



Family Participatory Care in India: Partnering with families to care for small and sick new-borns

Arti Maria

**MD,DM Neonatology
India**

Year 2007

State of Newborn care

SETTING

- 16 bedded
- referral neonatal intensive care unit of north India
- Severe HR constraints



Incessant Alarms !!



Wet Babies !



IV swellings!



Misplaced Tubes/probes!!



Common scene outside the neonatal unit.....
Parent Attendants lined waiting..... !!





“Can we start ‘engaging’ the waiting parent attendants *as nursing aides* for their own babies?”

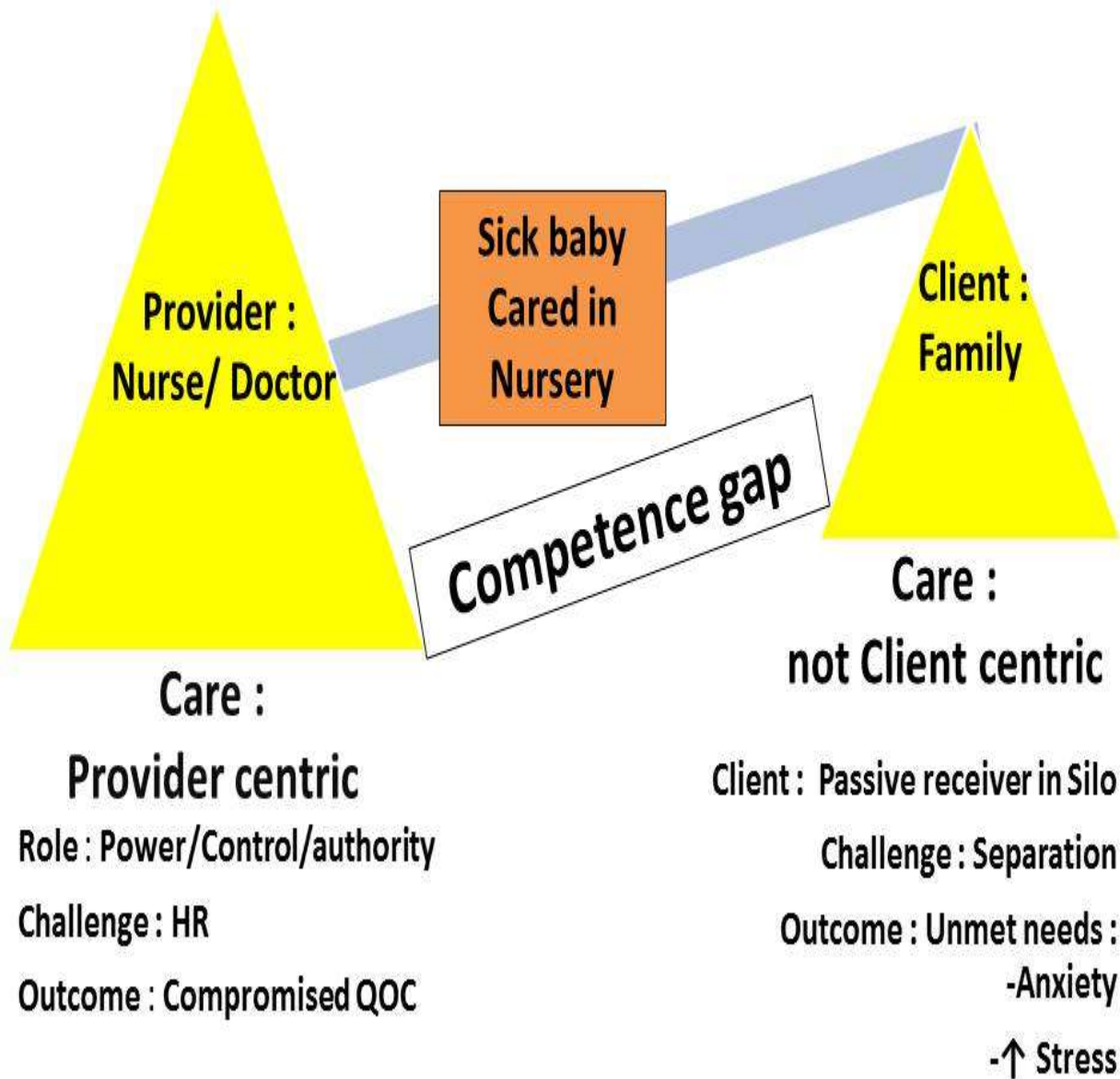
WHAT DID WE SEE?

FRINGE BENEFITS!!!

- Parents
- Babies
- Nurses



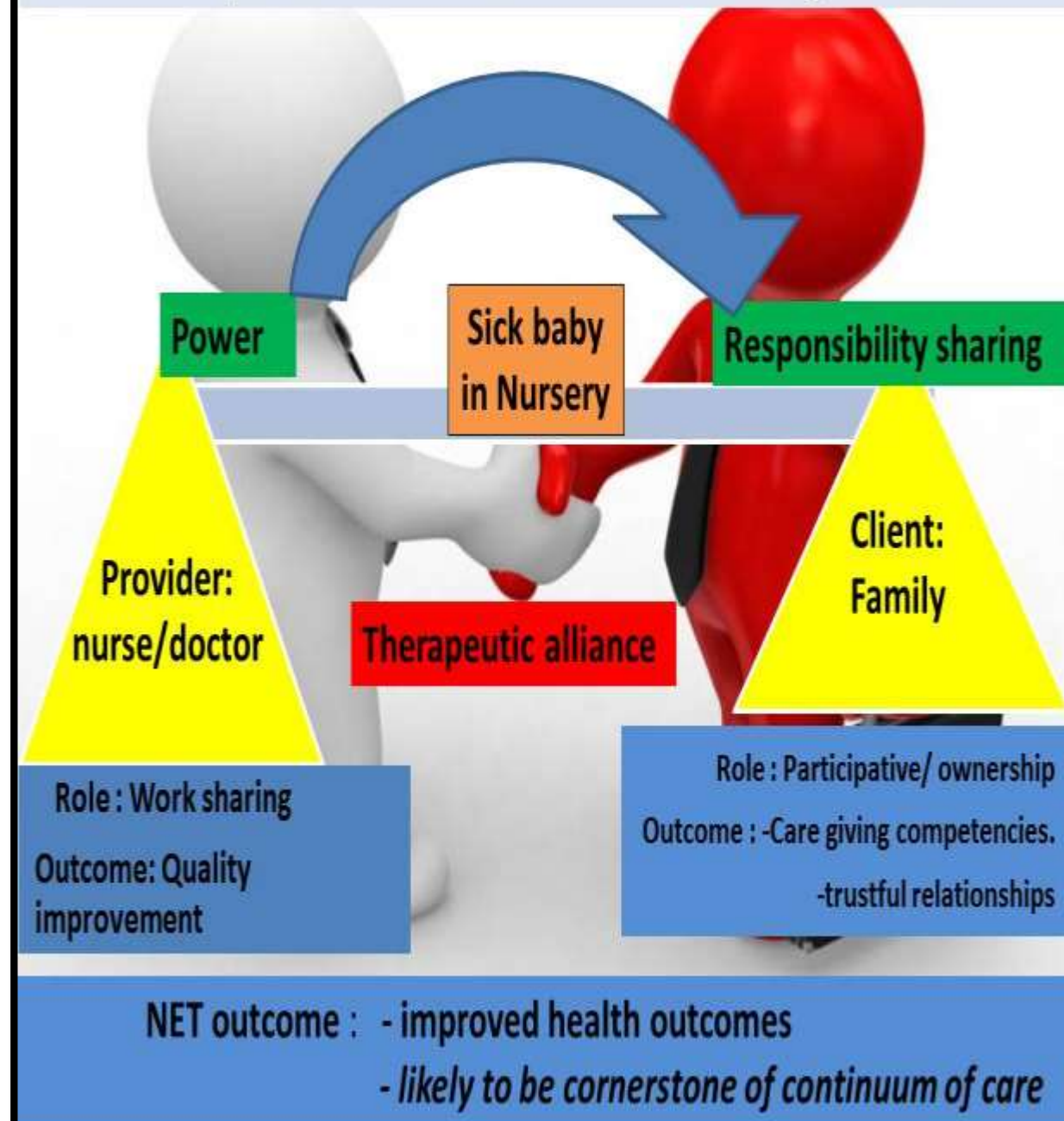
Conventional Model for care of a sick newborn



Gaps: Conventional care

- Less Attention to
 - Sick babies' development
 - Psychosocial needs of family
- Parental involvement in care/decision making is: limited.
- Universal human workforce shortages: compromised QoC.
- Lack of continuum of care at home.

Family Centric Care : A Paradigm Shift



An *approach*,
an *attitude*,
a *mindset*,
a *concept*

WHAT is FCC?

that **aims to develop and nurture family's role in partnership** with **health care team** in care of a patient .



Family-Centered Care to Complement Care of Sick Newborns: A Randomized Controlled Trial

ANKIT VERMA, ARTI MARIA, *RAVINDRA MOHAN PANDEY, [§]CHAROO HANS, ARUSHI VERMA AND [#]FAHIMA SHERWANI
 From Departments of Pediatrics and [§]Microbiology, PGIMER and Dr. RML Hospital; ^{*}Biostatistics, AIIMS; and
[#]Management Studies, IIT, New Delhi, India.

TABLE III SUMMARY OF OUTCOMES IN THE TWO GROUP OF SICK NEWBORNS

Outcome variables	Control group (n=147)	Intervention group (n=148)	Mean difference (95% CI)	P value
Culture positive nosocomial infection rate	7.17	6.43	0.74 (-4.21, 5.6)	0.76
Culture negative nosocomial infection rate	9.86	10.56	-0.70 (-6.6, 5.2)	0.82
Duration of stay, median (IQR)	11 (7,18)	11.5 (7,17.5)		>0.05
Mortality, No. (%)	13 (8.8)	10 (6.8)	(0.042, 0.134)	0.5
Breastfeeding rate, No. (%)	98 (66.7)	119 (80.4)	(0.59, 0.74)	0.007

No ↑ in Infection
↓ Hospital stay
↑ Breast feeding

Audio-Visual Training Tool : 4 Modules

1- Entry Protocol



2- Developmentally Supportive Care



2- Developmentally Supportive Care contd...(Feeding)

AV Training Module Contd...



3- Kangaroo Mother Care



4- Preparation for Discharge and care at Home



Institutionalising Family Centred Care: The Process

Induction at Admission & Identification of Primary Care Provider



1

Daily Trainings Scheduled



2

Demonstrations and Practice



3

Supervised Learning



4

Peer To Peer Learning



5

Independent Doing



6

Discharge Counseling



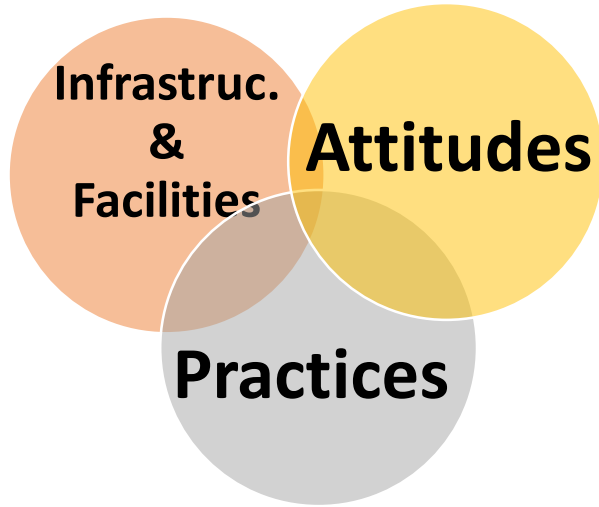
7

Continuum of Care at home



8

Implementation

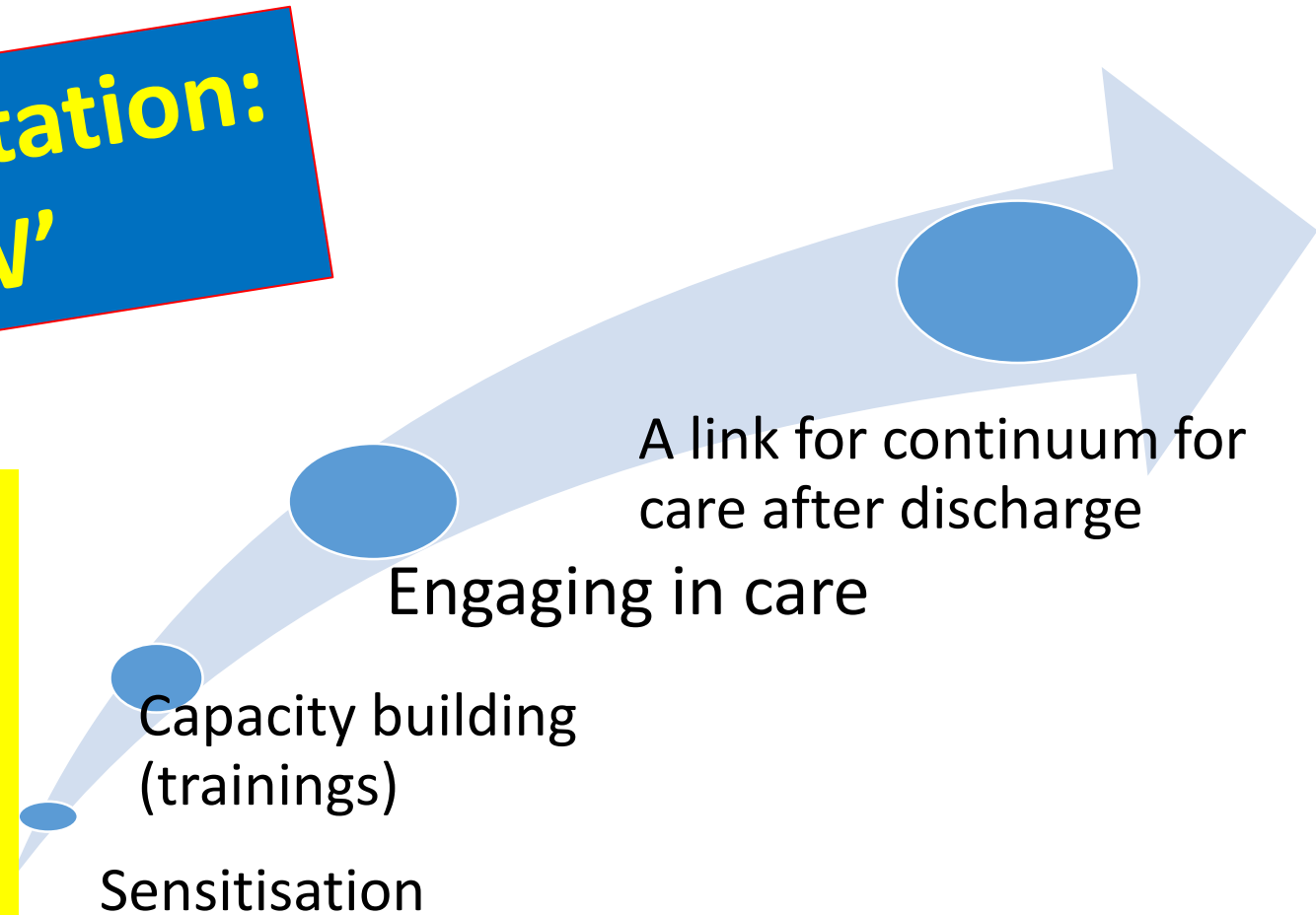


Aim: Getting *mother to participate in care of* their babies through acquired competencies

**Implementation:
'HOW'**

Lessons Learnt

- **Mothers:** Easy buy in!
- **Providers:** Challenges!!
 - ❖ Accepting P-A as a co-partner in care !
 - ❖ Diminished authority?
 - ❖ Watch Dog Effect!!
 - ❖ Tend to task shift!!
 - ❖ Expected to deliver a standard of care !!



Measures & Attributes of Implementation

(June'16-July'17)

1. Measure of Implementation

- Workspace readiness
(Infrastructure-Facilities)
- Parent/Attendant preparedness *(Practices)*
- Staff preparedness *(Attitudes)*

2. Feasibility

- 61% Males
- 37% Fathers
- 20% Grandparents
- 41% > 50 years old
- 25% Illiterate

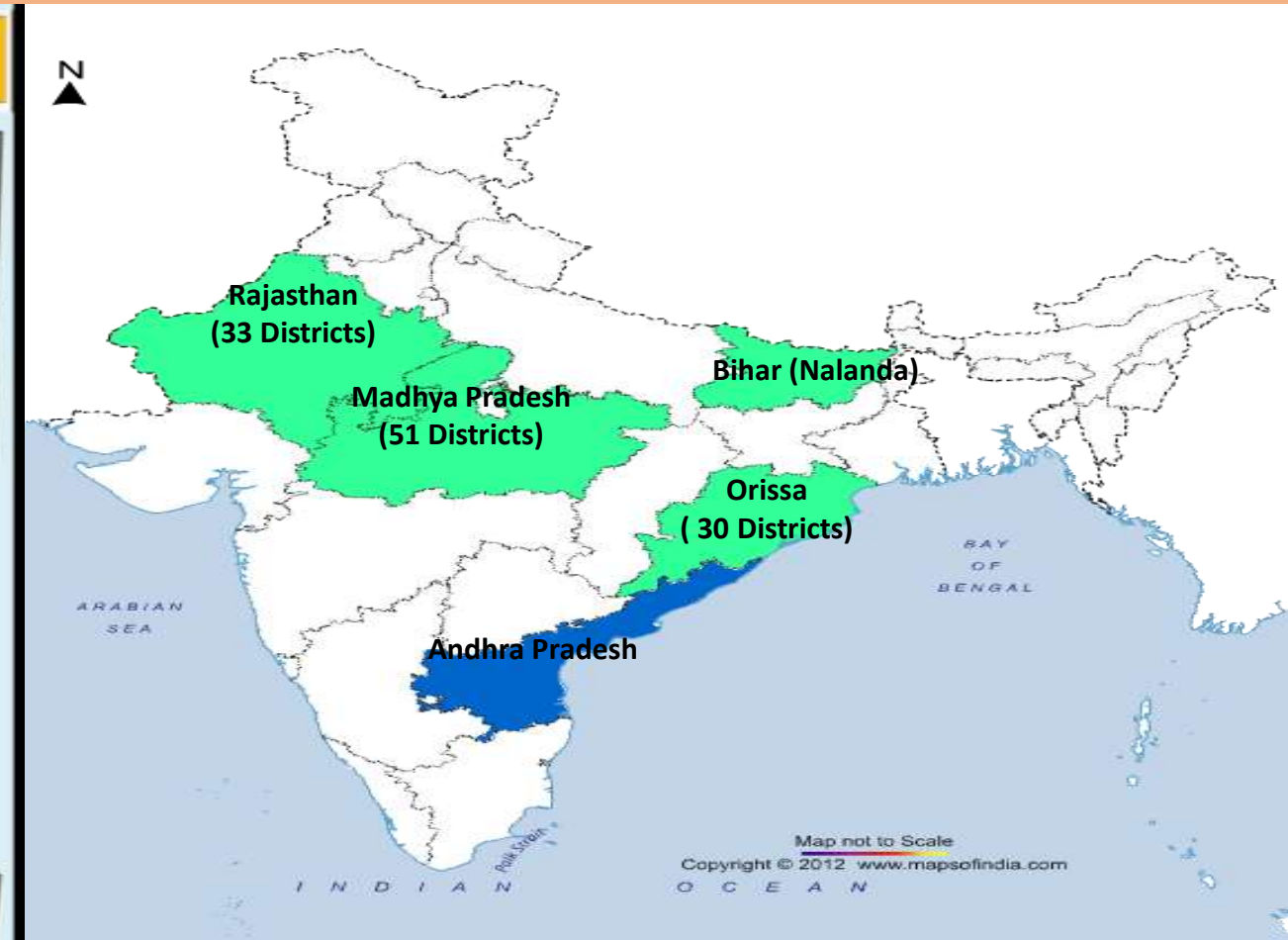
3. Acceptability

- Qualitative study (2016)*
- Primary gains:
(Empowerment, Skills, Continuum of Care)
 - Improved patient- staff relation

4. Measure of Quality of Care

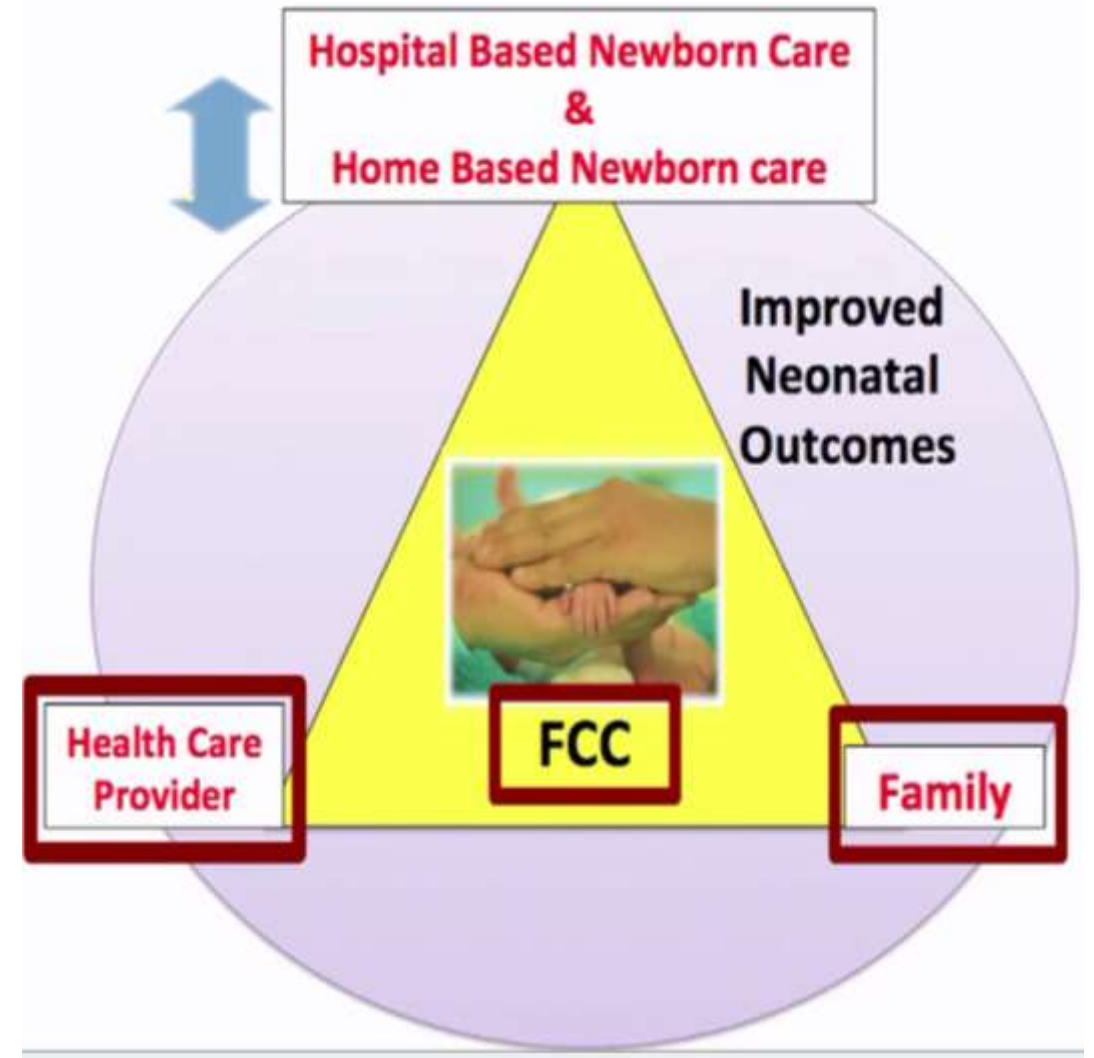
- Participatopn of Mothers in Care in processes of care**
- Nesting,
 - Positioning,
 - Cleaning,
 - Skin to Skin Care

Country Scale up (2014- till date).....



To conclude, Family Centred Care

- A humane way to care.
- Creates an opportunity for lifelong bonding.
- Family's right to a respectful care : (Need to protect, support & promote.)
- Operational feasibility & acceptability in Indian health care setting seem to be promising.



Family Centred Newborn Care holds the key for developing social accountability of health that may help achieve Sustainable Development Goals.

Acknowledgement

- NIPI, USAID-ASSIST, INCLEN
- National and state governments
- Babies and their families for participation and consent for pictures
- Our unit staff /doctors and RML Hospital

