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NATIONAL HEALTH MISSION
राष्ट्रीय स्वास्थ्य मिशन

FAMILY PARTICIPATORY CARE
FOR IMPROVING NEWBORN HEALTH

OPERATIONAL GUIDELINES
FOR PLANNING & IMPLEMENTATION

July 2017

Child Health Division
Ministry of Health and Family Welfare
Government of India

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Arun Kumar Panda
Additional Secretary &
Mission Director, NHM
Tele : 23063155, Fax : 23063156
E-mail : asmd-mohfw@nic.in

सत्यमेव जयते

भारत सरकार
स्वास्थ्य एवं परिवार कल्याण मंत्रालय
स्वास्थ्य एवं परिवार कल्याण विभाग
निर्माण भवन, नई दिल्ली-110011
GOVERNMENT OF INDIA
MINISTRY OF HEALTH & FAMILY WELFARE
DEPARTMENT OF HEALTH & FAMILY WELFARE
NIRMAN BHAVAN, NEW DELHI - 110011

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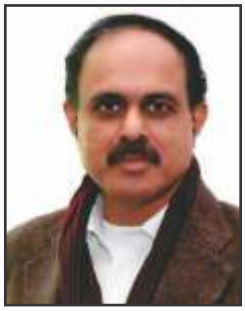

FOREWORD

Family-participatory care is an approach to health care that shapes health care policies, programs, facility design, and day-to-day interactions among patients, families, physicians, and other health care professionals. Service providers who practice family-participatory care recognize the vital role that families play in ensuring the health and well-being of children and family members of all ages. They respect each child and family's innate strengths and view the health care experience as an opportunity to build on these strengths and support families in their caregiving and decision-making roles. Family-participatory approaches lead to better health outcomes and wiser allocation of resources as well as greater patient and family satisfaction.

It has been acknowledged that emotional, social, and developmental support are integral components of health care. Family-participatory care is based on the understanding that the family is the child's primary source of strength and support and that the child's and family's perspectives and information are important in clinical decision making. Family-participatory health care experiences can enhance parents' confidence in their roles and, over time, increase their competence in taking care of their children. FPC is shown to enhance parent-infant attachment and bonding, improve breastfeeding rates and the wellbeing of pre- term infants while also decreasing their length of hospital stay.

I congratulate Child Health Division, Ministry of Health & Family Welfare in taking the initiative to prepare these Operational guide for implementing Family Participatory Care at SNCUs and urge the states to make the best use of this in adding another quality dimension to the newborn care.

(Dr. Arun K Panda)

वन्दना गुरनानी, भा.प्र.से.
संयुक्त सचिव

VANDANA GURNANI, I.A.S.
JOINT SECRETARY
Tel. : 011-23061706
E-mail : vandana.g@ias.nic.in

सत्यमेव जयते

भारत सरकार
स्वास्थ्य एवं परिवार कल्याण मंत्रालय
निर्माण भवन, नई दिल्ली - 110011
Government of India
Ministry of Health & Family Welfare
Nirman Bhavan, New Delhi - 110011

PREFACE

Family Participatory Care (FPC) has emerged as an important concept in health care with increasing awareness of the importance of meeting the psychosocial and developmental needs of children and of the role of families in promoting the health and well-being of their children. Family-participatory newborn care essentially means involving the families of sick and preterm newborns as partners in care giving and decision making in the newborn care facilities.

Typically the Special Newborn Care Units (SNCU) has focused upon technology driven, provider participatory care for sick newborns. Hospitalization of a sick newborn in these units not only separates the baby from her/his mother and but is an overwhelming experience for the parents who are often unprepared for the unexpected event when their babies are admitted in the hospital soon after birth. They have little support for addressing their stress, anxiety and feelings of helplessness. In recent years a new concept of Family Participatory Care has increasingly been embraced by newborn care facilities across developed countries and has become a standard practice in many newborn care units. FPC creates an environment that is developmentally supportive for the sick baby, and is culturally sensitive and responsive to family need for emotional support and information.

To implement this across the SNCUs in the country, "Family Participatory Care: Operational Guidelines for Planning and Implementation" has been developed by Child Health Division of the Ministry.

I am sure these Operational Guidelines will serve to guide the programme managers and service providers alike in establishing an optimal Family Participatory Care utilising the existing resources and at the same time linking with the Government of India Guidelines for Facility Based Newborn Care and Kangaroo Mother Care for low birth weight babies. Continued provision of essential care by parents over a longer period of time is likely to make a difference to survival beyond newborn period and to better long term outcomes.

(Vandana Gurnani)

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Dr. Ajay Khera
M.B.B.S., D.G.O., M.D. (Public Health)
Deputy Commissioner & Incharge
(Child & Adolescent Health)
Telefax : 23061281
E-mail : dcmch-mohfw@nic.in
ajaykheramch@gmail.com

सत्यमेव जयते

भारत सरकार
स्वास्थ्य एवं परिवार कल्याण मंत्रालय
निर्माण भवन, नई दिल्ली-110011

GOVERNMENT OF INDIA
MINISTRY OF HEALTH & FAMILY WELFARE
NIRMAN BHAVAN, NEW DELHI - 110011

Message

Improving the quality of newborn care to ensure better survival and quality of life is a continuing process and requires us to constantly innovate and adopt new practices. Government of India has committed to single digit Neonatal Mortality Rate (NMR) in India. India's effort to ensure survival of newborn has seen a paradigm shift in the last five years. Establishment of a large number of newborn care facilities at all levels of the health system is one of the most significant achievement.

Family Participatory Care has been introduced in the Special Newborn Care Units as a low-cost simple innovative approach that empowers parents to care for their newborns during hospitalization and to develop competence in ongoing essential infant care. Guidelines for planning & implementation of Family Participatory Newborn Care have been developed with the aim to guide the programme managers and service providers in delivering family responsive care through the large network of newborn care units in the public health system.

Child Health Division, Ministry of Health & Family Welfare acknowledges the technical support of NIPI Newborn Project, PGIMER Dr. RML Hospital, New Delhi along with domain experts in piloting the Family Participatory Care in Special Newborn Care Units and in synthesizing the learning and experiences into this operational guide. The division specifically acknowledges the contribution of Dr Arti Maria, Prof of Neonatology Dr. R M L Hospital New Delhi, Dr P K Prabhakar, Deputy Commisioner (Child Health), Dr Harish Kumar, Project Director-NIPI Newborn Project in finalizing the operational guideline.

I am sure this initiative will go a long way in improving quality of care for newborns and in empowering the parents in continuing the optimal care back at home.

(Dr Ajay Khera)

CONTRIBUTORS

Vision & guidance Ministry of Health and Family Welfare	Core team Conceptualization & drafting
Ms. Vandana Gurnani, Joint Secretary (RCH) Dr. Ajay Khera, Deputy Commissioner & In-charge (C&AH) Dr. P. K. Prabhakar, Deputy Commissioner (CH-II) Dr. Sila Deb, Deputy Commissioner (CH-I) Dr. Nimisha Goel, Consultant (CH) Mr. Vishal Kataria, Consultant (CH)	Dr. Harish Kumar, NIPI Newborn Project Dr. Deepti Agrawal, NIPI Newborn Project Dr. Renu Srivastava, NIPI Newborn Project Dr. Ashfaq Ahmed Bhat, NIPI Coordination Unit Dr. Rajat Khanna, NIPI Newborn Project Mr. Sharad Kumar Singh, NIPI Newborn Project
Technical Experts	**Implementation support State Health Mission**
Dr. Arti Maria, PGIMER, &R M L Hospital New Delhi Dr. Siddhartha Ramji, Maulana Azad Medical College, New Delhi Dr. Harish Chellani, Safdarjang Hospital, New Delhi Dr. Narendra Arora, The INCLEN Trust International Dr. Surendra Bisht, Swami Dayanand Hospital, Delhi Dr. Paul Francis, WHO Country office for India Dr. Gagan Gupta, UNICEF India office Dr. Pravin Khobragade, UNICEF India office Dr. Rajeev Gera, Project VRIDHI, IPE Global	Mr. Naveen Jain, MD-NHM, Rajasthan Ms. Shalini Pandit, MD-NHM, Odisha Dr. Rajshree Bajaj, DD-CH, Madhya Pradesh Dr. D. B. Sahu, NHM Odisha State Health Society, Bihar & State teams IPE Global Ltd NIPI Newborn Project (Bihar, Madhya Pradesh, Odisha, Rajasthan)

ABBREVIATION

ASHA	Accredited Social Health Activist
DSC	Development Supportive Care
FBNC	Facility Based Newborn Care
FGD	Focused Group Discussion
FMR	Financial Management Report
FPC	Family Participatory Care
GOI	Government of India
HBNC	Home Based Newborn Care
IEC	Information Education and Communication
INAP	Newborn Action Plan
JSY	Janani Suraksha Yojna
KMC	Kangaroo Mother Care
LBW	Low Birth weight
MCH	Maternal and Child Health
NMR	Neonatal Mortality Rate
NIPI	Norway India Partnership Initiative
PGIMER	Post graduate Institute of Medical education & Research
PIP	Programme implementation Plan
RCH	Reproductive and Child Health
SNCU	Special Newborn Care Units
TOT	Training of Trainers

TABLE OF CONTENTS

Section 1: Introduction to Family Participatory Care (FPC) **1**

1.1 Context 1

1.2 What is Family Participatory Care? 2

1.3 Rationale for Family Participatory Care 3

1.4 Benefits of Family Participatory Care 4

1.5 Purpose of this document 5

Section 2: Operationalizing Family Participatory Care at SNCUs **6**

2.1 Eligibility Criteria for participation in FPC 6

2.2 Steps in establishing FPC at existing SNCUs 7

2.2.1 Sensitization of State and District Managers on FPC 8

2.2.2 Prioritization of SNCUs for initiating FPC 8

2.2.3 Making required infrastructural enhancement in SNCU 8

2.2.4 Creating family participatory care environment in SNCU 9

2.2.5 Ensuring availability of supplies for parents-attendants 10

2.2.6 Training of SNCU staff for F P C 11

2.2.7 Role of Health Care Providers for FPC implementation 12

2.2.8 Institutional support for FPC 13

2.3 Implementation Process for FPC in SNCU 14

2.4 Record keeping and reporting on key indicators 19

2.5 Linking FPC with community based care 20

2.6 Budget provisions for operationalizing FPC 21

Annexure **25**

Annexure 1: Sensitization and skill building of parents-attendants: The Process 27

Annexure 2: Scope of parent- attendant skill building 29

Annexure 3: Template for scheduling FPC sessions 31

Annexure 4: Register for recording sessions attended by parents-attendants 33

Annexure 5: Observers' checklist to be used during mentoring / supportive supervision visits 35

Section 1

INTRODUCTION TO FAMILY PARTICIPATORY CARE

1.1 Context

India's efforts to ensure survival of newborns has seen a paradigm shift in the last five years. Improving the quality of new-born care in the newborn care units to ensure better survival rates and quality of life is a continuing process and requires us to constantly innovate and adopt new practices.

Increasing number of sick and small babies are now being treated in the newborn care units and are in need of continued care in the post neonatal period. Hospitalization of a sick neonate separates the baby from her/his mother and family. While the baby is admitted in the newborn care unit, the participation of parents /families in caring and decision-making regarding their own babies is severely limited. Also the psychosocial needs of babies and families remain unaddressed.

Data from follow up of sick and small babies discharged from newborn care units shows that after discharge up to 10% of babies do not survive till one year of life. While the baby is well cared during the stay in the hospital by the nurses and doctors, they have limited or no access to a trained service provider after discharge. This lack of continuity of care at the time of transition from health facility to home is one of the many reasons for increased mortality. The parents, who in general are uninformed and lack skills for essential care, have to assume full responsibility for their newborns/infants soon after discharge and at home.

As babies in the newborn care units are either sick or born with low birth weight, it is important that essential care is provided at home over a longer

period of time. This can be possible if parents are trained during their stay in the hospital to provide essential care to their sick and small newborns and explained what to do at the time of crises. This will not only help in improving survival of the babies after discharge from newborn care units but also help in the overall growth and development of the baby.

1.2 What is Family Participatory Care (FPC) ?

Family Participatory Care in paediatrics is based on the understanding that the family is the child's primary source of strength and support and their participation in the care of child admitted to hospital is important in decision making and long term care.

Family Participatory Care (FPC) provides a setting in which family is empowered, encouraged and supported as the constant care-provider, in addition to available nursing staff, to complement care of their sick newborn in nursery, from admission until discharge. However, the primary responsibility of care still rests with the doctor and nurse even though the family collaborates in partnership of care to their own baby.

The conventional model for care of a sick newborn involves delivery of care primarily by the nurse/doctor only and families are passive receivers i.e. the care is provider centric.

Family Participatory Care essentially means involving the families of sick and preterm newborns as partners in caregiving and decision making in the new born care facilities.

However, the primary responsibility of care continues to rest with the conventional health care provider namely the nurse and doctor.

FPC creates an environment in the nursery to bring the neonate back within the family's embrace by actively involving parents in care of their baby and by creating an environment that is culturally sensitive and responsive to the family-identified needs.

FPC has emerged as an important concept in health care and is a standard practice in the field of paediatric and newborn care in many countries. Several studies have evaluated the impact of FPC and has shown improved health outcomes for neonates and families.

In India, experiences from tertiary newborn care center (at RML-PGIMER, Delhi) and in SNCU across four states (with technical support from NIPI-Newborn Project) showed that this intervention is feasible, well accepted and relevant in our context. It has also shown that there is no increase in infection rate and better exclusive breast feeding rates (prior to discharge).

1.3 Rationale for Family Participatory Care

Parents of preterm and sick infants experience high stress levels and feelings of helplessness when their newborn is separated from them soon after the birth and hospitalised. Interventions to improve the provision of information and support for parents can reduce their stress and anxiety and thus improve the well being of the whole family.

The common problem of human resource constraint in newborn care facilities is closely linked to overburdening of staff, low compliance with aseptic routines resulting in compromise of quality of care. Encouraging parents to assume non medical aspects of their baby's care, FPC through this work sharing reduces some burden on the staff and thus improves quality of care.

Continuity of care is very important for families at the time of transition from hospital to home setting. Engaged as a constant caretaker from admission until discharge in essential care of their baby, allows parent baby interactions, and prepares them for better handling. These form the ground for better continuum of care at home after discharge that can make a difference not only to their survival but to the overall growth and development of the baby.

1.4 Benefits of Family Participatory Care

The practice of FPC is being widely accepted across newborn & paediatric care units for a range of advantages that it provides for all those involved: the baby (patient), the family and the staff.

Involving mother or parent-attendants has shown to be associated with decreased length of stay, enhanced parent–infant attachment and bonding and improved well-being of pre-term infants, better allocation of resources, and greater patient and family satisfaction. It can reduce the need for re-hospitalization and long-term morbidity.

Benefits of Family Participatory Care

Family	Newborn	Staff
• Greater parent and family satisfaction • More informed parents • Better coping with stress and anxiety • Enhanced parent-infant attachment and bonding • Improved breastfeeding rates • Better confidence and mental health among mothers • Better communication between parents and health staff	• Better weight gains • Shorter length of hospital stay • Higher breast feeding rates before discharge • Improved long term outcomes • Reduced need for rehospitalization	• Work sharing • Better quality of care • Better allocation of resources

1.5 Purpose of this document

This document is for all stakeholders involved in the process of planning and delivering newborn care. It will serve as guiding document for those intending to introduce Family Participatory Care in their facility as an integral part of facility based newborn care. This document provided details of infrastructure, training, role of health care providers and steps in the operationalization of Family Participatory Care in the newborn care unit.

Section 2

OPERATIONALIZING FAMILY PARTICIPATORY CARE AT SNCUs

Family Participatory Care intervention in newborn care units entails supervised delivery of care to haemo-dynamically stable, sick & preterm newborns by his / her parents-attendants in addition to the standard care provided by the nurse or doctor in the nursery.

Thus FPC has two distinct interventions:

1. Building capacities of parents-attendants in essential newborn care through a structured programme; and
2. Continuous supervision and support to parents-attendants providing care to their babies in the newborn care unit.

The parent attendants of newborns admitted to the newborn care unit will be trained through a training package that consists of an Audio -Visual module (which is structured into 4 sequential sessions) and a training guide. Each of the four sessions will be delivered over 60 - 75 minutes depending on the number of parents-attendants and number of skills to be taught. The training package has been prepared in simple language, with easy to understand explanations. The states should translate the videos in local languages. The domains of skill building are summarized in the annexure 2.

The most important part in making FPC functional is the ongoing support and supervision by staff in improving skills of mothers when they are by the side of their newborns and are actually participating in the care under the overall guidance of the nurses and the doctors.

2.1 Eligibility Criteria for participation in FPC

Parent -attendant who willfully wants to participate and proposes to be available round the clock for providing continuity of delivery of care to their baby should be involved in FPC.

Only those trained are allowed to participate in FPC under constant supervision of staffs. Parents can participate in the care of babies who do not require oxygen and IV fluids and the weight is above 1500 gms.

Parents-attendants are involved in a limited way for maintaining hygiene, cleaning the soiled baby, positioning of babies, and alerting the staff if they notice anything unusual with the baby.

Mother is always preferred if she is available and fit enough to take care, as she is the one who is likely to be the sole provider at home for this baby. Father should always be encouraged to participate. Only those relatives who are likely to stay for at least a month with the baby can be involved where either of the parents are not able to participate.

Eligibility of parent- attendant to participate in care of the admitted newborn can be decided by the Nurse in charge or by experienced senior nurse, designated by the in-charge.

Families of all newborns admitted in SNCU should however be included in the training programme.

It is however re-emphasized that the primary responsibility for the wellbeing of the babies remain with the staff of the SNCU/NICU and the parents are, at all times, supervised by nurses while caring for their babies.

2.2 Steps in establishing Family Participatory Care at existing SNCUs

To set up FPC at a facility essentially requires attention to:

a) Infrastructure / design of the unit that provides physical comfort to families;

b) Attitudes of staff that demonstrates empathy and support towards families; and

c) Practices that empowers the family and enables their participation in the care of the baby.

The following steps address these aspects of attitudes, infrastructural modifications and practice that will help in establishing FPC at SNCUs:

1. Sensitization of State and District Managers on FPC
2. Prioritization of SNCUs for initiating FPC
3. Making required infrastructural enhancement in SNCU
4. Creating family participatory care environment in SNCU
5. Ensuring availability of supplies for parents-attendants
6. Training of SNCU staff for SNCU
7. Role of Health Care Providers for FPC implementation
8. Institutional support for FPC

2.2.1 Sensitization of State and District Managers on Family Participatory Care

Sensitization meeting of state and district programme managers should be held to orient them to the concept and philosophy of FPC as an integral part of newborn care.

The programme manager should also be informed about the resources available that can also be utilized for implementing FPC such as facility based new born care, KMC units, MCH wings, JSY wards and the free referral transport.

2.2.2 Prioritization of SNCUs for initiating Family Participatory Care

While FPC can be implemented in all SNCUs the prioritization is recommended where there is adequate infrastructure and manpower.

2.2.3 Making required infrastructural enhancement in SNCU

Ensure the following for starting FPC.

a) Lying in beds for mothers

b) Hand washing area

c) Gowning area

d) KMC room

e) Breast milk expression area

f) Lockers for parents

g) Shoe racks

h) Bed side chairs for mothers.

i) Sufficient space with furniture for conducting training activities

j) Audio Visual equipment for training

2.2.4 Creating family participatory care environment in SNCU

Creating an environment that is family-participatory requires an attitude of healthcare providers to accept parent-attendants as partner in care for a sick neonate and thus demonstrate so in their practices.

Attitude of the staff of a unit where FPC is being practiced must demonstrate:

- Respect to families irrespective of their culture, and socio economic background.
- Empathetic & supportive attitude (reflected in voice, tone, eye contact and attitude).
- Being sensitized, trained and well aware of this changed practice and concept of family-participatory care in the unit.

Practices in the unit must demonstrate:

- Facilitated and supported environment for participation of parent-attendants in care of their babies.
- Visits allowed for primary care provider family members after they have learnt the nursery entry protocols.
- Accessibility of doctors/nurses for communication and face to face interaction to provide necessary information and guidance to the parents-attendants.

2.2.5 Ensuring availability of supplies for parents-attendants

With the introduction of FPC, there will be an increase in requirement for supplies/commodities that shall be used by parents-attendants for following protocols for entry into the newborn care unit. These are already part of the hospital supply but would be required in increased quantities.

1. Soap (liquid or bars) and 24x 7 water supply
2. Pre sterilized hand wipes
3. Gowns
4. Slippers
5. Baby linen, diaper, cotton etc. (for cleaning of soiled baby)
6. Steel drums (to ensure 24x7 availability of auto clavable hand wipes and parents' gowns, babies' linen, diapers etc.)
7. Cheatle forceps with auto clavable holder bottles
8. Feeding equipment (paladai, cups, spoons)
9. IEC material for dissemination, distribution and display

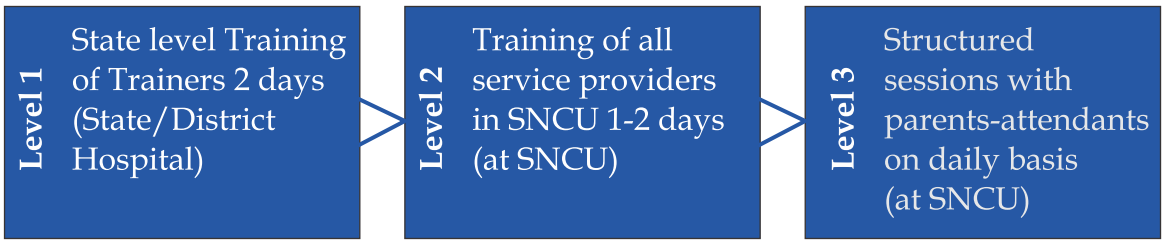
2.2.6 Training of SNCU staff for Family Participatory Care

Training and sensitization of health care providers at facility level will be done by the trainers who would have been trained at the Training of Trainers (TOT) conducted at state level. A state level Training of Trainers can be organized with the help of the experts who are implementing FPC in their units. Each batch should preferably have 24 participant and not more than 30. Each batch will have 1-2 doctor and 2-4 nursing staff (including Nurse Incharge) from each SNCU.

These trainers after being trained at the TOT would be required to sensitise and train all their doctors, staff nurses who are involved in neonatal care routinely in the SNCUs.

Once all the staff has been sensitised and trained, parents' skill building and trainings can be initiated by the nurses. Staff nurses will primarily train the parents-attendant in various domains of infant care through structured sessions organized daily. It is critical that all the nurses in the unit are well trained in the content and methodology of this training package and in providing continuous support to parents-attendants in practicing these skills by their baby's side during the baby's stay in the facility.

The skills and motivation of the nurses will determine the success of FPC. While nurses can take on the role of day to day training of parents of newborns, doctors also have an equally important role in mentoring the team and providing guidance for implementation of FPC. Both the Doctor Incharge and Nurse Incharge must work together to ensure that the training programme for parents –attendants are regularly and successfully implemented.



2.2.7 Role of health providers for FPC implementation

Roles and responsibilities:

A. Focal point for FPC: A doctor positioned at the SNCU should be designated the overall in- charge of the FPC. His/her role will be to:

- Provide overall guidance and supervision for initiation of FPC in the local unit
- Train all staff in the delivery/conduct of FPC
- Motivate parent-attendants to participate in FPC programme by interacting with them at time of admission & subsequently
- Check continually for the quality of the structured training programme for parents-attendants and provide an ongoing support and supervision

B. Nurse In-charge will:

- Ensure training of all staff members posted in the newborn care unit
- Develop microplan (duty roster) for training sessions for parents-attendants & monitor its achievement each month
- Supervise FPC structured training programme for parents-attendants and data recording on day to day basis
- Identify, on day to day basis, parents-attendants eligible for attending different sessions
- Mobilize the necessary resources (eg; equipment, supplies) required to conduct the sessions and practice FPC
- Must ensure the individualized pre discharge counseling sessions with the key family members are held for every baby before discharge.

C. Nursing staff at SNCU are envisaged as the backbone of the FPC as they will conduct structured sessions for parents-attendants on a day to day basis. They will be involved in:

- Conduct of sessions for parents-attendants
- Maintaining relevant records
- Helping parents-attendants to practice skills in the nursery environment
- Maintaining the infrastructure and resources allocated for FPC training.

2.2.8 Institutional support for FPC

As FPC is an integral part of facility based newborn care, the existing system of collaborating centres for FBNC should provide mentoring support to the State/district level SNCUs for initiating FPC, implementation as per guidelines and quality checks. Each state should aim at establishing a state resource centre for new born care. FPC should be included in the existing supportive supervision checklist in use for recording of the observations and recommendations. Some of the observations to be made by mentors with regards to the FPC implementation are provided in annexure 5.

Quality aspects of Family Participatory Newborn Care should be reviewed in the SNCU Review meetings.

2.3 Implementation Process For Family Participatory Care in SNCU

Making FPC a practice at SNCU involves following steps:

A. Sensitization and counselling of parents-attendants at time of admission

B. Identifying the primary caregiver

C. Conducting daily FPC training/ skill building sessions

D. Engaging mothers/Parent- Attendant bedside in care provision at SNCU

E. Discharge counselling

The entire process is depicted in Annexure 1.

A. Sensitization& counselling of parents-attendants at time of admission

Initial counselling of the parent-attendant from a service provider (preferably the doctor) can go a long way in sensitizing the parents to the concept of FPC and to assess their willingness to participate in the care of their baby about to be admitted to the SNCU. It is also an opportunity for the service providers to understand the family constraints and to assess who are the caregivers and key decision makers in the family.

B. Identifying the primary caregiver

It is quite possible that babies whose mothers have delivered recently are not able to participate in the first few days. Fathers of all babies should be encouraged to participate in the care of their babies as far as feasible. Where parents are available, they should both be inducted into the programme. When both of them are unavailable, another close family member can be included. It is important to emphasize that only the identified primary caregiver/s who are likely to be involved in the long term care of the baby be included in training sessions.

Holding an induction session gives an opportunity to the health care provider to identify the Parent-attendants; counsel and appraise them

regarding the neonate's health condition; to sensitize them regarding the family participatory care programme and also to share details regarding the skill building training sessions.

During the induction session at/after admission

- Communicate to family about neonate's condition.
- Briefly sensitize regarding FPC and seek their willingness for participation.
- Identify 1- 2 care providers who will be available and undergo capacity building to participate in FPC from admission until discharge.

C. Conducting FPC sessions on a daily basis:

As new babies may get admitted and discharged on a daily basis, sessions should be conducted daily. Considering that many parent-attendants are likely to be available for a limited period of time (5-7 days, depending on the baby's condition), the window of opportunity for capacity building will be short.

In each facility practicing FPC, should ideally have a separate room with adequate and appropriate facilities for conducting sessions with parents-attendants and include the following:

- Sufficient space for all parents-attendants to
  - sit comfortably during the session;
  - interact with one another;
  - do hands-on training using equipment (such as mannequin or scrub station) as part of activity-based learning
- Equipment for training for screening of videos using LCD TV or laptop,

There are four sessions for parent –attendant skill building as described below. Weekly/monthly rosters/schedule for nurses conducting the training session with parents-attendants should be planned by the Nurse Incharge and the progress assessed on weekly/monthly basis. The template for scheduling of sessions in the SNCU is provided in Annexure 3.

Session 1: Protocols for entry into the Nursery

Ideally, parents-attendants of all babies must participate in this session prior to entry into the SNCU. This session prepares parents- attendants to enter the nursery following the standard protocols including hand washing & gowning. Parents should be able to participate in this session as early as possible after admission, preferably within first 24-48 hours of baby's admission. They can then be allowed to entry into the nursery. Although the baby's condition may not allow the parents to participate actively in their immediate care, yet being able to visit their baby will go a long way in relieving anxiety and stress and help the mothers of very sick babies to eventually establish breastfeeding.

Session 2: Developmentally supportive care & Feeding

Parent-attendant who have participated in the first session and who are well versed with the steps of handwashing and entry protocols, can participate in the session on the following day. The session introduces the concept of developmental care of newborns and discusses about how to modify the nursery environment and nursing practices. Skills like positioning of preterm babies and nesting are also taught to parents. The session also includes discussion and demonstration of various feeding methods such as breastfeeding, and feeding with katori and spoon using expressed breast milk.

Session 3: Kangaroo Mother Care

This session focuses on the Kangaroo Mother Care, which is primarily relevant or most useful for babies with birth weight less than 2000 grams. Therefore parent-attendants of LBW babies should be taken through this session.

Session 4: Preparation for discharge

This session deals with preparation for discharge and continuing care of the baby in the home environment. All parent-attendants must participate in this session prior to discharge. Parent-attendant should ideally participate in this session when their baby is shifted to step down unit. This provides them with an opportunity to put into practice some of the knowledge that they have acquired through this session and also gain more confidence in caring for their baby independently, in the home environment.

Scheduling of Sessions

Session	When to hold the session
Session 1 (Nursery Entry Protocol)	Daily Start preferably within first day of admission after identifying the primary care provider/ parent-attendant. Repeat till entry protocol is learnt thoroughly.
Session 2 (Developmentally Supportive Care & Feeding)	Daily Start after the 1st session is learnt and parent-attendant is ready to take entry into nursery and reinforce as required.
Session 3 (KMC)	For KMC eligible babies, session should be held, as early as when the doctor advises to initiate it. However, reinforcement sessions may be held as per the need of mother/ Parent- attendant.
Session 4 (Preparation for discharge)	• Start viewing of session 4 when discharge is planned in next 2-3 days. • In case of the unplanned discharge, at least one tutored session must be held before discharge with the key parent-attendants of baby who were and will likely be engaged in care at home.

- It may be good idea to conduct session 1 in morning and session 2 in the afternoon shift. By scheduling session in both morning and afternoon shift, the workload is distributed across the day and across the team members. All sessions should be held as per the schedule every day at the pre-decided hour.
- By involving all staff members, the FPC will be institutionalized and there will be collective ownership for its success. The monthly or weekly scheduling, specifying the name of the person responsible for conducting the session each day will ensure that the sessions are held as per the plan.
- The participation of parent-attendants should be planned in such a way that they are not required to attend more than one session on the same

day. This will help avoid information overload and overwhelming the parents who are already in a state of anxiety.

- There are likely to be few exceptions to the general plan described here (eg; parent-attendants whose babies are discharged in 3 days or less; baby is referred to higher centre midcourse etc.), in which case it is left to the discretion of the nurse-incharge to decide the best way in which parent-attendant can participate in the sessions relevant to them.

D. Engaging mothers/ parent-attendants bedside in care provision at SNCU

After going through training sessions where they have been tutored and demonstrated the skills, mother/ parent-attendants need to be practicing the skills by their baby's bedside in the nursery. However, before they can independently perform any activity they are supervised by the nurse and facilitated by the process of lateral peer to peer learning.

Parent-attendants are there to complement the care of their own baby and thus providers have to be mindful of shifting tasks to mothers beyond the prescribed scope.

E. Discharge counselling

An interaction with family must be organized and planned individually for each baby before discharge by preferably the team of both doctor and nurse. The key decision makers from the family and primary care providers of the baby should attend this interaction. During this session the providers try to emphasize on key issues of post discharge care at home and address any concerns and queries in that family's context regarding baby's care at home.

2.4 Record keeping and reporting on key indicators

The following additional indicators should be reported by SNCUs on a monthly basis. Apart from the facility level record keeping, programme managers should monitor FPC by collecting data on the following.

Facility Indicators of FPC

S. no.	Parameters to be recorded	Indicator	Data source	Maintained by	Frequency of recording
1	Family participatory care at identified sick new born units made functional.	a) No. of SNCUs where FPC is initiated* /total number of functional SNCUs in the state (Criteria for initiation: All providers trained; parents actively participate in caring for their baby by taking on non-medical tasks) b) No. of SNCUs in which families participate* in care of admitted newborns *(Criteria for participation : Mother/parent –attendant stays for atleast 3-4 hours with the baby at a stretch)	Training records Observation & display of policy; feedback from parents (questionnaire)	Programme Managers	6 monthly
2	To monitor that sessions are being held regularly	Number of SNCU admitted newborn's families participated in training /total number of newborns discharged from SNCU in the month	FPC session register (Annexure 4)	Nurse staff	Monthly
3	Enhanced skills of mothers/ families for providing optimal care to sick & small new borns.	Number of babies <2000 grams birth weight whose families participated in the session on KMC / Total number of babies < 2000 grams birth weight discharged	FPC session register (Annexure 4)	Nurse staff	Monthly

Qualitative Feedback in the form of interviews and FGDs with staff nurses and parents-attendants and mothers can be undertaken by mentoring institutions periodically and should provide additional inputs for the fine tuning of the programme.

Additionally among high risk SNCU graduates, outcomes such as re-hospitalisation rate and the post-discharge mortality should be tracked during Follow up of SNCU discharged babies up to one year of age as described in the next section.

2.5 Linking Family Participatory Care with community based care

Many newborns die in the community after being discharged from newborn care units /SNCUs due to either lack of adequate care at home or delay in timely health care seeking during sickness. Mother and family often lack the knowledge and essential skills of newborn care for these high risk vulnerable neonates who are most at risk of dying either at facilities or subsequently at home after discharge.

FPC is and should be viewed as an integral part of Facility based Newborn Care that aptly links to home based newborn care. FPC by building care giving competencies during period of hospitalization will likely lay firm foundations for continuum of care and better survival after discharge from hospital to home and improving overall health outcomes of the newborn infants.

In this regard GOI is implementing Follow up of SNCU discharges up to one year and the schedule for these visits is as follows:

I. In case of SNCU discharged newborns, the day of discharge from SNCU is to be taken as day one. ASHAs will make the first home visit within 24 hours of discharge (Day 1) and complete the remaining home visits as per HBNC visit schedule i.e. 3,7,14, 21, 28 and 42nd day from the day of discharge.

II. On completion of these visits ASHA will conduct follow up visit once every quarter starting from 3rd month onwards till one year of life i.e., four visits at the completion of 3rd, 6th, 9th and 12th months of life.

These visits will ensure compliance with discharge instructions, promoting early child development and promoting Kangaroo Mother Care (which includes skin to skin contact, warmth and exclusive breastfeeding including special feeding for small babies). If danger signs are detected, then the new-born are referred back to the concerned facility.

Child Death Review should be conducted as per GOI guidelines in order to identify the systems response to the prevent repetition of lapses after ascertaining the medical, social and programmatic reasons for mortality and to or take corrective actions.

2.6 Budget provision for operationalizing Family Participatory Care

In 2014, GOI released operational guidelines for setting up of KMC units at SNCUs. It had budgetary provisions for the similar infrastructure, equipment and supplies as those required for FPC. Therefore the recommendation is that for one time cost the budget may be proposed in PIP and in case the SNCU has made the structural enhancements for the KMC unit then the proposal may be made for the additionalities required under FPC.

The recurring cost for FPC should be mobilized from the annual recurring cost provided to SNCU under NHM.

The training of doctors and nurses on FPC can either be budgeted as part of Child Health Trainings based on the revised RCH training norms in the annual state PIP. The programme officer must ensure the provisions for boarding, lodging and travel as interdistrict providers will be included in a batch and thus adequate budget may be proposed. An indicative budget guides the manager to propose for the same.

Provision for following budget heads should be made for the following:

1. Infrastructural requirements
2. Logistics and supplies (includes TV / Laptop etc)
3. Adaptation of training package in local language
4. Training of trainers at State / Divisional level
5. IEC / Poster material in regional language

An illustrative budget is presented in this section.

Operationalizing FPC : Illustrative budget

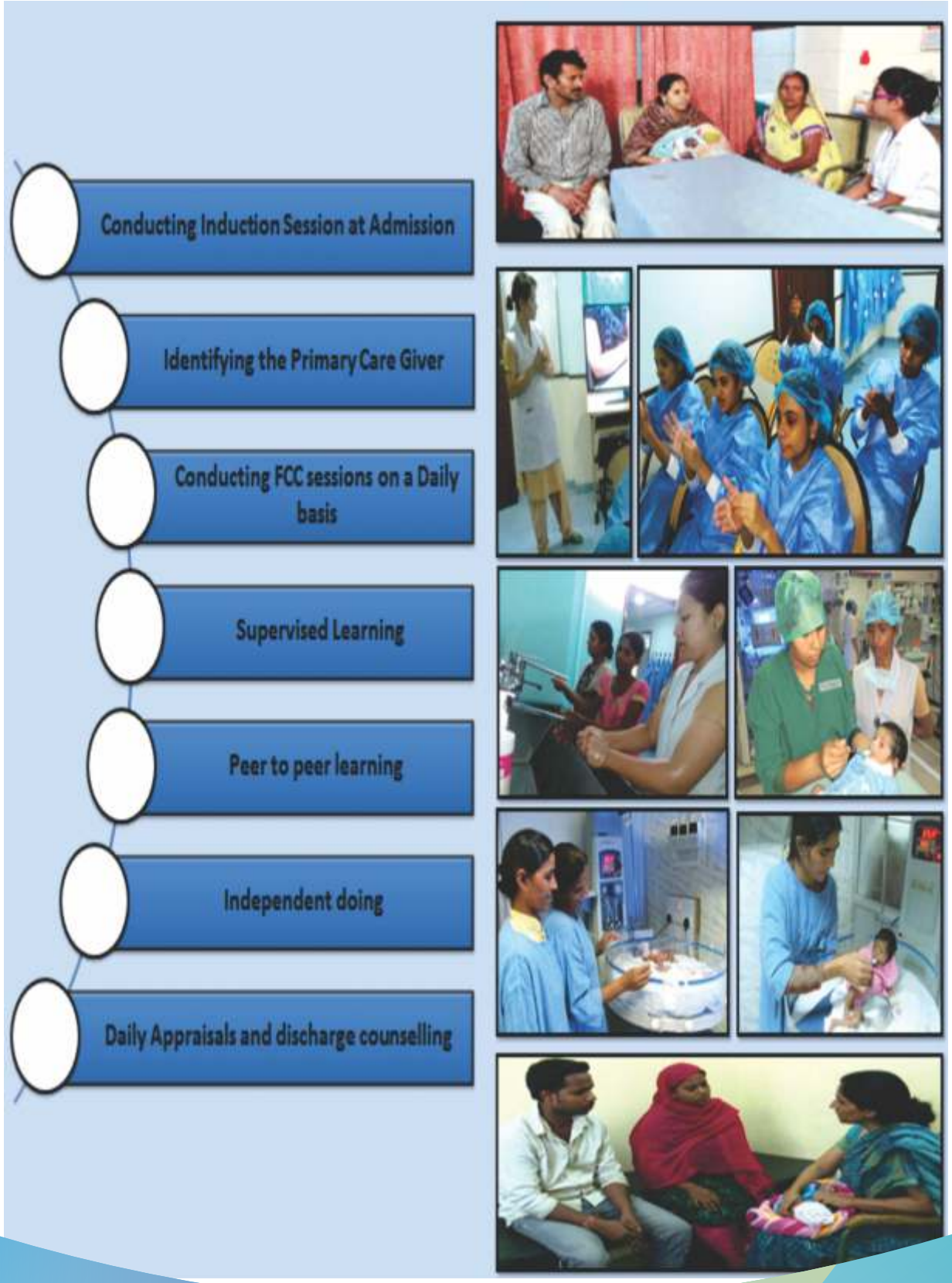
S.N.	Particulars	Number	Unit Cost	No. of Days	Amount (in Rs.)	Remarks
1	**Infrastructure**					
	To be budgeted as provisioned for KMC Unit	(Refer to operational guidelines for KMC & Optimal Feeding for LBW babies GOI 2014 and prepare the budget under the same heads)				
2	**Supplies**					
	To be budgeted under the annual operational cost of SNCU	Additional cost for FPC to be added to the annual recurring cost of SNCU proposed under FMR Code A2				
3	**FPC training Budget**					
	Translation of training Guide and Dubbing of Audio Visual Package in Local language				Lumpsum 150,000	
4	**Printing of Training Package & IEC**					
	Layout				50,000	
	Printing	500	250		125,000	
	IEC				50,000	
5	**Training of trainers (ToT) at State level**					
	No. of Participants/per batch	24 (Average) Doctors & Nurses working at SNCUs				
	No. of Resource Persons	3 per batch				
5.A. Resource Person						
A.1	Honorarium, Resource Persons-Full Day	3	2000	2	12000	As per State RCH Norms and as per actuals.
A.2	Travel of resource persons (from duty station to the training venue and back including station transfers)	3	10000	1	30000	
A.3	Accommodation for trainers (single room)	3	3000	2	18000	
A.4	Hiring of Vehicle for trainers and participants	3	2000	2	12000	
5.B. Trainees Expenditure						
B.1	TA to Participants	24	2000	1	48000	As per State RCH Norms and as per actuals.
B.2	DA to Participants (Group A Equivalent/Doctors)	8	700	2	11200	As per State RCH Norms and as per actuals.
B.3	DA to Participants (Group B, C/Nurses)	16	400	2	12800	

S.N.	Particulars	Number	Unit Cost	No. of Days	Amount (in Rs.)	Remarks
B.4	Refreshment (Lunch, Tea, Dinner etc.)	24	500	2	24,000	
B.5	Accommodation for trainees (on twin sharing basis)	24	2000	2	96000	
5.C. Expenditure related to Training						
C1	Hiring of venue including Hiring of TV, DVD, Laptop with power back up support	1	2500	2	5000	As per actuals may vary
C2	FPCModule and DVDs, Stationery (Folder with one pen and writing pad)	24	300	1	7200	As per State RCH Norms and as per actuals.
C3	Incidental Expenses: Overhead (Banner, Certificate etc.)	1	2500	1	2500	For each batch
	Subtotal for State TOT				**278,700**	
6. District Level Training at SNCU						
6.1	Training Material, refreshment etc.	20	500	1	10,000	per SNCU

Annexure

Annexure 1:

SENSITIZATION AND SKILL BUILDING OF PARENTS-ATTENDANTS: THE PROCESS



Annexure 2:

Scope of Parent- Attendant Skill Building

Session	Domains covered in the session
Session 1 **(Nursery Entry Protocol)**	• Sensitization to FPC • Preparation for entry into nursery • Hand washing • Gowning • Familiarizing with environment of nursery
Session 2 **(DSC & Feeding)**	• Developmentally supportive care (DSC) • Cleaning the soiled baby • Breastfeeding • Expression of Breast Milk • Paladai feeding/ katori feeding • When to alert the provider?
Session 3 **(KMC)**	• Kangaroo Mother Care (KMC)
Session 4 **(Preparation for discharge)**	• Preparation for discharge & care at home • Hand washing/Prevention of infection/ Hygiene • Sponging / Cleaning • Appropriate Clothing/Thermal care • Breast feeding & KMC • Care of the cord & eye • Danger signs & seeking medical help • Follow up & compliance with discharge instructions • Immunization

Annexure 3:

Template for scheduling FPC sessions

Staff Roster for conducting sessions with parents-attendants						
	Morning shift				Evening shift	
Date/day	Session planned & name of the staff	Held Y/N	Session planned & name of the staff	Held Y/N	Session planned & name of the staff	Held Y/N
01.01.2017	Session 1: Anita		No session		Session 4: Reena	
02.01.2017	Session 1: Jose		Session 2: Jinny		Session 3: Sunita	
03.01.2017	Session 1: Jose		Session 2: Jinny		Session 3: Sunita	

Annexure 4:

Register for recording sessions attended by parents- attendants

ID number	Name/ID	Date & time of admission	Birth weight (grams)	Participated in any Session (Y/N)				Specify outcome (Discharged, Referred, Died, LAMA)	Discharged from unit Y/N
				Entry protocol	DSC & feeding	KMC	Discharge counselling		
Monthly Total									

The last three columns can be added in the routine reporting register of SNCU when FPC is initiated in the unit.

Annexure 5:

Observers' checklist to be used during mentoring / supportive supervision visits

Sr. No.	Observations	Yes/No	Remarks
1	Designated area for organizing session with parents-attendants, equipped with AV equipment & chairs		
2	Schedule for organizing parents-attendants sessions displayed/available in SNCU		
3	Sessions for parents-attendants being held routinely (talk to mothers/staff)		
4	Supplies such as gowns , slippers and handwash/ soap etc. available for parents-attendants to observe mandated entry protocols		
5	Bedside (next to Radiant Warmer) chairs for mothers to sit comfortably		
6	Parent-attendant are assisted by nurses for breastfeeding & KMC		
7	Mothers can demonstrate the steps of hand washing		
8	Mother/s (scheduled for discharge) is/are aware of danger signs		

Note: *The items on this checklist should be integrated into the mentoring checklist for SNCU*

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