>
</tr>
<tr>
<td>Enrolment at the hospital</td>
<td>Formats and registers were developed to capture key home-based care indicators</td>
<td>Referrals and linkages to various services tracked and strengthened</td>
</tr>
<tr>
<td>Home visit to ensure hospital follow up, adherence to ART, Micro, Macro and OI drugs</td>
<td>Needs identification and referrals to various services expanded</td>
<td>Analysis of key indicators such as discordant to concordant, disclosure status, HIV testing status, self care training, care givers training status were strengthened and data usage ensured</td>
</tr>
<tr>
<td>Motivating HIV test for children and spouse</td>
<td>Capacitating PLHIVs and care givers through home visit and training intensified</td>
<td>Qualitative review of home-based care components addressed gap areas</td>
</tr>
<tr>
<td>Data were captured in daily dairy</td>
<td>Patient tracking system was established to track patient progress</td>
<td>Patient wise information sharing to hospital strengthened and streamlined</td>
</tr>
<tr>
<td>Home based care, needs identification, referral and linkages were limited</td>
<td>outreach workerclient ratio adjusted</td>
<td>Onsite mentorship by TA, project coordinators, child counselors, Community Health nurse intensified</td>
</tr>
<tr>
<td></td>
<td>Child focused services intensified</td>
<td>ORWs were capacitated in documentation and data usage</td>
</tr>
<tr>
<td></td>
<td>Patient wise information sharing to hospital initiated</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Onsite home-based care mentorship by technical assistance</td>
<td></td>
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</tbody>
</table>

The various services provided under TNFCC home-based care program is detailed in the diagram below. The activities are primarily done by outreach workers and supported by project coordinators, child counselors and community health nurse.
TNFCC Home Based Care Activities

- Child focused activities
- Rapport Building and exploring family status
- Needs Assessment
- Psychosocial support
- Facilitating Disclosure
- Promoting positive living
- Care givers identification and training
- OI identification, management
- Adherence counselling and monitoring
- Tracking clients progress
- Ensuring accessibility to hospital services
- Providing palliative care
- Referral and linkages
- Facilitating formation of support group

- Referral and linkages
- Ensuring accessibility to hospital services
- Providing palliative care
- Adherence counselling and monitoring
- Tracking clients progress
Mentorship Concept

Mentorship is a well known concept established in majority of the field primarily to strengthen knowledge and skills of an individual in a particular field or component.

A mentorship is a supportive relationship established between two individuals where knowledge, skills, and experience are shared. The mentee is someone seeking guidance in developing specific competencies, self-awareness, and skills in early intervention. The mentor is a person who has expertise in the areas of need identified by the mentee and is able to share their wisdom in a nurturing way.

In this relationship, the mentee has the opportunity to ask questions, share concerns, and observe a more experienced professional or parent within a safe, protected environment. Through reflection and collaboration between the mentor-mentee pair, the mentee can become more self-confident and competent in their integration and application of the knowledge and skills gained in the mentorship demonstrating best practice. (Source - Family Support Network of North Caroline)

The mentorship established between two individuals is unique to their needs, personality, learning styles, expectations, and experiences. Mentorship can be defined in numerous ways:

"Providing regular opportunities for individuals and groups, less experienced and more experienced, in training and service settings, to reflect together about their hands-on work." (Fenichel, 1991)

"A protected relationship in which learning and experimentation can occur, potential skills can be developed, and the results measured in terms of competence gained rather than circular territory covered." (Boston, 1976)

Mentorship is a process whereby an experienced, highly regarded, empathetic person (the mentor), guides another individual (the mentee) in
the development and re-examination of their own ideas, learning and personal and professional development” - American Standing Committee on post graduate Medical and dental Education’s support.

Rationale for implementing Home Based Care mentorship:

Since the inception of the program the outreach workers and staff in TNFCC program undergone various trainings [Annexure I - List of trainings and technical updates provided] and technical update sessions. The knowledge and skills learnt through these trainings has to be translated into field implementation. Support monitoring visits, review of monthly technical report, focus group discussion on understanding home-based care component, and baseline knowledge assessment revealed greater need for handholding, and onsite mentoring to strengthen outreach worker knowledge, skills and practice. There was also greater need for developing uniformity in service delivery, strengthening program quality and developing mentorship skills within the implementing organization. This has effected in initiating the home-based care mentorship program.

Objectives of home-based care mentorship:

The objective of the home-based care mentorship program was

- To strengthen outreach worker knowledge and skills in implementing home-based care program
- To develop minimum package for home-based care services
- To strengthen documentation skills and data usage

Process and steps

First round of home-based care mentorship:

The first round of mentorship was carried out to all NGOs by the technical assistance team over twelve months, which included assessment of staff understanding on different components of home-based care, existing practices, documentation and usage of data, knowledge assessment, technical update sessions and onsite mentoring through participatory home visits and case discussions. The activity aimed at enhancing their understanding on home-based care, assessing the current practices, areas of improvement and focus, developing their skills and techniques in providing effective home-based care.

The mentorship started with an initial assessment of home-based care practices to all NGOs by the technical assistance team with the following objectives

1. To review the home-based care practices carried out by the outreach workers including documentation
2. To update the staff with knowledge and skills to do effective home-based care
3. To demonstrate skills and techniques to provide nursing care
4. To analyze and brainstorm solutions for the difficult case studies
5. To provide technical assistance in providing home-based care through home visits
During the two days of initial assessment the following activities were carried out by the mentor by applying adult learning principles

- Discussion with outreach workers on the current home-based care practices which included planning home visit, identifying the need, purpose and activities carried out during the visit
- Discussion and review of various topics covered for PLHIVs and Care givers training program
- Review and discussion with staff about the home visit documentation
- Discussion with the staff on writing case studies and best practices documentation
- Technical update session on home-based care using the home-based care guide developed by I-TECH (International Training and Education Centre on HIV/AIDS)
- Mock session by outreach workers on OI Management followed by feedback and demonstration session
- Discussion with staff on difficult case studies and possible solutions
- Participatory home visits with outreach workers and project coordinators
- Discussion with staff and management on observations and areas of improvement

After the initial assessment NGO wise report was prepared using the following grid and shared with partners for follow up.

<table>
<thead>
<tr>
<th>S.No</th>
<th>Programmatic Components</th>
<th>Observations</th>
<th>Recommendations</th>
<th>Proposed Follow up action</th>
<th>Person responsible</th>
</tr>
</thead>
</table>

Overall the following areas were identified for mentorship follow up:

- Capacitating outreach workers in
  - Planning home visit based on the needs identified and tracking hospital key indicators
  - Para-counseling skills [Problem identification, dealing with different situations, appropriate referrals etc…]
  - Case presentation and discussion
  - Patient wise data tracking and usage
  - Capacitating PLHIVs and care givers by following minimum standards and demonstration sessions
  - OIs identification, management and referrals
  - Facilitating disclosure, discussing safe and safer sex practices etc…
  - Needs identification, usage of resource directory and linkages to required services
  - Documentation
- Capacitating project coordinators in
  - Structured program review
  - Facilitating case discussions
Facilitating internal capacity building sessions for outreach workers

Providing onsite mentorship

Onsite mentorship:

Based on the initial assessment technical assistance team did twelve mentorship visits to each NGO which focused on the areas identified for mentorship follow ups. The various activities as part of mentorship included

1. Participatory home visit to clients along with outreach workers and project coordinators/Child Counselors included but not limited to
   a. Lost to Follow up clients
      i. Not willing for hospital visit and treatment
      ii. Not willing for home-based care
      iii. Taking alternative treatment at other places
   b. Eligible not started on ART clients
   c. Client not disclosed status to spouse/family
   d. Not willing to bring spouse/children for HIV testing
   e. Counseling discordant couples on safe/safer sex practices, condom demonstration
   f. Poor health seeking behavior [Poor hygiene, not regular to hospital visit, poor adherence etc...]

   During the participatory home visit the mentor were able to assess outreach workers core skills, areas of improvement and based on this appropriate skills and knowledge development were focused onsite and in the fortnightly and NGO coordination meeting. This activity has helped the outreach workers to develop counseling skills, build confidence on providing effective home-based care focusing various components and motivating difficult clients for treatment and home-based care.

2. Participation in fortnightly review meeting included
   a. Technical update sessions
   b. Facilitating case presentation and discussion
   c. Capacitating project coordinators in conducting review meeting
      i. Review of planned activities
      ii. Data presentation and analysis
      iii. Usage of data

3. Participation in support group meetings focusing on
   a. Outreach workers facilitation skills
   b. Methodology adopted in training support group members
   c. Information provided and its appropriateness
   d. Follow up of each support group meeting
   e. Usage of external resources for facilitating support group meeting
4. Capacitating outreach workers on documentation and data usage, this included
   a. Review of documentation practices
   b. Building skills on effective documentation
   c. Collecting patient wise data and tracking clients progress
   d. How to use data for planning home visit and follow up

5. Capacitating outreach workers on needs identification and follow up, this included
   a. Importance of needs identification
   b. Assessing needs using various strategies
   c. Capturing needs identified in daily dairy and home-based care sheet
   d. Using resource directory including reference, identifying potential source, approaching through proper channel, referral and continuous follow up
   e. Documentation

6. Periodic knowledge and skill assessment and feedback

7. Involving outreach workers and key staff in counseling mentorship training which included
   a. Training on basic counseling skills
   b. Behavior change and communication session

Over the period the mentors were able to see good improvement among outreach workers in
- Needs identification
- Planning home visit
- Increase in referrals and linkages, usage of resource directory
- Patient wise tracking and information sharing with hospital
- Knowledge and skills
- Sharing of case studies in fortnightly review meeting and NGO coordination meetings
- Applying different strategies in motivating clients especially lost to follow up and eligible not started on ART etc...
- Diversifying topics during support group and care givers training using participatory techniques
- Strengthening self care and care givers training component during home visit
- Focusing on specific issues such as disclosure, family members testing, safe and safer sex practices, children issues etc...
- Documentation and usage of data for home visits

The project coordinators were able to adhere to the review meeting guidelines and incorporate technical updates, case discussion on a regular basis. Their knowledge level on using the data, reviewing outreach workers, field visit with outreach workers has increased to a larger extent.
During the mentorship visit with outreach workers and support staff [as for as home visit is concerned] technical assistance team has observed few challenges such as

- High case loads
- Documentation
- Poor health seeking behavior among clients [even if the spouse or care giver is motivated]
- Stigma and discrimination, disclosure issues which was the barrier for doing home visit
- Geographical location and transport facility
- Poor economic status of the family

Based on the observations technical assistance team again [The first mid course correction took place at the end of first year] made mid course correction in year III which included

1. Increasing outreach workers based on the case load
2. Strategizing home visit following key criteria such as
   a. ART missed follow up clients
   b. ART LFU clients
   c. ART Clients
   d. ART eligible not started clients
   e. Pre - ART LFU clients
   f. Follow up based on the needs and issues identified
   g. Pre - ART clients who are in regular hospital follow up
3. Simplifying formats and registers for documentation
4. Recruiting community health nurse to provide onsite mentorship for outreach workers at Salem and Tirunelveli cluster since these two clusters had high client load
5. Expanding child focused services to all the blocks to ensure onsite mentorship and addressing children issues

In the beginning of year III induction training for newly recruited outreach workers, community health nurse, child counselors were conducted. The mentors continued to assist project coordinators, community health nurse, and child counselors to carry out onsite mentorship for outreach workers.

**Second round of home-based care mentorship**

The second round of mentorship carried out over eight months included

1. **Focus Group Discussion with field staff by an external consultant to comprehend the activities under home-based care, their knowledge and skills, and training needs**

**Key findings:**

- Staffs were well trained on knowledge aspects. Staffs were able to systematically articulate the various activities they do under home-based care and explain the key activities under each component
• 90% of the staff considered their work to be sacred and a spiritual process which gives more satisfaction
• 85% of the staff knowledge on HIV/AIDS, OI management, ART, and home-based care were found to be adequate
• Staffs were able to articulate and explain key issues such as adherence monitoring, ART preparedness and patient education, components of care givers and self care training etc...
• Staff had hesitation in addressing safe and safer sex practices, condom demonstration to opposite sex
• Staff expressed need for developing interpersonal communication skills, usage of IEC materials, handing children issues
• Participation of men in home-based care program comparatively less when compared to women
• All staff expressed that the recently conducted counseling training helped them to enhance their para-counseling skills and it was very useful
• Staff expressed handholding in dealing with difficult clients
• Involving key stakeholders and resource mobilization was well articulated and shared during the discussion
• Referring to legal issues, access to legal issues highlighted as a major problem as it leads to stigma and discrimination and breach of confidentiality
• Staff expressed concerns on economic issues, absence of care givers as most of them are widow, more responsibility on women and children, absence of care at terminal stage due to long distance and poor economic status, and inadequate nutrition

Based on the focus group discussion, minimum standards of home-based care activities, guidelines for various activities under home-based care was developed and shared with all NGOs to ensure uniformity. Based on the needs identified the outreach workers and key staff were trained on the following topics as part of home-based care and counseling mentorship program by an external consultant who did basic counseling skills training under counseling mentorship program.

1. Facilitating disclosure
2. Safe and safer sex practices, condom demonstration
3. Positive living
4. Bereavement counseling, care of death and dying
5. PPTCT issues

2. Capacitating mentors with in the organization

The objective of this activity was to strengthen mentorship skills among project coordinators, child counselors and community health nurse, sustain mentorship with in the organization and strengthen program quality.
Process and steps

Curriculum and tool development:

Based on the focus group discussion, needs assessment using GOARL Matrix, TNFCC program goal and objective of the mentorship program four days curriculum for training of mentors and tool for mentorship visit was developed by the technical assistance team which is attached as Annexure II and III.

Four days training for mentors

Home Based Care Mentorship training program for project coordinators, Community Health Nurse, and Child Counselors [Where Community Health Nurse is not available] was organized from 5th to 8th March 2008 at House of Peace, Yercaud. In all 21 staff participated in the training program. The objective of the training was

- To make participants understand the concept of Mentorship and Mentors role in enhancing staff knowledge, attitude, skills and program quality
- To get comprehensive understanding of home-based care activities carried out across NGOs in TNFCC program
- To enable participants to come to a common understanding on Home Based Care activities of TNFCC program
- To improve the quality of home-based care

The Mentorship training focused on building participants’ knowledge, attitude and skills through participatory methods and applying adult learning principles. The participants were involved in role-play, group discussion, simulation and brain storming exercise to share their knowledge and experience from the field which further enhanced participant’s knowledge with practical experiences. The participants were also given resource materials and hand outs [Attached IV] to read and relate with their learning’s.

Key outcomes:

Through this training the participants were able to understand

- The concept of Mentorship and Mentors role in enhancing staff knowledge, attitude, skills and program quality
- The various methodologies adopted in Mentorship
- The qualities of Mentor
- Comprehensive activities and minimum standards under TNFCC home-based care program
- The importance of following common guidelines, checklist to ensure uniformity in service delivery and enhancing program quality
- Importance of mentorship in providing quality service to the PLHIVs and family members

3. Onsite mentorship by Project Coordinators, Community Health Nurse and Child Counselors

Onsite mentorship by project coordinators, community health nurse and child counselors were carried out over six months using the mentorship tool
developed by technical assistance team. The various activities under onsite mentorship included

a. Initial mentorship visit by mentor to assess outreach workers knowledge, skills, attitude and practice through participatory home visit, review of documentation and data usage
b. Follow up mentorship visit based on the initial and follow up assessment findings including participatory home visit, input on gap areas, usage of data
c. Technical update session and case discussion during fortnightly review meeting
d. Participation in support group meetings
e. Outreach worker wise performance review through tracking hospital key indicators.

4. Periodic review of mentorship by technical assistance team
   a. Through case discussion
   b. Participatory home visits
   c. Knowledge and skill assessment
   d. Supportive monitoring visit
   e. Review of monthly technical report
   f. Review of documentation
   g. Participation in review meetings
   h. Case conferencing
   i. Discussion with mentor and mentee's
   j. Review of fortnightly review meeting minutes
   k. Review of completed mentorship assessment tool
   l. Participation in support group meetings
   m. Feed back session with mentors

5. Tool development to assess home-based care mentorship process and outcome [Annexure V]

6. Focus Group Discussion to evaluate the outcome of home-based care mentorship
# Key outcomes of home-based care mentorship program

## Qualitative outcomes of home-based care components

<table>
<thead>
<tr>
<th>S.No</th>
<th>home-based care programmatic components</th>
<th>Initial mentorship assessment - Observations</th>
<th>Recommendations provided for follow up</th>
<th>Improvement observed after first and second round of mentorship</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Program review</td>
<td>During the fortnight and monthly review meeting staff spend the entire day for documentation and report submission</td>
<td>Individual staff review, target Vs achievements, case studies sharing, best practices sharing, challenging case studies sharing and discussion, plan for the next week/month etc… should be part of the review meeting agenda</td>
<td>The agenda for the fortnightly review meeting is streamlined across all NGOs where Individual staff wise review, tracking of performance indicators, technical update sessions, case studies sharing and discussion, data analysis and usage, plan for next week is part of the agenda and review meeting guidelines</td>
</tr>
<tr>
<td>2</td>
<td>Needs identification</td>
<td>Needs identification of PLHIVs and their family members is lacking</td>
<td>Outreach workers need to ensure this activity for every clients and their family. This assessment will facilitate in doing appropriate linkages and referral services.</td>
<td>Needs identification and documentation has increased tremendously across all NGOs. Patient wise need is documented in the home visit sheet and based on these appropriate linkages to government and other services ensured. This was evident in the supportive monitoring visit where the assessment team were able to see increase in referrals to various services</td>
</tr>
</tbody>
</table>
| 3 | Planning Home visit | Outreach workers need to plan the home visit based on the needs identified and with a specific purpose which is lacking in program implementation. | Project coordinators should ensure that each outreach worker has a plan for home visit and it should be submitted in the first day of the week. The weekly plan and the daily plan should be followed strictly to ensure this activity regularly. | Planning home visit across all outreach workers is streamlined where all the outreach workers follow key criteria before planning for home visit that includes:
- ART missed follow-up clients
- ART LFU clients
- ART clients
- ART eligible not started clients
- Based on needs/issues identified
- Pre - ART LFU clients
- Pre - ART clients
The weekly plan is submitted based on the proposed criteria and reviewed by the project coordinators during the review meeting. |
| 4 | Motivational counseling | Motivational counseling for hospital follow up (especially to client not on ART) is very critical to ensure regular follow up to access hospital based services. Helping the PLHIVs to build their capacity and increase their health seeking behavior is lacking. | Outreach workers to build their Para counseling skills and should work on improving the clients capacity in terms of understanding the importance of hospital follow up and the necessity to take care of their health. In addition the outreach workers need to be clear on the NGO services in addition to the services given under TNFCC program. | Outreach workers are now confident about counseling clients with various problems and capacitated to increase health seeking behavior among clients. The mentorship and training on basic counseling skills have helped them to build their Para counseling skills which are evident during their case study presentation in ESRM meeting, and case conferencing at the NGO coordination meetings. The same is reflected in the focus group discussion also. They are able to deal with issues pertaining to disclosure, safe and safer sex, motivating LFU clients for regular hospital visit due to various reasons etc… |
| 5 | Adherence monitoring | Clients’ adherence level is not documented in the home visit form. The process of monitoring and the steps involved needs to be recorded clearly. Mostly adherence monitoring is done for the ART clients alone. | Outreach workers to ensure adherence monitoring for both ART and Non ART clients. Adherence for OI drugs, ATT, Micro and Macro is also very essential to improve QOL. The process and how they assess adherence should be recorded in the home visit sheets. | During home visit the outreach workers are able to counsel and track adherence percentage for ART, Micro and macro supplements, OI drugs and document in the home visit sheet. This is evident during the support monitoring visit and outreach workers information sharing with the hospital where they are able to share adherence related issues to the counselors and nutritionist on a regular basis. |
| 6 | Training on self care | Self care training for clients is limited to giving information on personal hygiene, taking medicines regularly, information on nutrition, drinking boiled water and information on going for regular hospital visit. | Staffs need to ensure that all PLHIVs are capacitated on self care which should not be limited to giving information alone. Outreach worker need to build the PLHIVs capacity on home-based care and do demonstration for managing OIs. This will result in increasing health seeking behavior. | Formats and registers capturing PLHIVs trained on self care are streamlined across all NGOs which was lacking in the first year where information’s where documented in the daily dairy. PLHIVs are trained on the various topics given in the home-based care training manual developed by I-TECH during home visit and support group meeting. PLHIVs are much capacitated and they are able to articulate on CD4, importance of positive living, importance of initiating ART and adherence, usage of condoms, importance of nutrition, etc... This was evident during the supportive monitoring visit. |
| 7 | Care givers training | Care givers training are limited to giving information during the care givers program and some times during the home visit. Demonstration on OI management is limited to preparing ORS only. Nursing care, first AID demo and palliative care has not happened. | Outreach workers need to ensure that all the care givers are trained on home-based care (covering all the topics proposed in the home-based care giver manual) with demonstration. This can be ensured during the home visit and care givers training program. They also need to prepare the list of care givers in the program following the format given by technical assistance team. | This component has improved compare to the first year. They are able to identify care givers and train them on managing HIV. During interaction with care givers they were able to articulate about management of HIV, using home-based care kit box, importance of precautionary methods, etc... Still there is larger scope for improvement in terms of capacitating all the care givers at the same level. |
| 8 | OI identification and management | During the home visit it was identified OI identification, home care management and referral is lacking. Outreach workers need to improve their knowledge on OI identification and management. | Project coordinators should ensure that all the outreach workers read the home-based care guide and update their knowledge. During the review meeting they should share the case studies and have a discussion to improve analyzing skills and overcome critical case studies. | Knowledge level on OI identification, home management and when to refer to hospital has increased among outreach workers [Knowledge assessment outcome]. They were able to articulate the various symptoms and possible associated OIs during the FGD and in the NGO coordination meetings. |
| 9 | Support Group meeting | Topics are repeated in all the support groups. Capacity building of PLHIVs to take over the support group is lacking | Outreach workers to see that they don’t repeat the topics again and again in the support group meeting also they need to capacitate the PLHIVs to facilitate the support group | Outreach workers are able to diversify the topics in the support group meeting which is evident during the supportive monitoring visit, review of support group meeting minutes and interaction with support group members. The support group members were very impressive in articulating the purpose of support group, the various benefits they get through support group, Knowledge on HIV, ART, Nutrition, importance of condom usage, adherence to treatment, various services available for PLHIVs, managing OIs etc… and the benefit the get through home visit by the outreach workers. There is larger scope for capacitating all the PLHIVs at the same level which need to be ensured in future. |

| 10 | Referral and linkages | This component should be strengthened especially to linkages to welfare schemes and services | Outreach workers need to do the block level resource directory in addition to the resource directory done at the district level. Establishing linkages should be part of their weekly plan. | District level and Taluk level [containing block level information] resource directory is updated and available with all NGOs. Outreach workers knowledge level on various schemes and the process followed in availing various schemes were well articulated during the supportive monitoring visit. Each outreach workers have one copy of Taluk level resource directory. Apart from linkages to government schemes each NGOs were able to mobilize minimum of 50,000 to more than 1 lakh in year three alone. |
| 11 | Documentation | Documentation needs considerable improvement. Patient wise tracking system, documenting in daily dairy, home-based care sheet, documenting home-based care activities needs strengthening. Project coordinators need to ensure outreach workers are capacitated in Documentation. Tracking patient wise progress, documenting the interventions and follow up needed during the home visit in home-based care sheet, uniformity across all outreach workers need to be ensured. | Formats and registers to capture the various activities under home-based care are streamlined across all the NGOs and among outreach workers. Patient wise tracking is well established across all outreach workers in the program. The various activities done under home-based care is well documented in the home-based care sheet and supportive formats. This was evident during the support monitoring visit. |
| 12 | Staff knowledge and skills | Staff knowledge on HIV, home-based care issues needs considerable improvement. Staffs need to know the difference between home visit and home-based care, components of home-based care, knowledge on HIV, ART and other issues in-depth. They also need to understand that home-based care is not only for the PLHIVs it is for the family as a whole. Family members are attended in the absence of PLHIVs only. Exclusive home visits are not planned for the care givers / family members. | Staff knowledge, skills, practice and attitude has increased from 49% to 70% at the end of first round of mentorship and 81% at the end of second round of mentorship. During the supportive monitoring visit the assessment team was able to see the outreach workers are impressive in articulating their knowledge, practices and skills [in handling difficult case studies]. The same response is evident during the focus group discussion with the mentee's. |
Quantitative outcome on key Home Based Care indicators

a. **Referral and linkages:** In year III out of 3390 clients referred for various services such as government schemes, nutritional support, food assistance, educational support, livelihood support etc... 67% of them got benefited which resulted in leveraging community resources and ensuring access to other services.

b. **Disclosure to spouse / family members:** 90% of the clients followed by TNFCC NGOs have disclosed their status to at least one family member.

c. **Maintaining discordancy:** >99% of the discordant couples are able to maintain their discordancy level which is very good outcome of home-based care follow up and HIV prevention measures including counseling on safe and safer sex practices, condom demonstration & distribution, and motivating for periodic HIV testing of negative partners.

d. **Capacitating PLHIVs on self care:** 80% of the clients followed by TNFCC NGOs are trained on self care training through home visit and support group meetings.

e. **Capacitating care givers on managing HIV:** 71% of the care givers identified by TNFCC NGOs are trained on managing HIV at the home level including symptoms management, adherence, universal precaution, importance of hospital follow up etc...

f. **ART eligible not started:** Through consistent efforts and motivation counseling 75% of the ART eligible clients at the end of year III are initiated on ART.

**Recommendation from mentee’s:**

During the focus group discussion with the mentee’s they expressed the need for more onsite technical input, increase in onsite mentorship in-terms of frequency of the visit, and modeling by the mentors.

**Recommendation from mentors:**

Mentors expressed the need for more technical input to build their knowledge and skills as new developments are taking place every now and then [at-least once in three months], and self assessment tool to evaluate and set goals for their improvement.

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**Excerpts from FGD**

“Mentorship was very useful in-terms of developing our skills on approaching clients, motivating clients for follow up, identifying clients’ problems, dealing with specific issues” - FGD with mentee’s

“Mentors accompanying us during home visit give us more confidence and we are able to learn from them while they are handling difficult case studies” - FGD with mentee’s

“Our documentation skills and patient tracking has improved through mentoring” - FGD with mentee’s

“Mentorship helps to improve program quality and uniformity across all ORWs” - FGD with mentors

“We could see positive changes such as improvement in documentation, usage of data, prioritizing home visit, focusing on key components of home-based care such as capacitating PLHIVs and family members, disclosure, needs identification, staff knowledge on home-based care etc... these positive changes really helps to improve the quality of the program” - FGD with mentors

“In our work experience this is the first time we heard the name mentorship and underwent the process. It is very unique because it involves lot of activities directed to build staff capacity and program quality. Training stops with imparting skills and the follow up is limited to an extent, whereas mentorship involves training, technical updates, case discussions, participatory learning etc... which is very unique” - FGD with mentors
Conclusion

Delivery of quality home-based care services requires structured and multi-prong technical assistance strategies, including didactic and hands-on training, ongoing onsite mentorship, case presentation and discussion, and modeling by mentors.
Annexure I: List of training and technical updates

Training programs

1. Six days induction training for program staff
2. Five days induction training on home and community based care
3. Training in HIV nutrition
4. Adherence and Pediatric counseling
5. Advanced nutrition training
6. Refresher Medical training for hospital staff
7. Two days pediatric counseling training for counselors and Project Coordinators
8. Life skills education for child counselors and project coordinators
9. Two days induction training for program staff [Newly recruited staff]
10. Three days induction training for program staff [Newly recruited staff]
11. Refresher training on Life Skills Education for Child counselors, project coordinators and selected out reach workers
12. Training on basic counseling skills through counseling mentorship program
13. Second round of counseling mentorship training focusing on specific home-based care and counseling topics such as disclosure, safe and safer sex practices etc...
14. Four days home-based care mentorship training for mentors

Technical updates

1. Technical update on HIV and legal services
2. Technical update on ICTC program and policy
3. Technical update on organizing Taluk Level coordination meeting and resource mobilization
4. Technical update on Nutrition and HIV
5. Technical update on OI identification and management
6. Technical update on handling lost to follow up clients, eligible not started on ART
7. Technical update on home-based care and priority areas
8. Technical update on patient tracking and information sharing
Session I: Understanding on Home Based Care activities of TNFCC program

Methodology: Group discussion [GOARLS matrix]

Time: 2 hrs

Objectives:

• To get comprehensive understanding of home-based care activities carried out across NGOs in TNFCC program
• To enable participants to come to a common understanding on Home Based Care activities of TNFCC program
• To understand the goal, purpose, and importance of home-based care program in enhancing quality of life of PLHIVs and family members

Session II: Exploring family status and needs assessment

Time: 2 hrs

Methodology: Group discussion, brain storming and lecture method

Objectives: The objectives of the session is to enable the participants

• To understand the importance of exploring family status
• To understand the importance of needs assessment
• To understand the various methods used to explore family status
• To help participants to use the information for enhancing program service delivery

Topics

1. Sociological assessment
   Family background
   Disclosure status
   Testing status
   Discrimination
2. Physical assessment
3. Psychological assessment
4. Occupation and economic condition
5. Education status [Parents and children]
6. Health and hygiene
7. Needs of the family

Session III: Understanding the various counseling needs of PLHIVs and their care givers

Time: 2 hrs

Methodology: Group Discussion, Case study discussion and presentation
Objectives: The objective of the session is to enable the participants

- To come to a common understanding on the various counseling needs of PLHIVs [adults and children] and care givers
- To understand the core areas which, contribute in improving positive living and strengthening family support
- To understand the importance of follow up counseling in addressing the core areas
- To understand the various strategies, skills and process needed to address issues related to different types of counseling

Topics

- Defining the various counseling needs of PLHIVs [Adults and Children] and care givers
- Core areas which helps in improving the positive living and strengthening family support
- Importance of follow up counseling in addressing the core areas
- Steps, process and skills needed for providing different types of counseling

Session IV: Capacity building of PLHIVs and care givers

Time: 2 hrs

Methodology: Group Discussion

Objectives: The objective of the session is to enable the participants

- To understand the importance of capacity building for PLHIVs and care givers
- To understand the role of capacity building in increasing health seeking behavior and building family members ownership
- To understand the various methodologies used in capacity building activities
- To come to a common understanding on the curriculum [topics] expected for self care and care givers training

Topics

- Importance of capacity building for PLHIVs and family members [Care givers]
- Link between capacity building and health seeking behavior
- Methodologies used in conducting capacity building activities
- Difference between health education and capacity building
- Curriculum for self care training
- Importance of identifying care givers, types and their roles
- Curriculum for care givers training
Session V: Prevention of infections in the home  
Time: 2 hrs

Methodology: Group Discussion, Role Play and Presentation

Objectives: By the end of the session the participants will know

- Who is at risk of the infection
- How to prevent infection at home [Practice Universal Precautions]
- The correct way of using condom
- How to maintain personal and environmental hygiene
- Safe disposal of waste includes sharp instruments, blood and blood products

Topics

- Maintaining Good personal hygiene
- Disposal of waste
- Preventing HIV infection in the home
- Maintaining good environmental hygiene
- Universal precautions and PEP

Session VI: Management of Symptoms
Time: 8 Hrs

Methodology: Group Discussion, Role Play, Case study and presentation

Objectives: By the end of the session, the participants will be able to:

- Identify symptoms of the various infections associated with HIV/AIDS
- Treat the symptoms at home
- Know when home treatment is not enough and when the person should be taken to a doctor / health care providers
- Demonstrate the various steps and procedures in treating symptoms at home

Topics

- Fever
- Diarrhea
- Dehydration
- Nausea and vomiting
- Tiredness and weakness
- Skin problems
- Mouth and throat problems
- Respiratory problems
- Psychosomatic illness
- Dementia
- STIs
- TB
Session VII: Women and HIV

Time: 2 hrs

Methodology: Group Discussion and presentation

Objectives: By the end of the session, participants will be able to

- Understand and describe the medical problems faced by women with HIV
- Recognize the signs when a woman requires medical help
- Understand and describe the importance of proper care for a woman, from pregnancy to child birth, and afterwards
- Recognize the symptoms is a woman during pregnancy and childbirth that require medical help

Topics

- Medical problems faced by women with HIV
- Pregnancy and child birth
- Post natal care of the HIV infected mother and her infant

Session VIII: Children and HIV/AIDS

Time: 2 hrs

Methodology: Presentation and group discussion

Objectives: By the end of the session the participants will be able to

- Describe the major and minor signs of HIV infection in children
- Understand the various steps of looking after a HIV positive child
- Understand the needs of orphans

Topics:

- Signs of HIV infection in children
- Care of HIV positive child
- Children orphaned by AIDS

Session IX: Palliative care

Time: 2 hrs

Methodology: Demonstration and Presentation

Objectives: By the end of the session, participants will be able to

- Recognize the signs of a person nearing death
- Understand the needs and worries of a person nearing death
- Care for a person nearing death
Know the precautions to be taken with the body of some one who has died of AIDS
Understand the importance of facilitating the grief process and addressing the needs of the family

Topics:
- Signs and symptoms
- Goal and methods of providing palliative care
- Caring some one who is dying [Adult and children]
- Taking care of children whose parent is near the end of life
- Preparing for death
- Precautions to be followed before funeral

Session X: Mentorship Concept and Principles
Time: 2 hrs

Methodology: Group Discussion, Role Play and Presentation

Objectives: At the end of the session, participants will be able to
- Concept of mentorship
- Understand the importance of mentorship in capacity building process
- Understand the principles and steps in mentorship
- Understand the do’s and Don’ts in mentorship

Session XI: Dissemination of guidelines and checklist for home-based care program, Mentorship visit and discussions
Time: 2 hrs

Methodology: Group Discussion and Presentation

Objectives: At the end of the session, participants will be able to
- Understand the prerequisite for implementing home-based care and mentorship program.
## Annexure III: Checklist for mentors

Name of the ORW: _____
Block: _____
Date: _____
Area Visited: _____
Number of home visits done during the assessment period: _____

<table>
<thead>
<tr>
<th>Assessment areas [Knowledge, Attitude and Skills]</th>
<th>High</th>
<th>Adequate</th>
<th>Low</th>
<th>Poor</th>
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<tbody>
<tr>
<td>1 Staff motivation and involvement in the program</td>
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<td>2 Staff sensitivity towards PLHIVs issues</td>
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<td>3 Maintaining confidentiality and ensuring privacy</td>
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<tr>
<td>4 Identifying PLHIVs and family needs</td>
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<tr>
<td>5 Interpersonal communication skills</td>
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<td>6 Problem identification</td>
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<td>7 Prioritization of needs</td>
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<td>8 Para - counseling skills</td>
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<td>9 Knowledge on HIV / AIDS</td>
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<td>10 Knowledge on ART</td>
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<tr>
<td>11 Knowledge on Nutrition</td>
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<tr>
<td>12 Home Based Care training skills</td>
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<tr>
<td>13 Handling difficult and crisis situation</td>
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<tr>
<td>14 Patient tracking and usage of data</td>
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<td>15 Knowledge on universal precaution methods</td>
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<td>16 Coping skills to different situation</td>
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<td>17 Knowledge on addressing children issues</td>
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<tr>
<td>18 Knowledge on safe and safer sex practices</td>
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<tr>
<td>19 Networking and linkages with other stakeholders</td>
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<tr>
<td>20 Care givers identification and training</td>
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<tr>
<td>21 Addressing stigma and discrimination issues</td>
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<td>22 Addressing disclosure issues</td>
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<td>23 Condom demonstration</td>
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<tr>
<td>24 Usage of IEC / BCC materials</td>
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<tr>
<td>25 Referrals to other services</td>
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<td>26 Treatment preparedness</td>
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<tr>
<td>27 Follow up and effective completion of referrals</td>
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<tr>
<td>28 Adherence monitoring</td>
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<td>29 Low cost nutrition demonstration</td>
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<td>30 Promoting kitchen garden</td>
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<td>31 Planning home visit</td>
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<td>32 Documentation</td>
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<tr>
<td>33 Training on usage of home-based carekit</td>
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<td>34 Training on usage of children kit</td>
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</tbody>
</table>
## Format for Mentorship Report

<table>
<thead>
<tr>
<th>Outreach workers areas of improvement identified</th>
<th>Information and support provided to the outreach worker during the visit by the mentor</th>
<th>Recommendations to be followed by the outreach worker</th>
<th>Remarks</th>
</tr>
</thead>
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Signature of the ORW:

Signature of the Mentor:
Annexure IV: List of IEC materials provided during home-based care mentorship training program

- Living Positively with HIV: A Follow-up Counseling Toolkit - Facts You Need to Know
- Living Positively with HIV: A Follow-up Counseling Toolkit - Mental Health
- Living Positively with HIV: A Follow-up Counseling Toolkit - Telling Your Partner
- Living Positively with HIV: A Follow-up Counseling Toolkit - Stigma and Discrimination
- Living Positively with HIV: A Follow-up Counseling Toolkit - Safer Sex
- Living Positively with HIV: A Follow-up Counseling Toolkit - Disclosure
- Living Positively with HIV: A Follow-up Counseling Toolkit - Compendium of Tools

- Flip Chart - HIV / AIDS udn Nambikkaiyodu Vazdhal - Thodar Aalosanai Karuvi - Neengal Terindukollavendiya Unmaigal (Tamil)
- Flip Chart - HIV / AIDS udn Nambikkaiyodu Vazdhal - Thodar Aalosanai Karuvi - Mananalam (Tamil)
- Flip Chart - HIV / AIDS udn Nambikkaiyodu Vazdhal - Thodar Aalosanai Karuvi - Thunaivarukku Arivithal (Tamil)
- Flip Chart - HIV / AIDS udn Nambikkaiyodu Vazdhal - Thodar Aalosanai Karuvi - Kalangappaduthuthal and Verupaduthuthal (Tamil)
- Flip Chart - HIV / AIDS udn Nambikkaiyodu Vazdhal - Thodar Aalosanai Karuvi - Padukappudan Udaluravu (Tamil)
- Flip Chart - HIV / AIDS udn Nambikkaiyodu Vazdhal - Thodar Aalosanai Karuvi - HIV Nilaiai Velipaduthuthal (Tamil)

- Booklet on ART

- Posters on ART and its importance
### Annexure V: Home-based Care Mentorship Assessment Tool

<table>
<thead>
<tr>
<th>Visit</th>
<th>Name of the Outreach Worker</th>
<th>Name of the Mentor</th>
<th>Date of Visit</th>
<th>Documents Reviewed</th>
<th>Number of Home-based Care Mentorship Visits Done</th>
<th>Key Observations</th>
<th>Technical Inputs Provided During the Visit</th>
<th>Areas of Improvement Identified</th>
<th>Follow Up After the Visit</th>
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<tbody>
<tr>
<td>I</td>
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<td>List what documents and give codes or nos e.g. 1. House visit sheet 2. Outreach worker daily diary 3. Individual patient hard copy register 4. Patient data base</td>
<td>Number of home-based care mentorship visits done</td>
<td>Key observations [includes strength and gaps in Skills, knowledge, documentation, etc]</td>
<td>Technical inputs provided during the visit</td>
<td>Areas of improvement identified</td>
<td>Follow up after the visit [e.g. input session or case discussion during weekly review]</td>
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<td>II</td>
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<td>Areas of improvement observed [refer to previous visit areas of improvement]</td>
<td>Key observations [includes strength and gaps in Skills, knowledge, documentation, etc]</td>
<td>Technical inputs provided during the visit</td>
<td>Areas of improvement identified</td>
<td>Follow up after the visit [e.g. input session or case discussion during weekly review]</td>
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<td>III</td>
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<td></td>
<td>Areas of improvement observed [refer to previous visit areas of improvement]</td>
<td>Key observations [includes strength and gaps in Skills, knowledge, documentation, etc]</td>
<td>Technical inputs provided during the visit</td>
<td>Areas of improvement identified</td>
<td>Follow up after the visit [e.g. input session or case discussion during weekly review]</td>
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</tbody>
</table>

**General Remarks:**

34
<table>
<thead>
<tr>
<th>Expectations from technical assistance team</th>
<th>List of IEC materials used</th>
<th>Remarks on IEC usage</th>
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