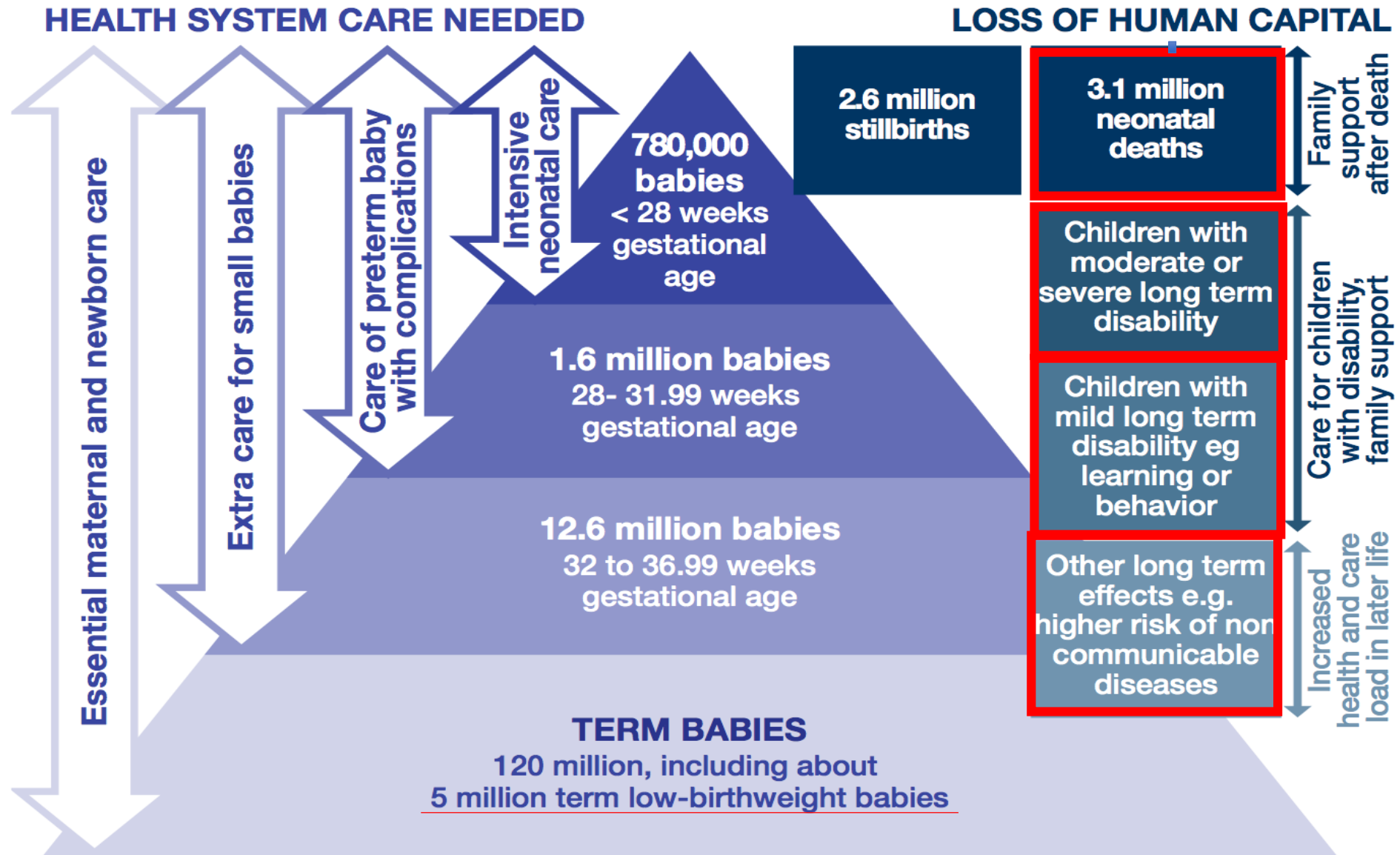


# Infant- & Family-Centred Developmental Care (IFCDC) in a global *systems* perspective



Björn Westrup Neonatology Karolinska Institute, Stockholm  
Kaye Spence Neonatology Sydney Children's Hospitals Network, Sydney

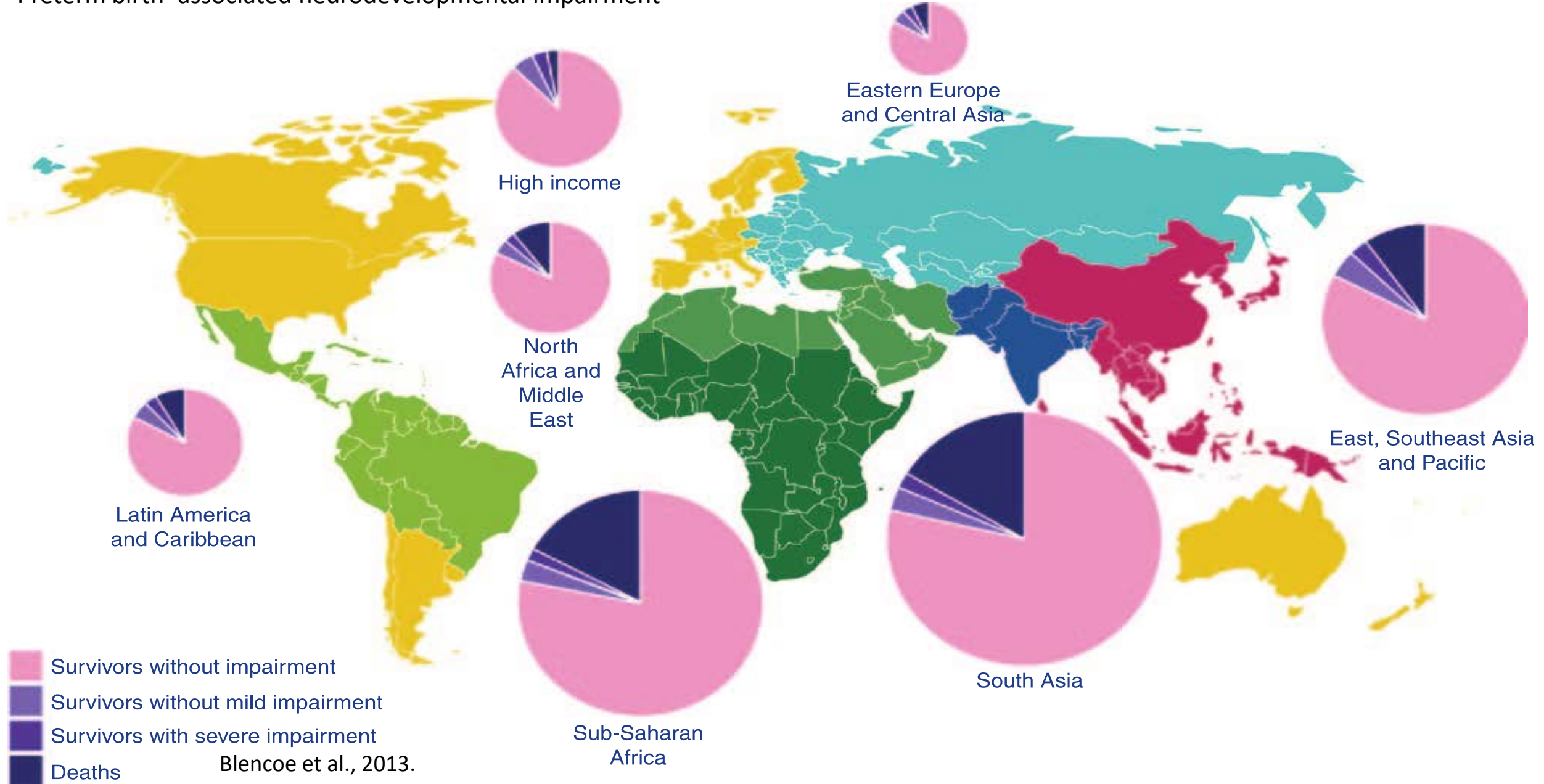
# A global systems perspective



Source: Analysis using data from Blencowe et al., 2012; Cousens et al., 2011; Liu et al., 2012

## • The Scale of the Problem

Preterm birth–associated neurodevelopmental impairment



***Nurturing care:  
promoting early childhood development***

*... the evidence now strongly suggests that parents, caregivers, and families need to be supported in providing nurturing care and protection in order for young children to achieve their developmental potential.*

*Pia R Britto, Zulfiqar A Bhutta, PhD et al. The Lancet Volume 389, Issue 10064, Pages 91-102 (January 2017)*

# Terminology

- Developmental Care (DC)
- Family Centered Care (FCC)
- Patient- & Family-Centered Care (PFCC) – USA
- Family Integrated Care (FiCare) – Canada
- Family Participatory Care (FPC) – India
- *Infant- & Family-Centred Developmental Care (IFCDC) – Globally*

# Terminology

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- *Infant- & Family-Centred **Developmental** Care (IFCDC) – Globally*

## *Infant- and Family-Centred Developmental Care (IFCDC)*

The *generic* term of *nurturing care of the newborn* with goal to ensure the best health and development into adulthood for every individual infant, by optimising both the *individual care* of the newborn as well as the *hospital systems*.

It is founded on the

- leading-edge work of *Berry Brazelton* and *Heidelise Als*
- *Declaration of Infants' Rights* – World Association for Infant Mental Health (WAIMH) 2016

Note that “*a generic term*”

A name relating to a *class* or *group* of things/entities

Non-specific

General

All-inclusive

Collective

Umbrella



# *Infant- and family-centred developmental care (IFCDC)*

**IFCDC** is founded on

- The Declaration of Infant's Rights
- Concepts of
  - neurobehaviour
  - neurodevelopment
  - parent-infant interaction (early relationship)
  - parental involvement
  - breastfeeding promotion
  - environmental and systems adaptation

# Declaration of Infants' Rights

World Association for Infant Mental Health

- Infants have unique nonverbal ways of expressing themselves and their capacities to feel, to form close and secure relationships, and to explore the environment and learn.
- All of which require appropriate nurturing since it is fundamental for building a lifetime of mental and physical health.
- Caregiving relationships that are sensitive and responsive to infant needs are critical to human development.
- Acknowledge the unique ways that infants express themselves and educate mothers, fathers, caregivers and professionals in their recognition of relationship-based attachment behaviors.

# Declaration of Infants' Rights

World Association for Infant Mental Health

- An infant is a citizen, and having the right for identity from the moment of birth.
- The infant's status of a person is to include equal value for life regardless of gender or any individual characteristics such as those of disability.
- The Infant has the right to be given nurturance that includes love, physical and emotional safety, adequate nutrition and sleep, in order to promote normal development.
- Provide adequate circumstances, including time for mothers, fathers, caregivers to get to know their infants and become skilled in providing for their infant's care and comfort

# Declaration of Infants' Rights

World Association for Infant Mental Health

- The infant shall, wherever possible, grow up in the care and under the responsibility of his parents

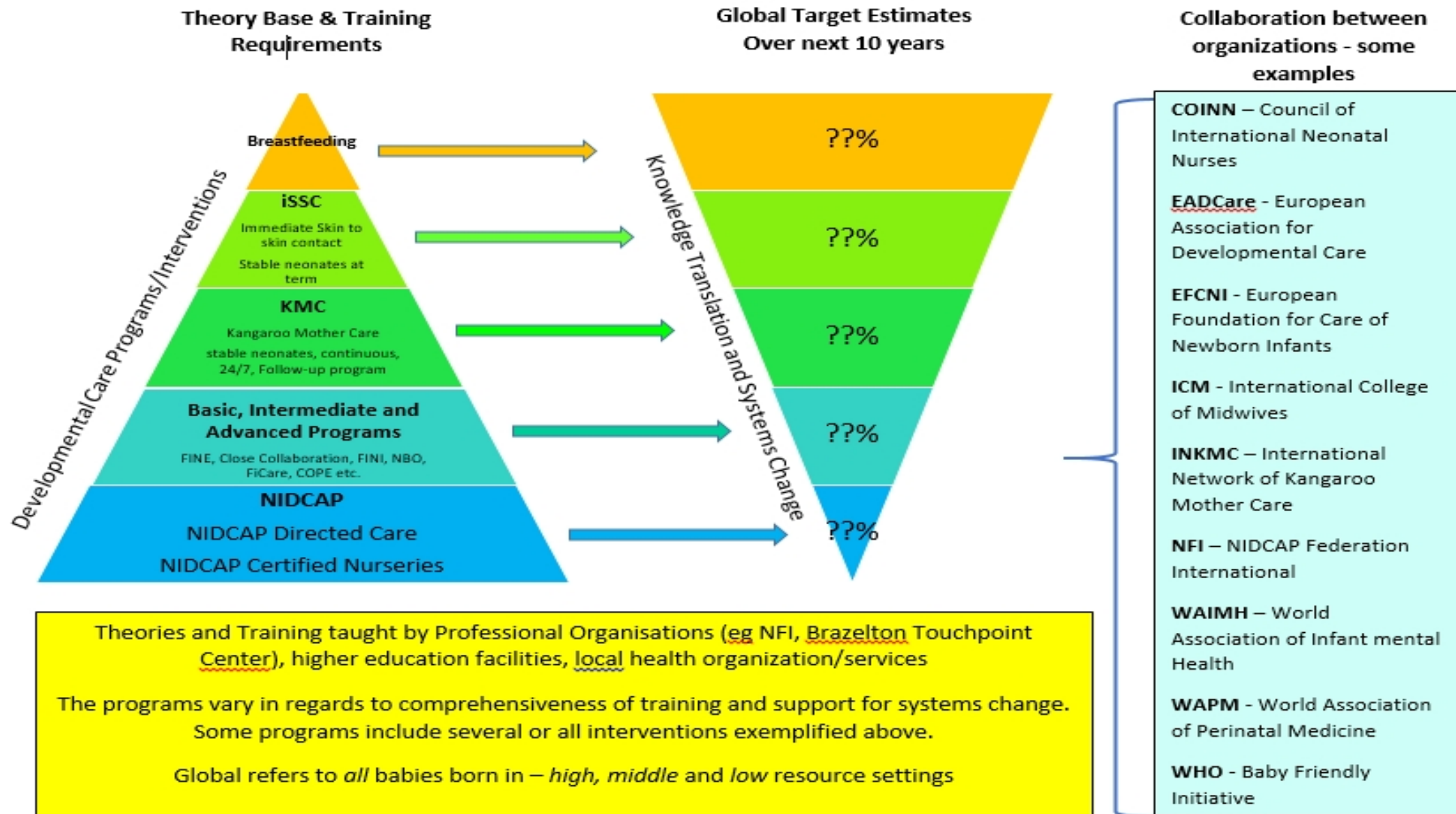
WAIMH. Declaration of Infants' Rights. 2016.

<https://perspectives.waimh.org/2016/06/15/waimh-position-paper-on-the-rights-of-infants/>

IFCDC has three core principles:

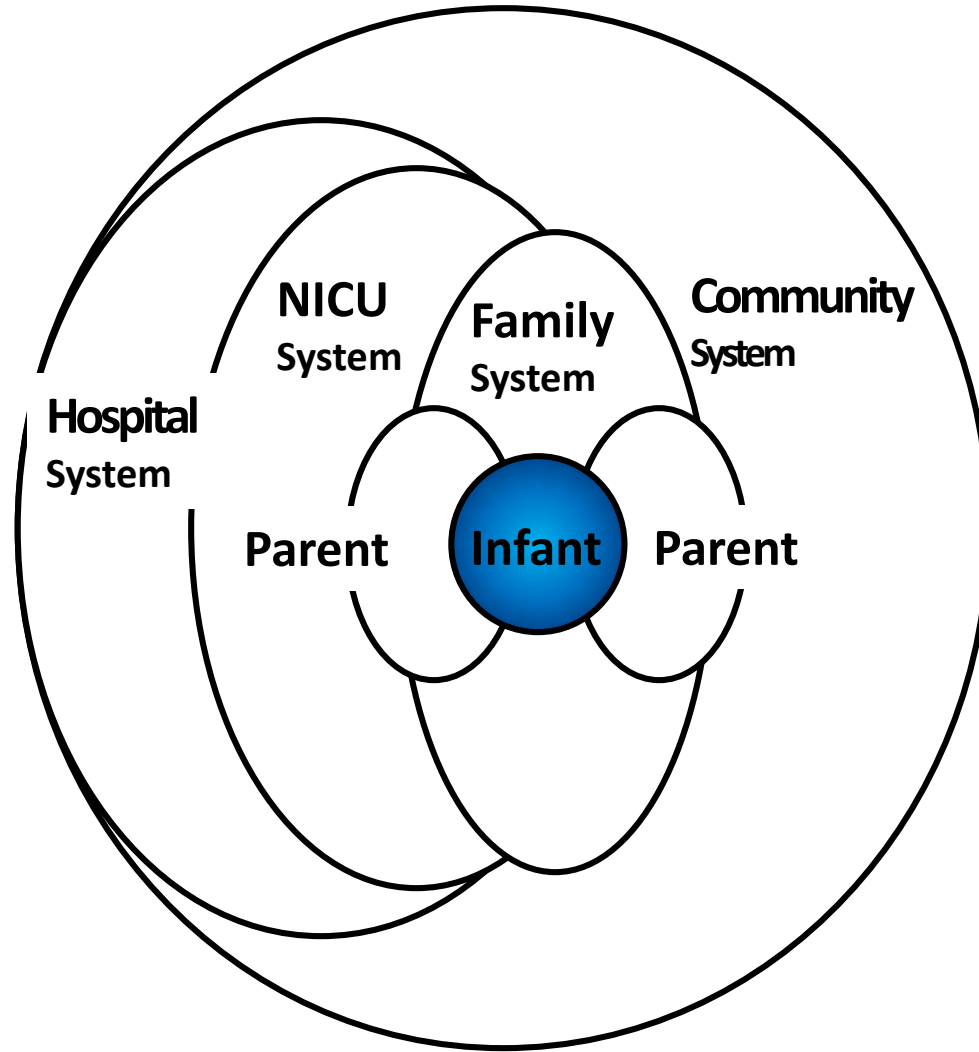
- *Sensitive* care based on the behavioural communication of the infant is an essential foundation for child development
- *Parent engagement* is good for
  - parental well-being,
  - parent-infant relationship and consequently
  - child development
- *Individualised care* gives the baby a voice of its own

# Global Perspective of Infant and Family Centered Developmental Care

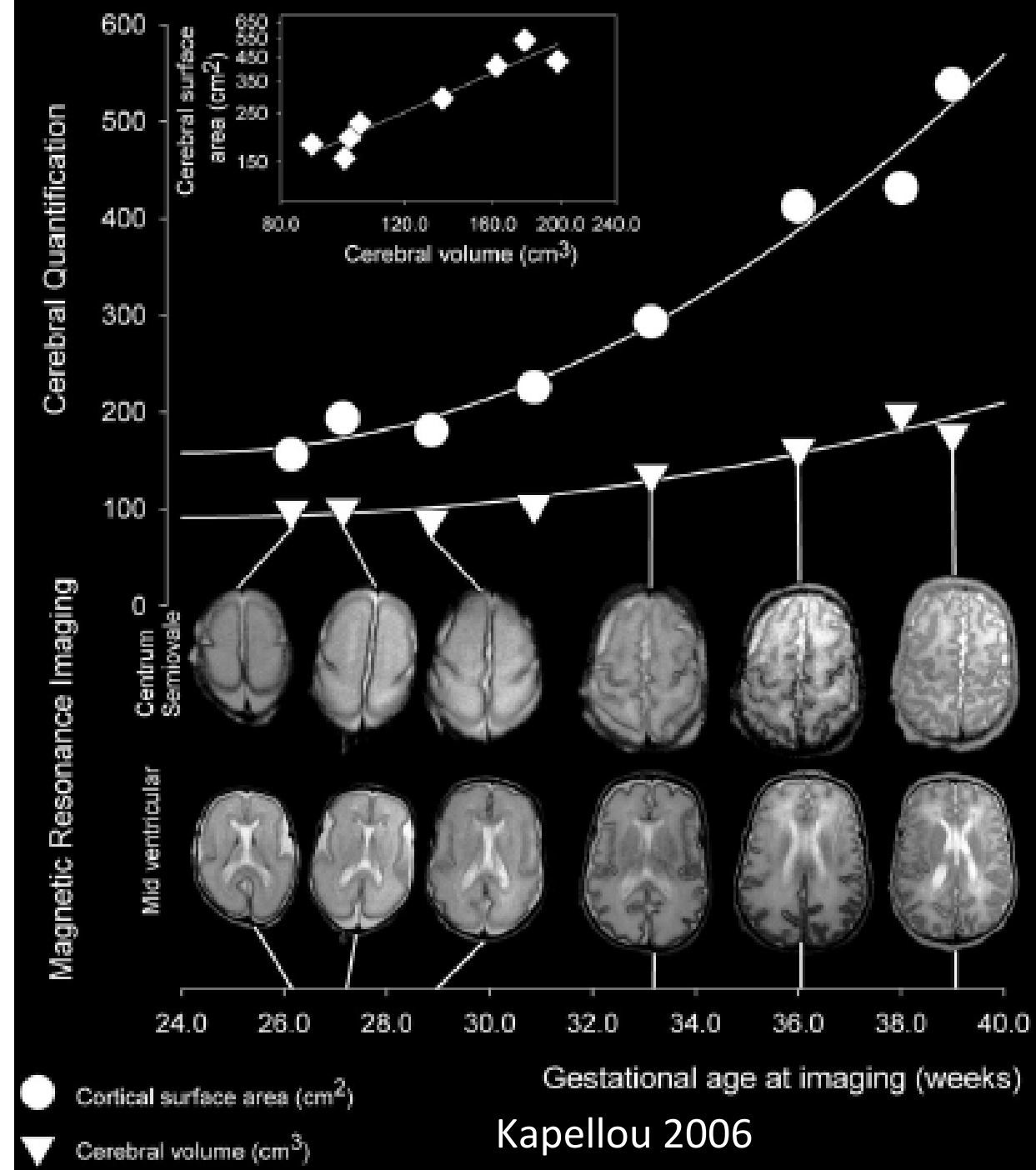


- <https://newborn-health-standards.org/>

# Synactive Model of systems perspective

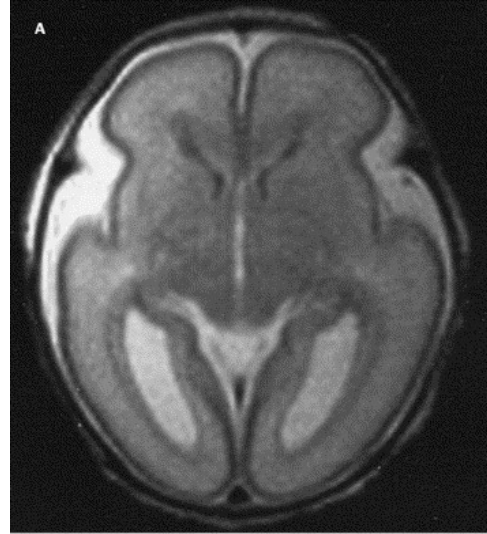




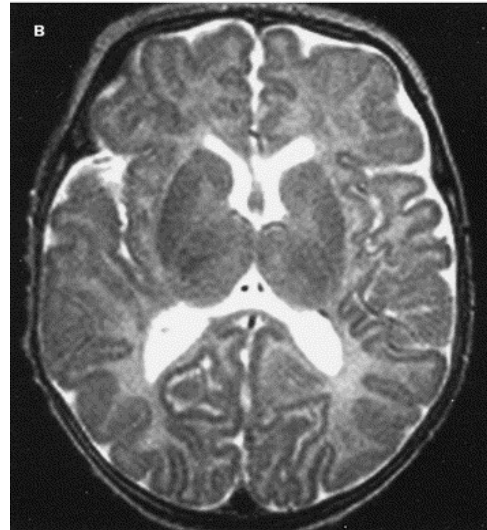


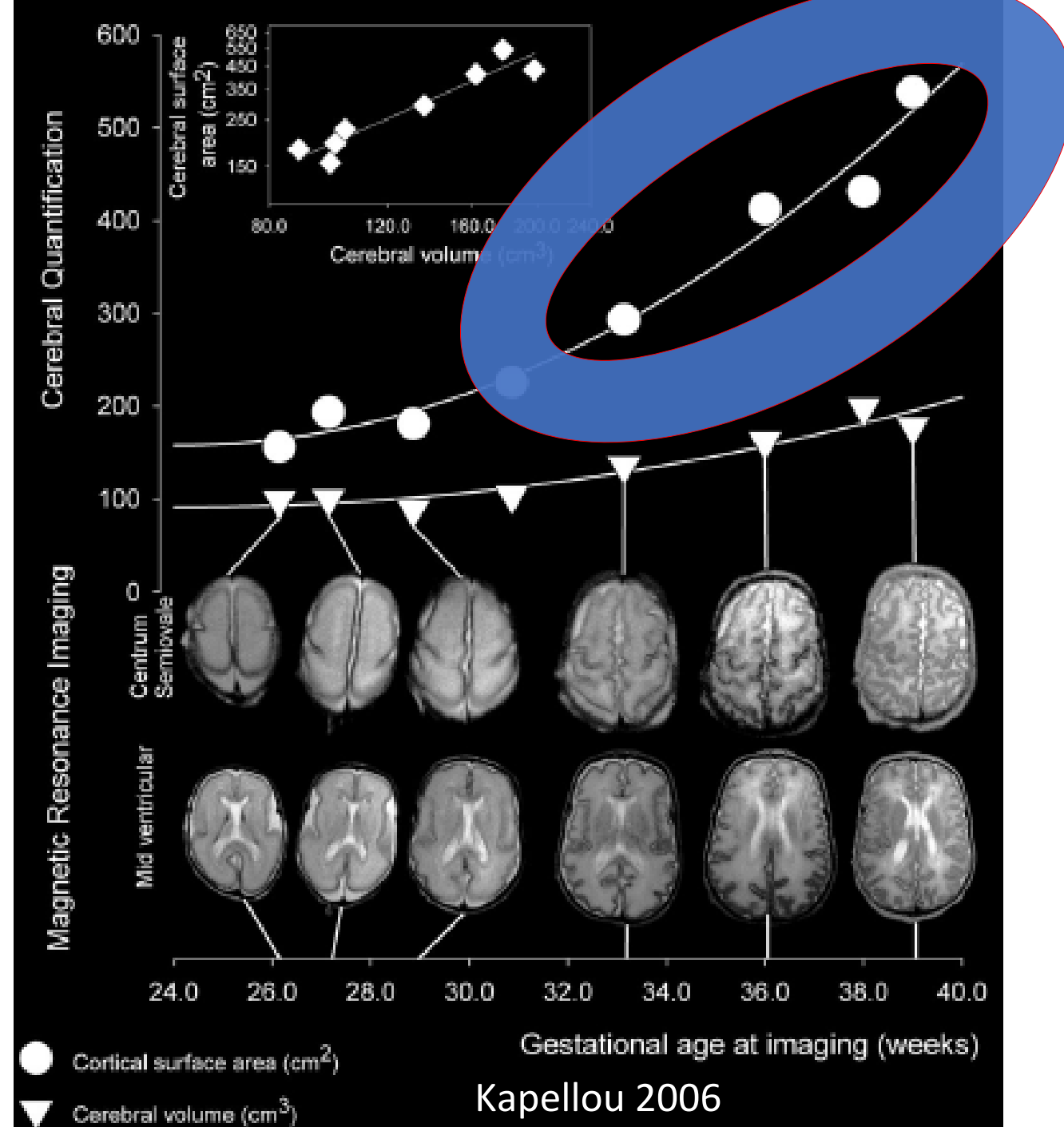
# Structure and function of the brain is different

25 weeks



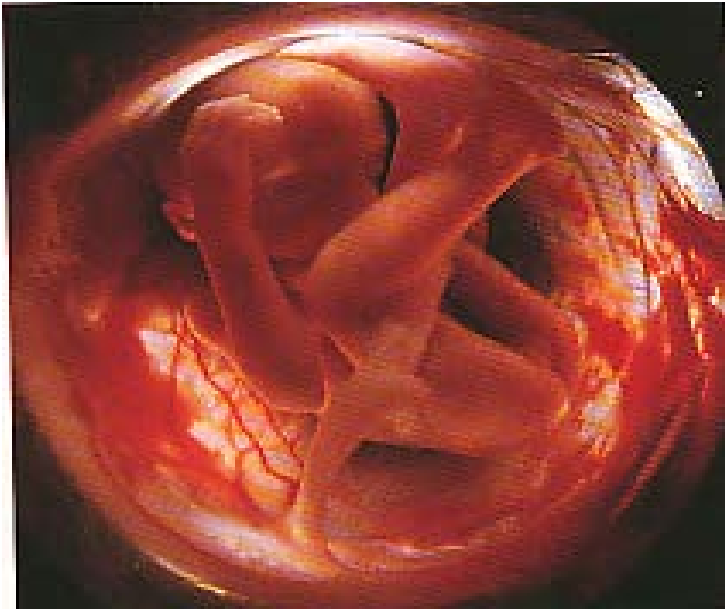
Term





The premature infants brain is undergoing a rapid development with delicate differentiation.

The development of the brain is regulated in our genes – but the fine regulation and differentiation is also dependent on sensory stimuli.

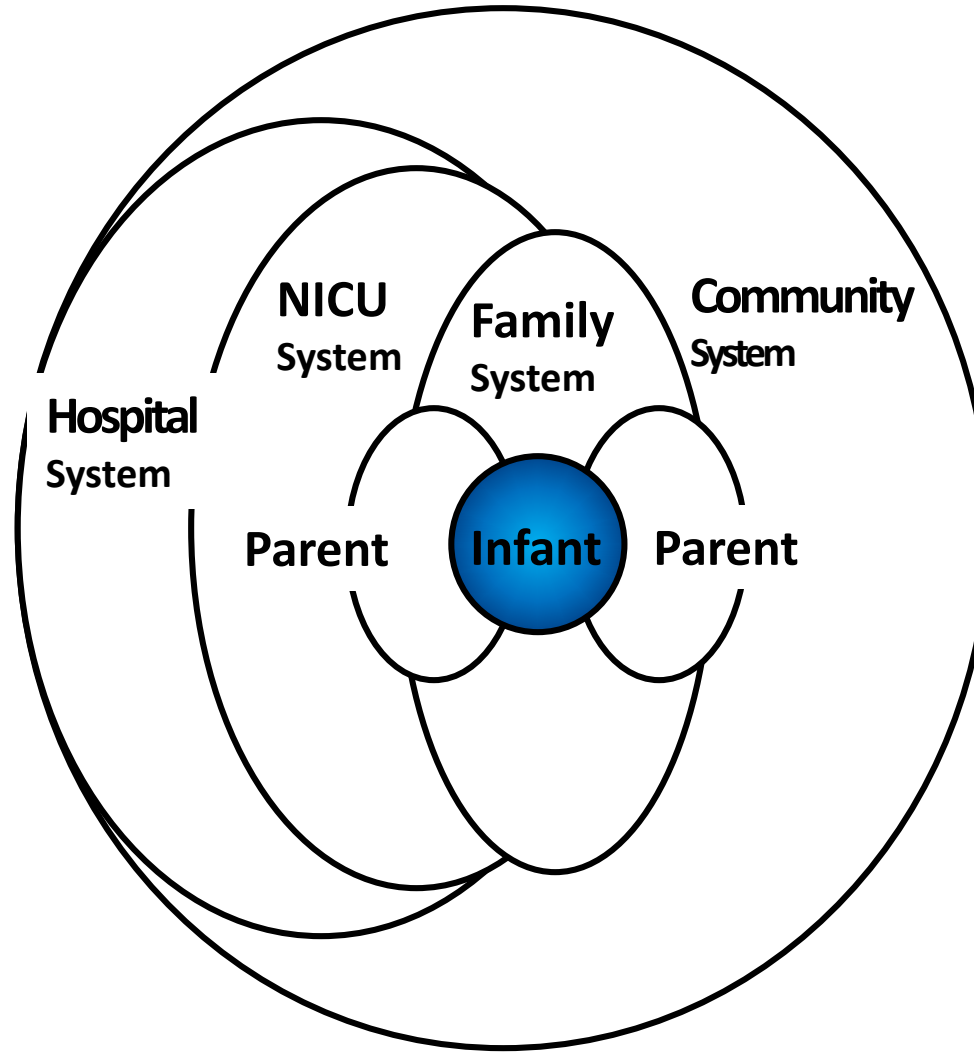


Evrard et al *Acta Paediatr* 1997; 422:20-26, Lagercrantz et al *Acta Paediatr* 2001;90:707-715)

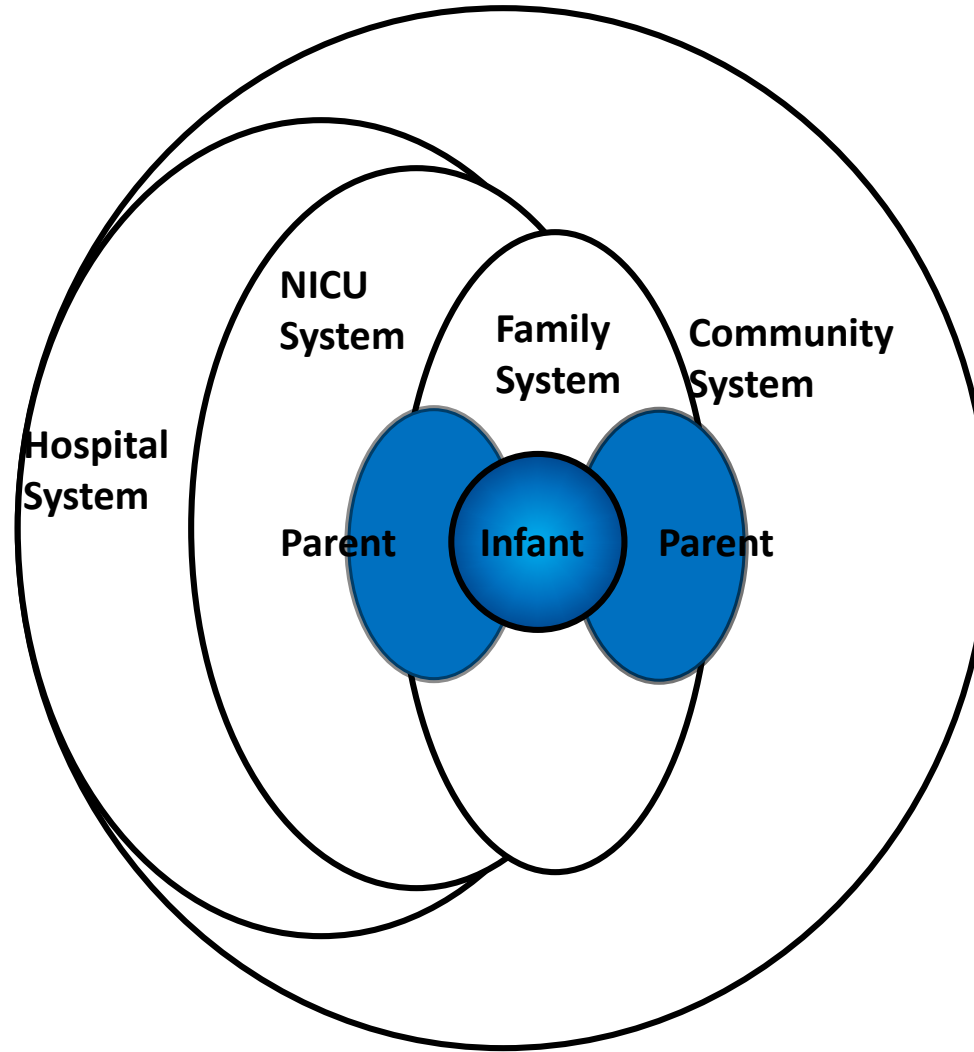
*Butta & Anand 2002, Als et al. Pediatrics 2004*

*Als et al. 2004, Brummelte et al. 2012*

## Synactive Model of systems perspective



## Synactive Model of systems perspective



# INSIDE MUM

Baby feels held  
& contained

peaceful

Reassuring movement  
with mum

Dark for developing eyes

Feels no pain

Constant temperature

Natural boundaries

Can “smell” or taste  
mum’s amniotic fluid



Hears mum’s voice

Hears mums  
heartbeat

Can sense mum’s emotions

Registers day and night  
by difference in light  
through the womb

Feels mums hand  
stroking her tummy

# IN INCUBATOR/WARMER

Hears loud sounds of stranger's voices

Hears slamming of incubator doors

Pain of injections

Feels movement as someone bumps incubator

Bright lights for sensitive eyes

Temperature changes as incubator is opened

No constant to stabilize baby



cannot hear mum's voice

Cannot hear mum's heartbeat

Does not feel contained

Fed through drip or NGT

Hears monitors beeping

Feels stranger's hands and voice

Smells antiseptic and plastic from gloved hand



# WHAT HAPPENS WHEN THE BABY IS SEPARATED FROM MOTHER?

## 1. First is Protest: (energy is being used )

Protest is to get mum's attention. The stronger and more assertive the baby is, the more it will protest. Preterm babies are often not strong enough to protest.

- the baby becomes stressed
- the heart rate increases
- the breathing is faster
- the hands and arms extend
- the legs extend and wave around
- fists clench



## 2. Second is Despair: (the body tries to conserve energy for survival)

- The baby becomes still
- the heart rate slows
- the breathing slows and is irregular
- the body becomes limp



# ON MUM'S CHEST

Registers day and night  
by difference in light

Pain of injections

Constant temperature  
from mother's skin

Feels SAFE  
& peaceful

Dark so can open eyes  
and connect with mum

Baby can sleep peacefully  
and brain wire properly



Eyes open

Can smell and  
taste mum's milk

Hears mum's voice

Calmed by mum

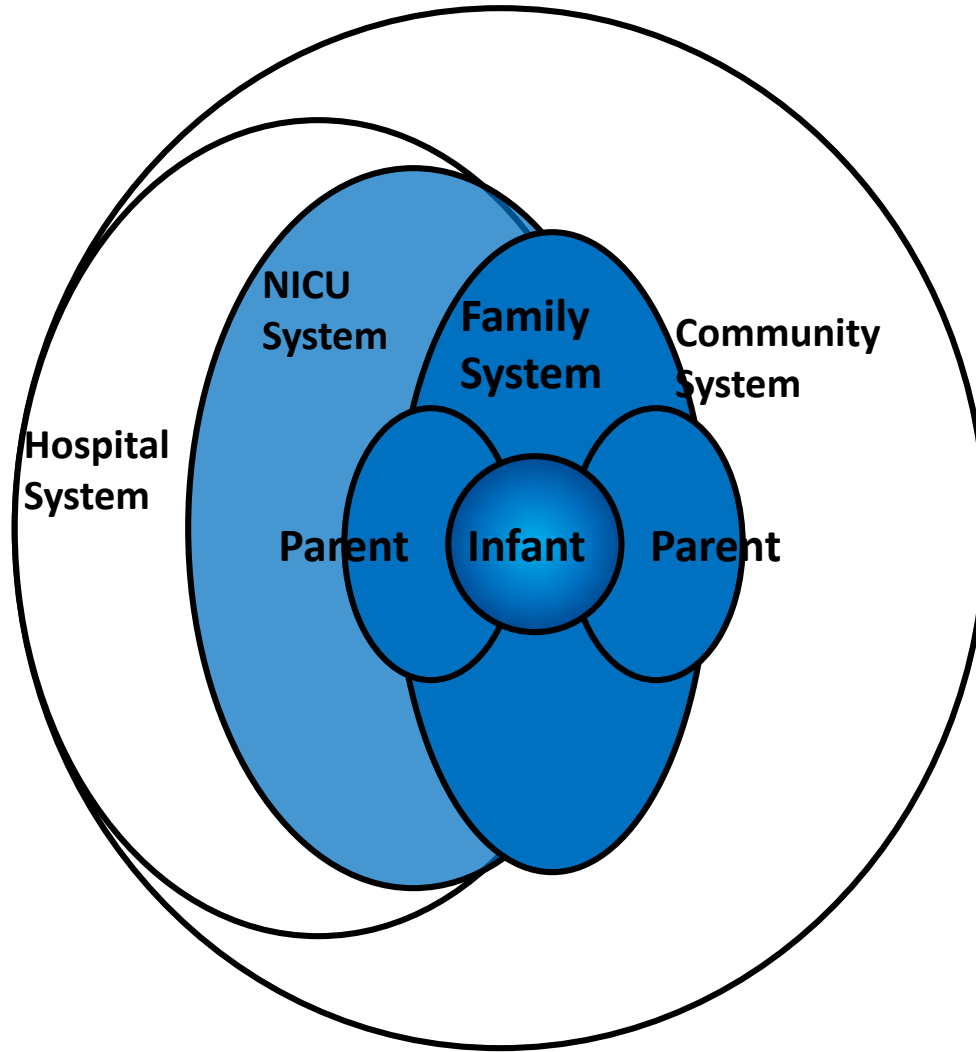
Hears mums  
heartbeat

Feels mums hand stroking  
her body

Reassuring Movement  
with mum

Can sense mum's emotions

# Synactive Model of systems perspective



## NIDCAP - *Newborn Individualized Care and Assessment Program*

*NIDCAP* is currently the most comprehensive IFCDC *programme* that really embraces *all* IFCDC aspects, theories and principles

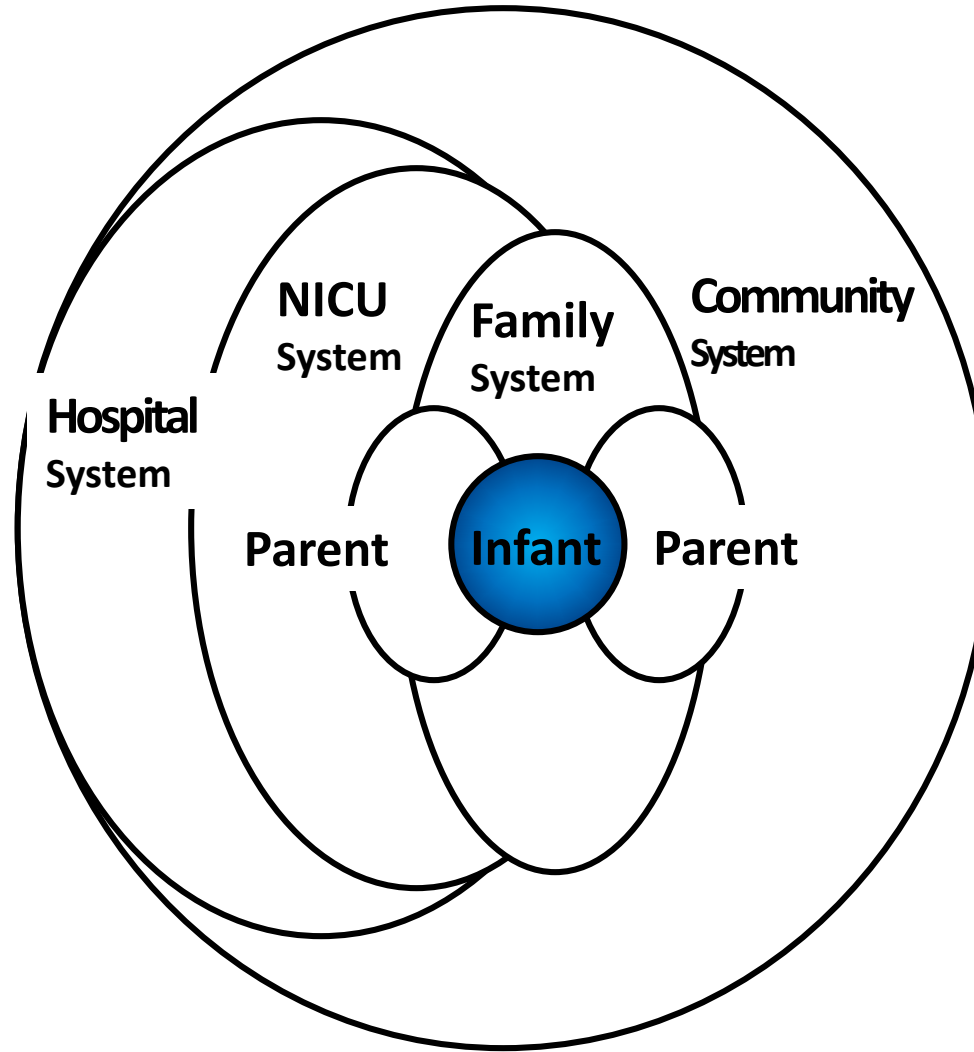
It differs from other interventions since it starts as soon as the baby is born – *the Ultra-Early Intervention*

- ❖ Alters the environmental, treatment, and caregiving events that create stress/disorganization and interfere with physiological homeostasis
- ❖ Promotes neurobehavioral organization of the infant by identifying and enhancing stable behaviours and reducing the incidence of stressful behaviours in order to support the emergence of maturation, energy conservation and recovery

## NIDCAP - *Newborn Individualized Care and Assessment Program*

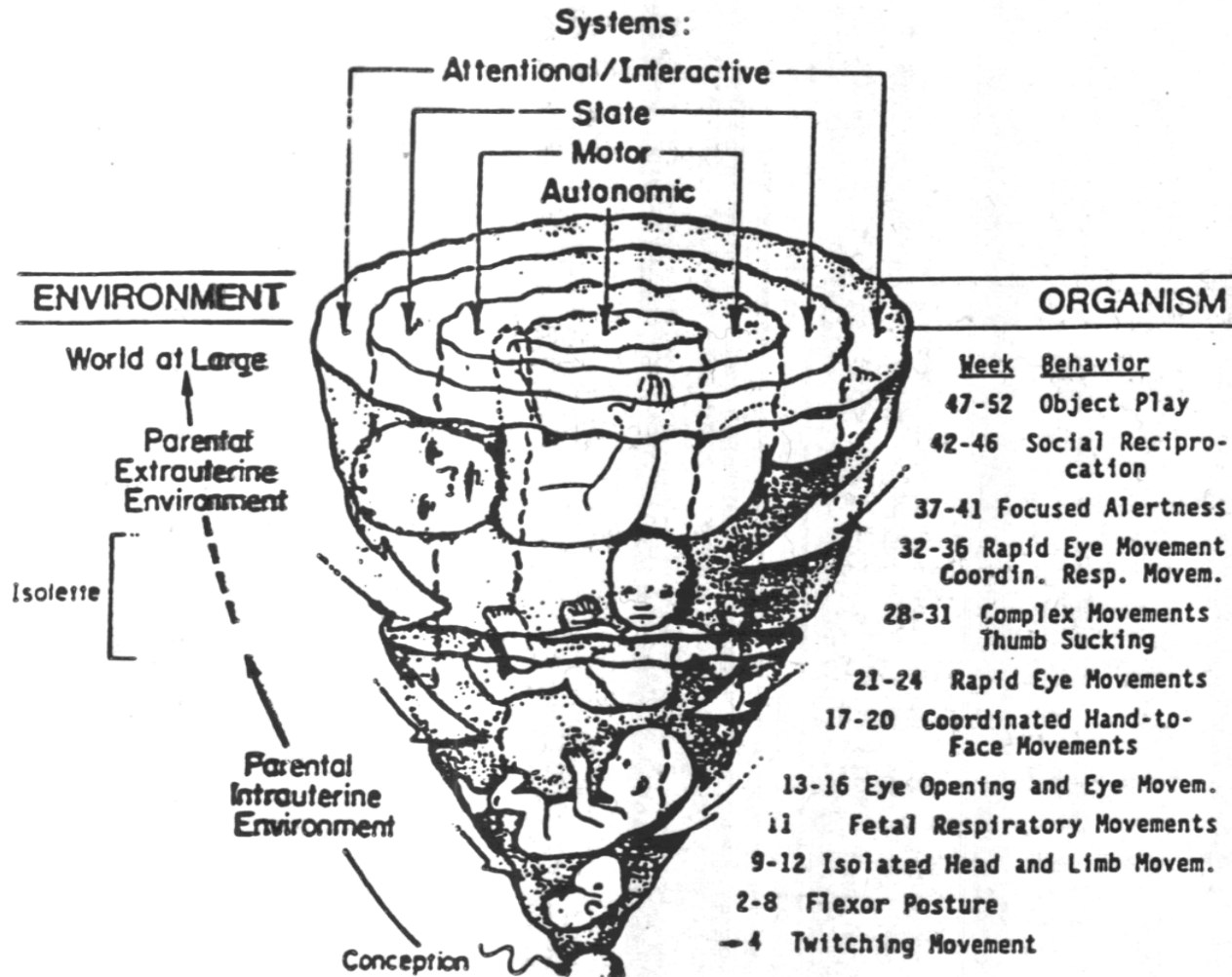
- ❖ Governed by the infant's current stage of development and current medical condition, NIDCAP promotes *resilience* by providing developmentally adequate support during:
  - care-giving
  - social interaction
  - examinations and procedures
- ❖ The parents are immediately guided how to understand the behavior of their baby. They are supported and encouraged to be actively involved as the infant's primary caregiver
- ❖ Promotes bonding and attachment

## Synactive Model of systems perspective





# MODEL OF THE SYNACTIVE ORGANIZATION OF BEHAVIORAL DEVELOPMENT



## The Synactive Theory subsystems:

- Autonomic
- Motor
- State-
- Attentional / Interactive

The synactive theory focuses on how the individual infant handles environmental experiences, and social interaction which can be supportive or disrupt the infant's balance

Whenever development occurs, it proceeds to a state of increasing differentiation

Breathing: irregular, deep or shallow to smooth and regular.

Movements: become better modulated and fine tuned;

Sleep-wake states: Diffuse to robust

The infant always strives for integration of the subsystems.

**Appropriate stimulus** – infant will *move towards* the stimulus

**Inappropriate stimulus** (timing, too complex or too intense)  
– the infant will *move away* from the stimulus and avoid it

Figure 1. Model of the synactive organization of behavioral development [from Als H, 1982; with permission]. Note: Approximate time

# Model of the Synactive Organization of Behavioral Development

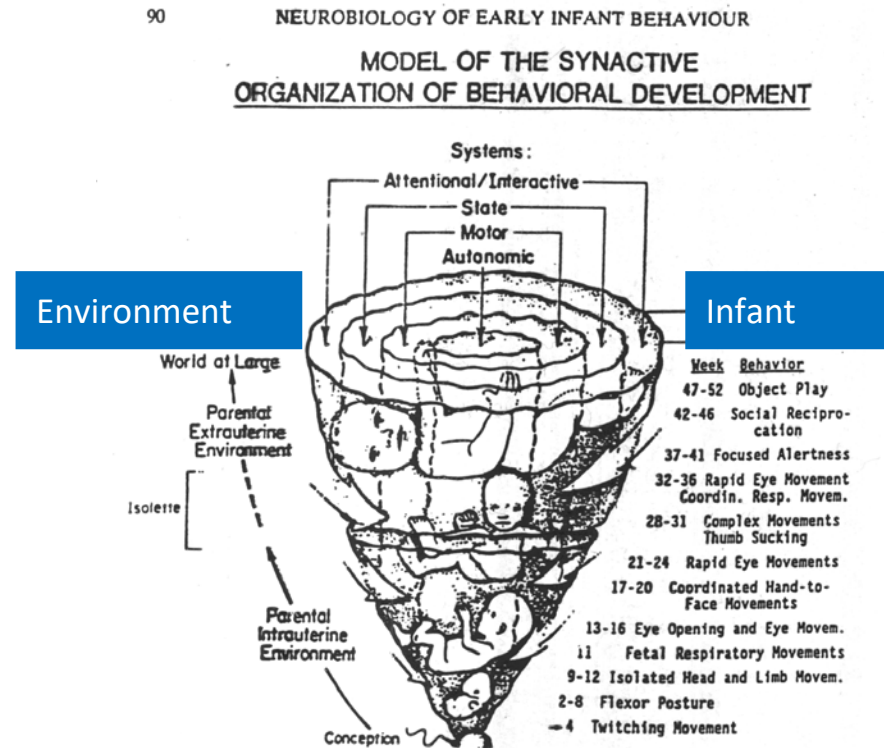


Figure 1. Model of the synactive organization of behavioral development [from Als H, 1982; with permission]. Note: Approximate time of appearance of selected fetal behaviors is listed on the right.

## The principles of synaction

- Continuous interaction between infant and environment
- Increasing differentiation of behavioural subsystems within the infant
- Continuous balance of avoidance and defence with approach and activation



The behavior of the infant is its primary way to  
communicate Als



# Autonomic-physiologic system

- Circulation
- colour
- respiration
- Bowel movements
- Temperature control
- Tremor, jitternes



# Motor system



# State system

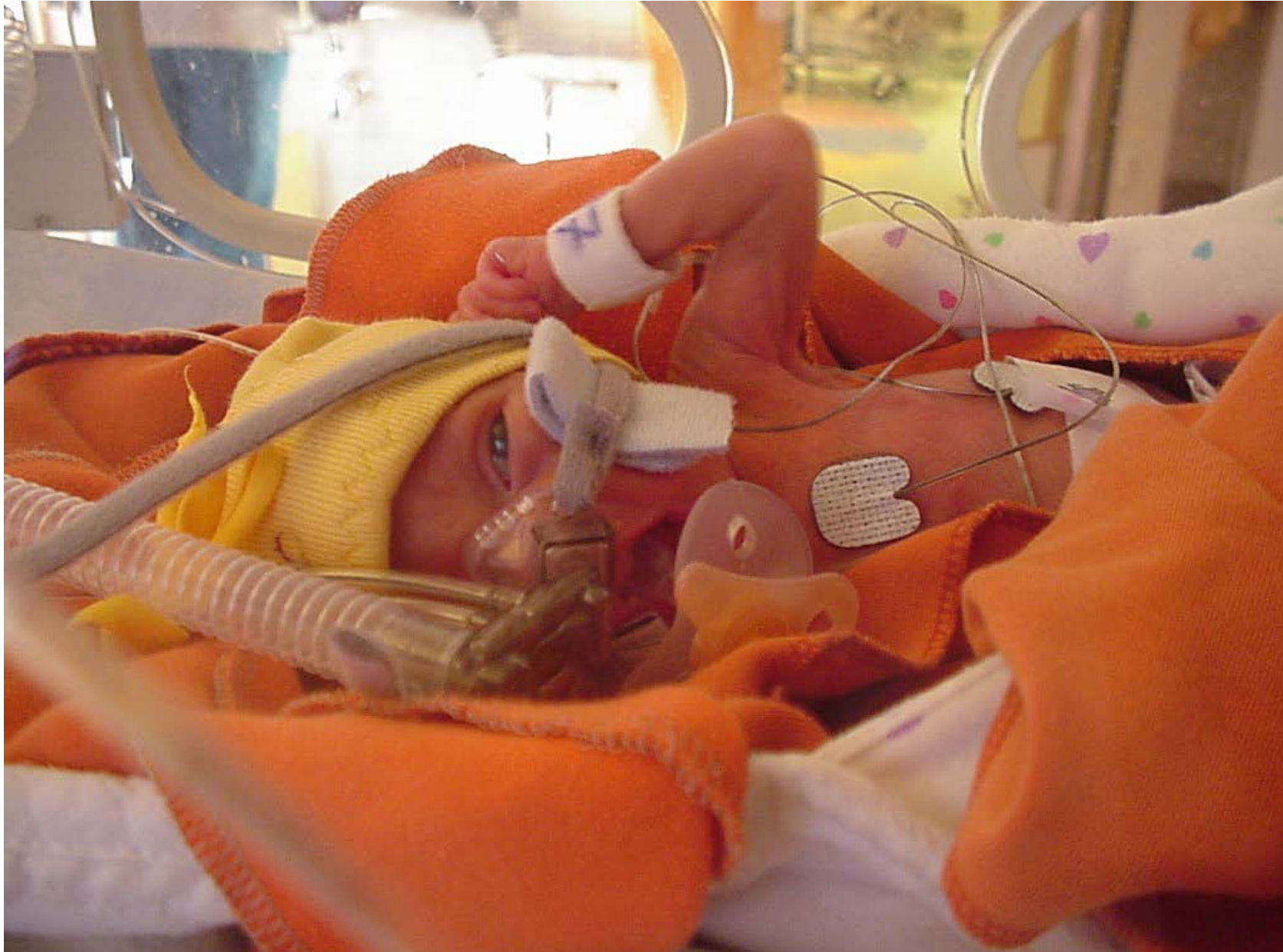


# Attentional and interactive system





# Observe



interpret





Support...





# Support during painful procedures



Shield infant from bright light and offer your finger to suck on





Sidelying, flexed position, support of the back and hands in the midline by the mouth





Infants with catheters or chest tubes requires more visual access  
but could be supported









... self-regulation:

control of bodily functions including autonomic stability,  
manage emotions, maintain focus and attention,  
enable social interaction -> parental bonding and infant attachment

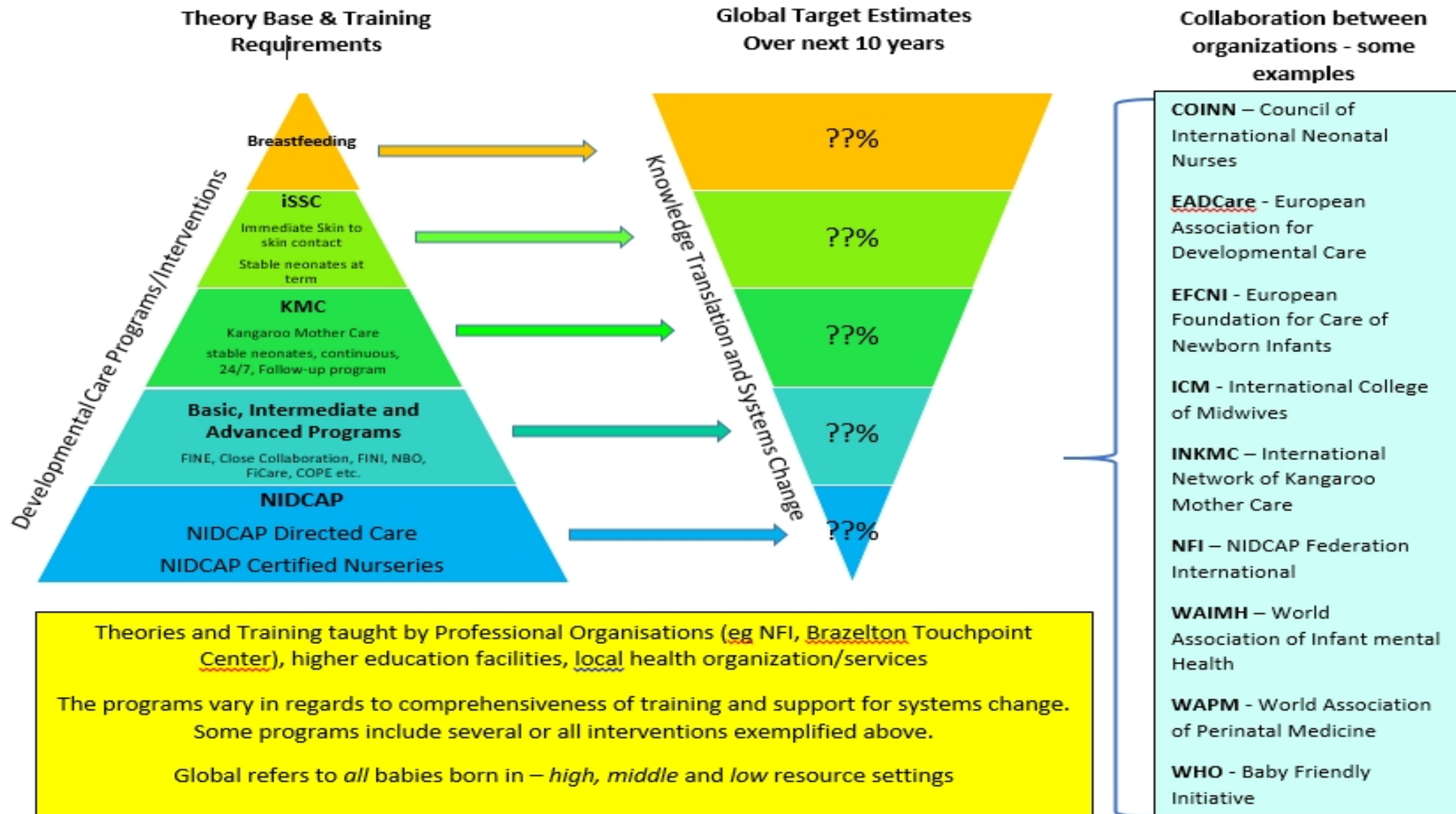


# selfregulation





# Global Perspective of Infant and Family Centered Developmental Care



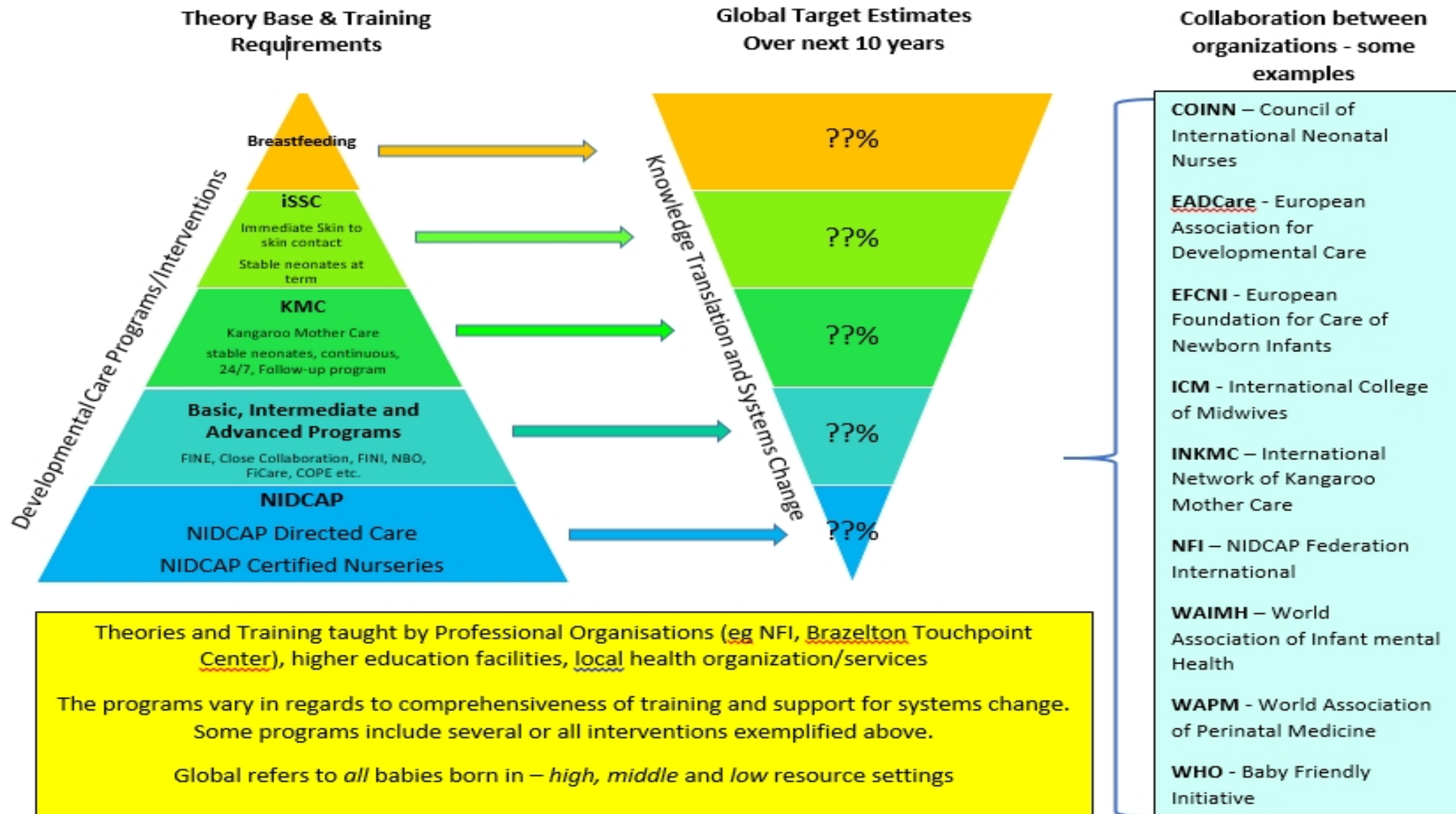


# Breastfeeding



- **Breastfeeding is the normal way** of providing young infants with the nutrients they need for healthy growth and development.
- **Virtually all mothers can breastfeed**, provided they have accurate information, and the support of their family, the health care system and society at large.
- **Colostrum**, the yellowish, sticky breast milk produced at the end of pregnancy, is recommended by WHO as the perfect food for the newborn, and feeding should be initiated within **the first hour after birth**.
- ***Exclusive* breastfeeding is recommended up to 6 months** of age, with continued breastfeeding along with appropriate complementary foods up to two years of age or beyond.

# Global Perspective of Infant and Family Centered Developmental Care



# The Scale of the Problem

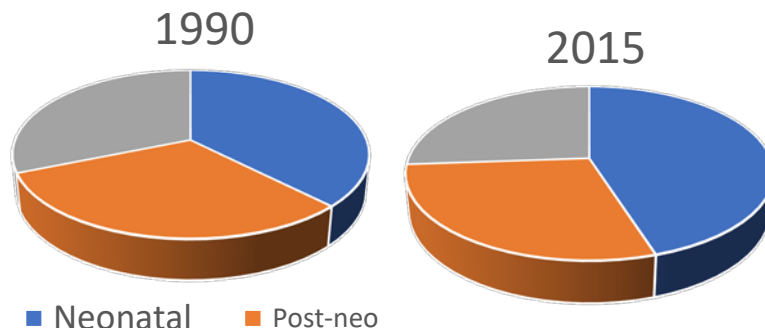
2.6 million neonatal deaths every year

**60% occur within 3 days of birth**

Neonatal preterm birth and neonatal encephalopathy top 2 leading causes of death in under 5 in 2015

High levels of long-term neurodevelopmental impairment among survivors

Progress in reducing mortality has been slowest in the neonatal period



## Kangaroo mother care - KMC



Effective low cost intervention recommended by WHO

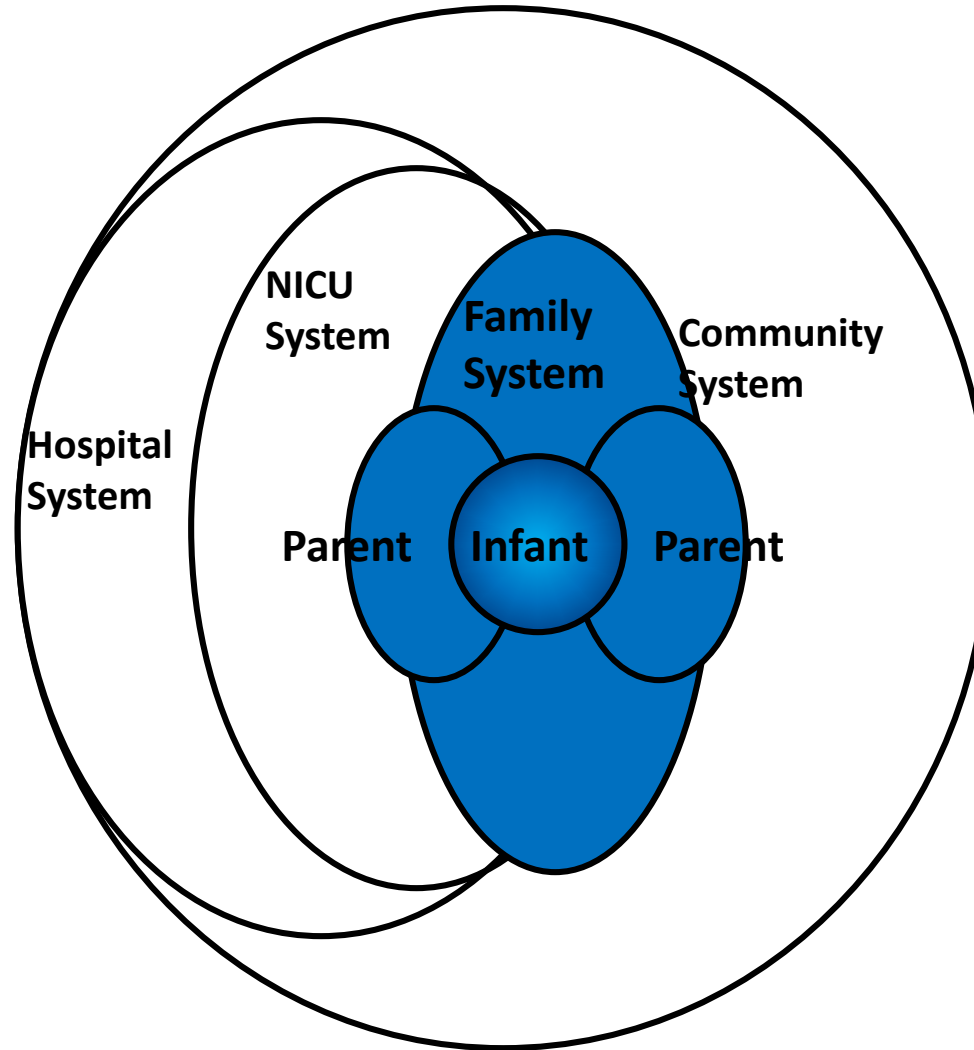
Continuous skin-to-skin contact, exclusive breastfeeding

Average 40% lower mortality, reduces infection, improves thermal control and nutrition

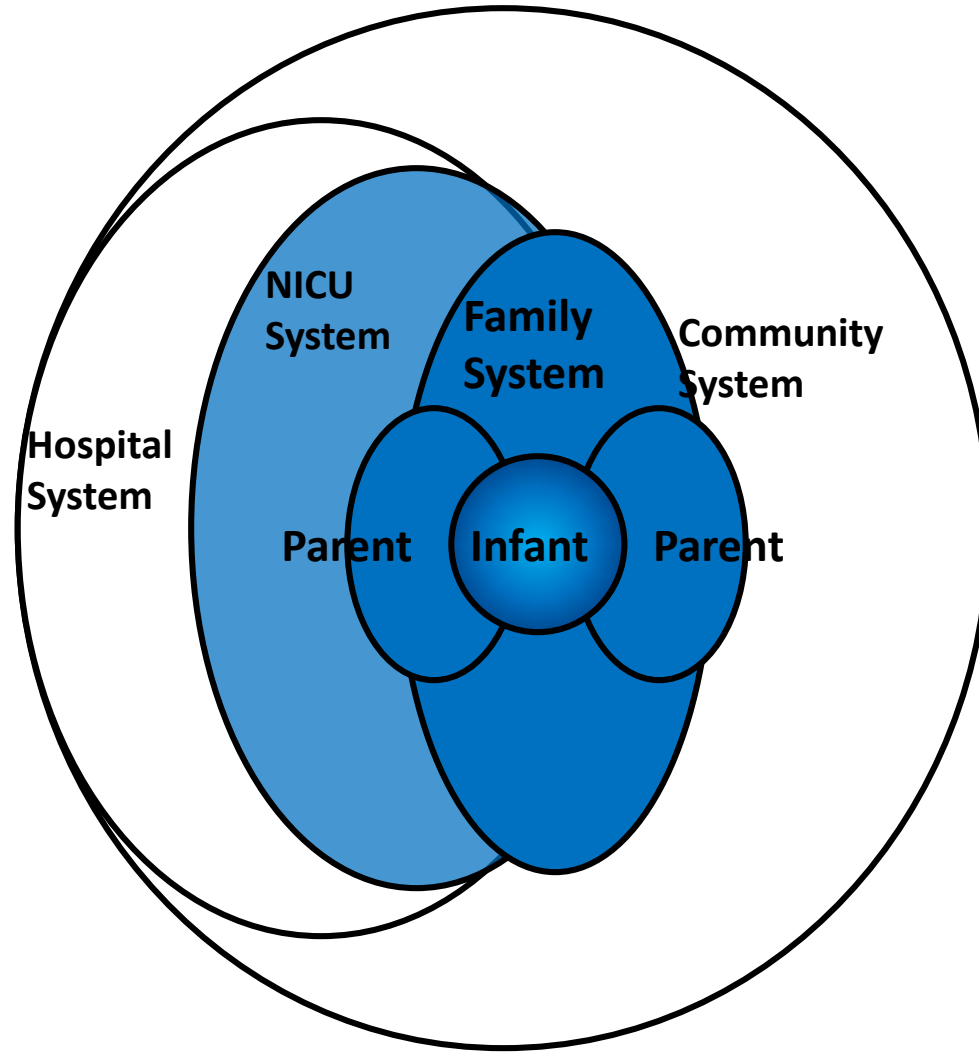
Currently introduced *after* stabilization, missing peak period of medical vulnerability

Small-scale studies suggest *immediate* KMC (iKMC) may reduce mortality and improve physiological state => WHO iKMC Study (2017...)

# Synactive Model of systems perspective



# Synactive Model of systems perspective





# Infant- and Family-Centred Developmental Care (IFCDC)

“The Karolinska Way” - NIDCAP based care



# Start the care in the Delivery Room

- NICU staff stay in the delivery room
- Connect to gases
- Colostrum expression and feeding
- Nasogastric tube
- Start enteral feeding
- iv line. Start iv fluid if needed
- Keep the infant warm and measure the temperature

Keep the  
family together

1522 gr in week 31.

Immediate SSC with  
mother and nCPAP.

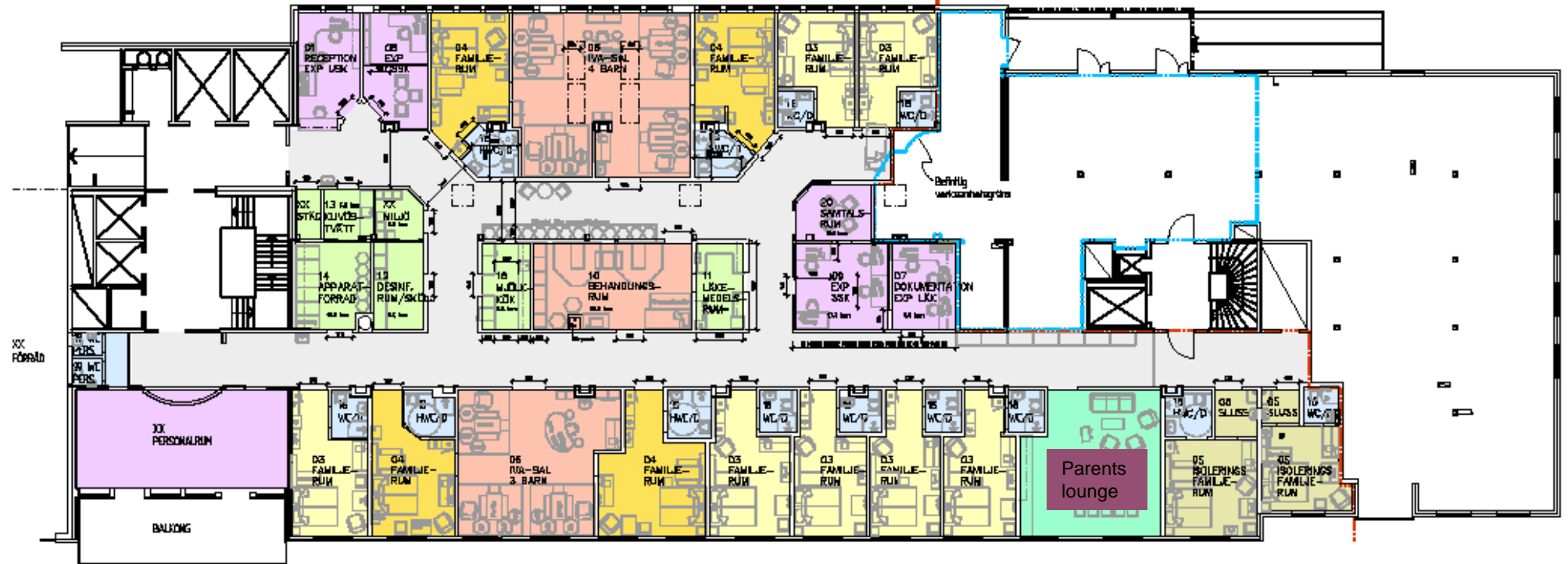
Periferal line.

At 30 min of age to  
incubator and transport to  
NICU

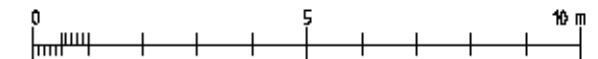


# Couplet Care

## NICU at Karolinska-Danderyd

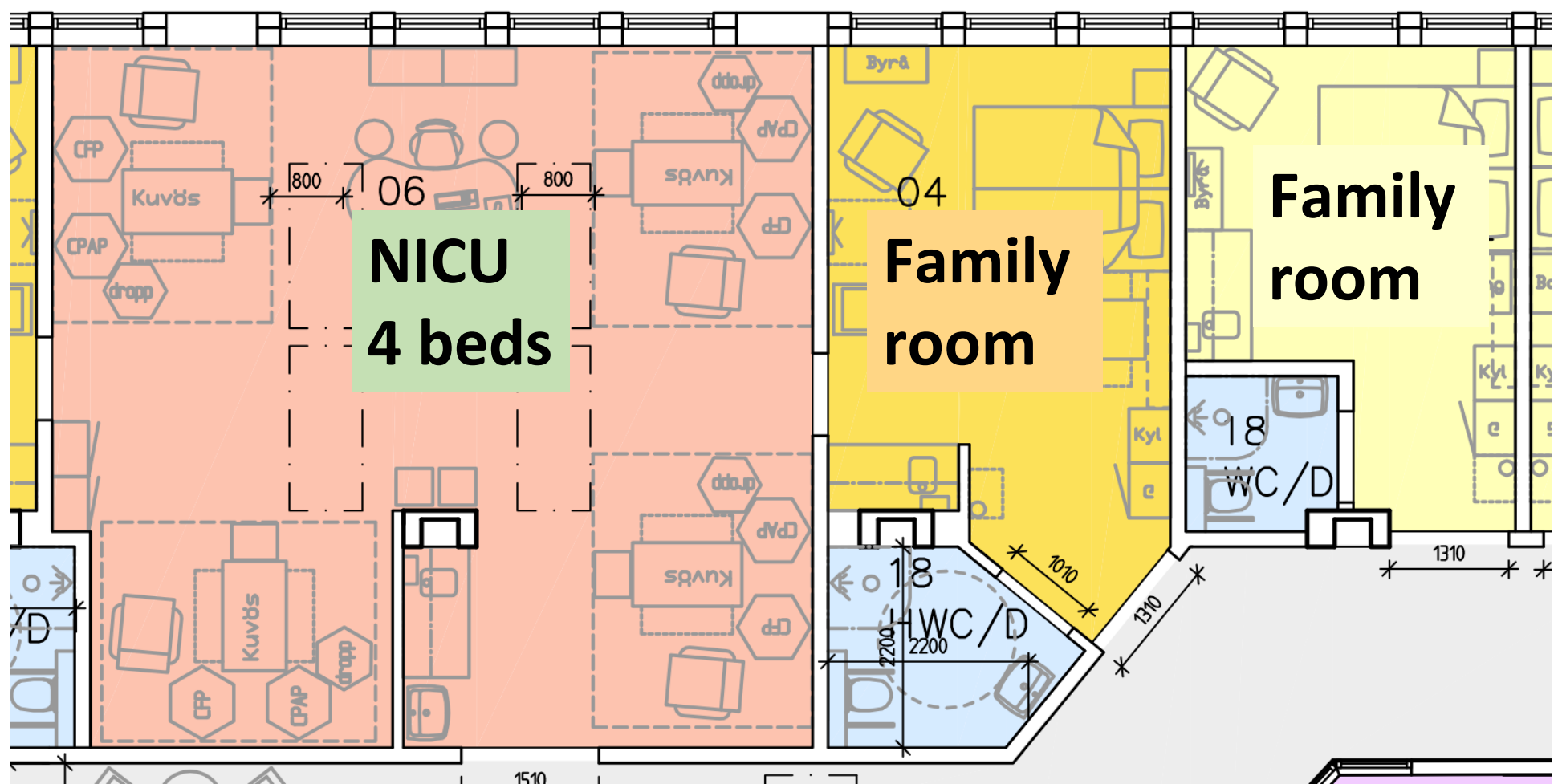


IVA-SAL I NORR BREDDAD.  
DÖRRAR TILL FAMILJERUM BREDDADE.  
JOURRUM OCH BESÖKS-WC HAR UTGÅTT.  
VISS OMDISPOSITION I MITTZONEN.



HELSKALA (A1): 1:100  
HALVSKALA (A3): 1:200

OMBYGGNAD AV NEONATAL - AVD. 20  
DANDERYDS SJUKHUS  
HUVUDALTERNATIV - 2008-05-13



**Either family room with parents or ICU room with 2-4 beds**

Plan för Karolinska Danderyd from 2009.

New Karolinska Solna 2016 and

Karolinska Huddinge from 2013 have similar design.

Recommended by NICU design experts (Robert White, JENS 2015, Budapest).

# *Mother Neonatal Intensive Care Unit (MNICU)*

## Safdarjang Hospital, New Delhi





*Mother Neonatal Intensive Care Unit (MNICU)*

Safdarjang Hospital, New Delhi

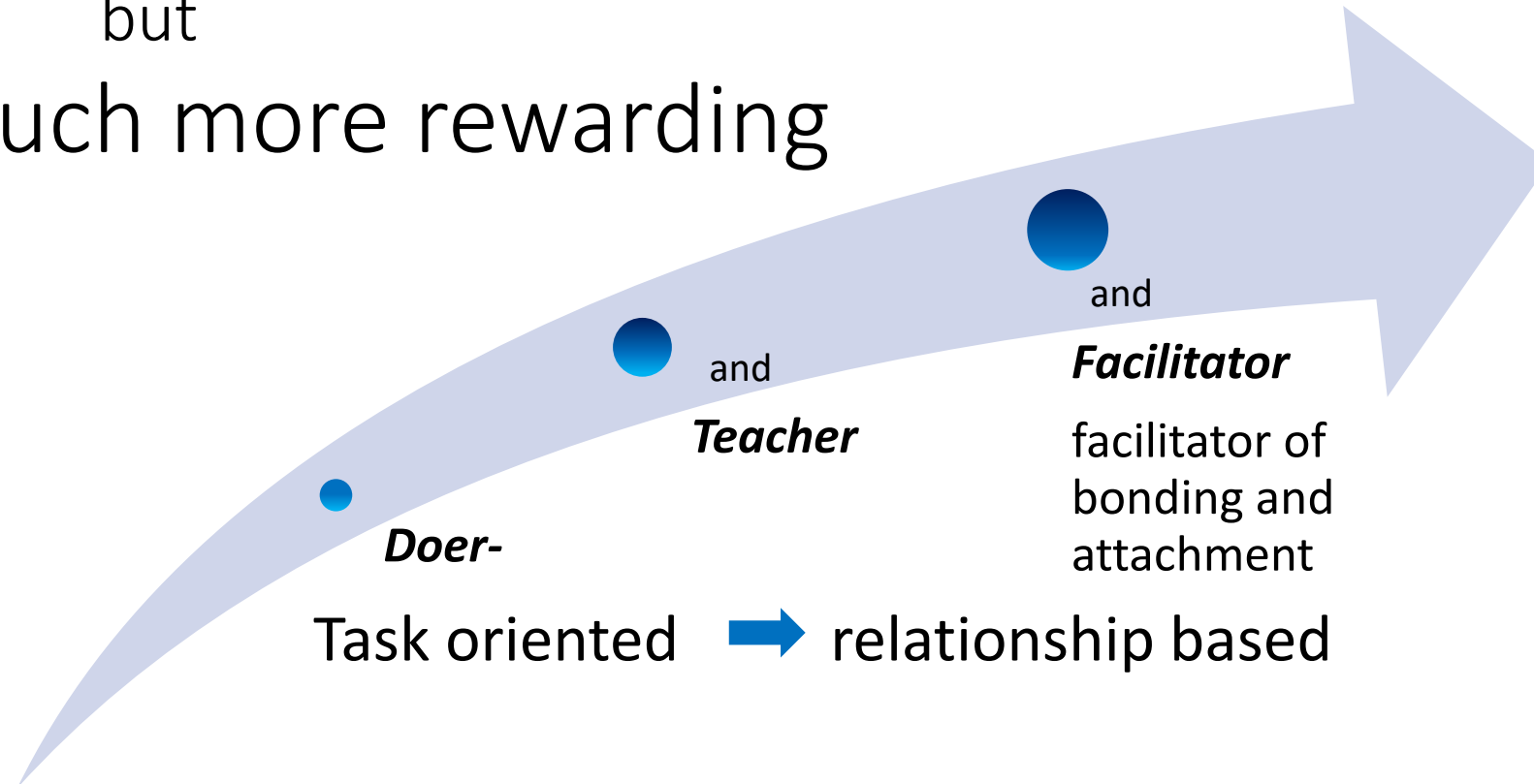
Mother, infant and grandmother/surrogate

# The role of the medical staff

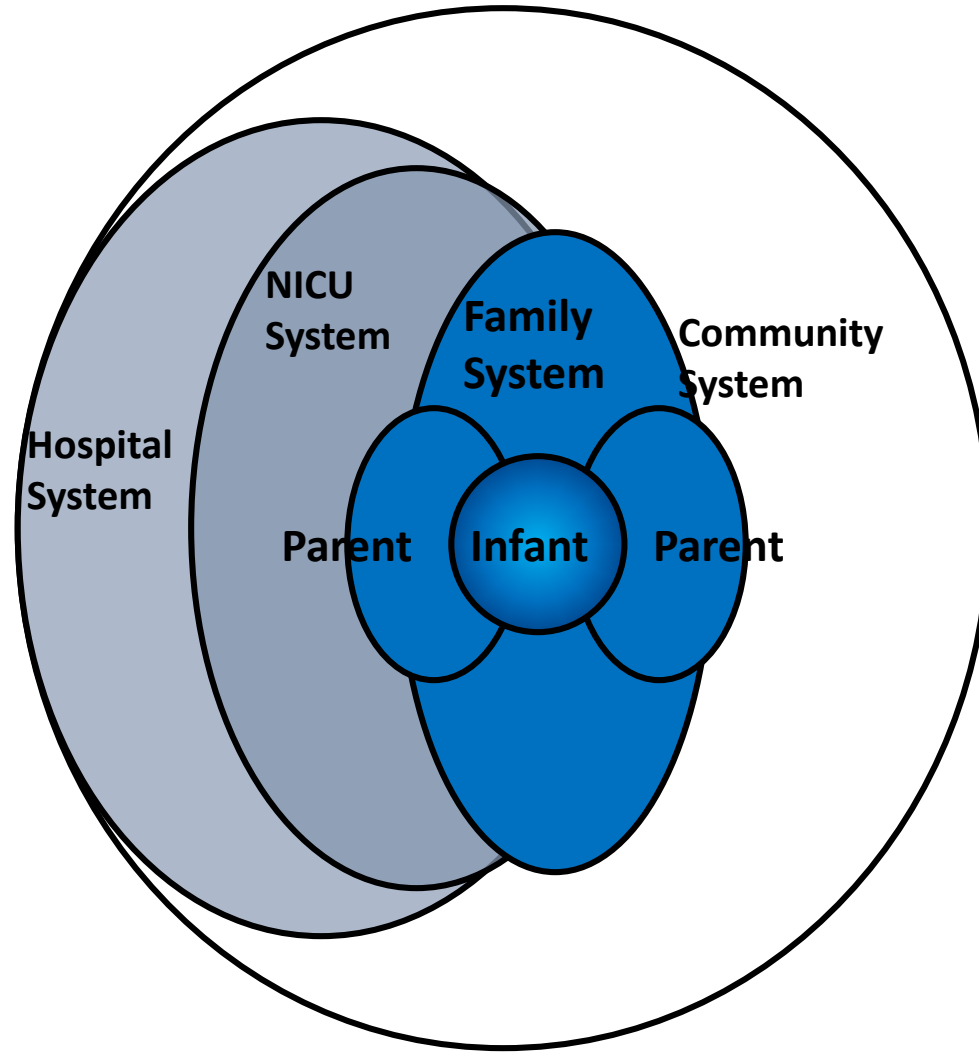
more complex and maybe challenging

but

much more rewarding



# Synactive Model of systems perspective



# *Couplet Care*

*coupling the medical care of the infant and mother in the NICU  
as soon as mother's condition allows*

- Early breastmilk production
- Lower blood pressure for PE mothers
- Less reported pain
- Lower stress and anxiety in mothers and fathers
- Parents the most important persons in the baby's life from the very start



Most mothers are eligible for Couplet Care,  
but not when:

- Eclampsia and severe pre-eclampsia
- Large bleeding or haemodynamic unstable
- Other reasons for ICU care
- Contagious disease
- Severe psychiatric illness





## Length of stay in *intensive care* (level II and level III)

Adjusted for: gestational age at birth<sup>A</sup>, non-Swedish-speaking background<sup>A,B</sup>, setting<sup>A,B</sup>

	Family care n = 183	Standard care n = 182	difference days
All infants <sup>A</sup> , mean	13.3	18.0	<b>-4.7 d</b> (p= .02)
<u>By gestational age</u> <sup>B</sup>			
24 – 29 w, mean	32.4	43.1	<b>-10.6 d</b> (p= .04)
30 – 34 w, mean	6.0	8.5	-2.5 d (p= .02)
35 – 36 w, mean	1.5	2.5	-1.0 d (p= .24)

# Infant morbidity

Adjusted for: gestational age at birth, non-Swedish-speaking background, setting

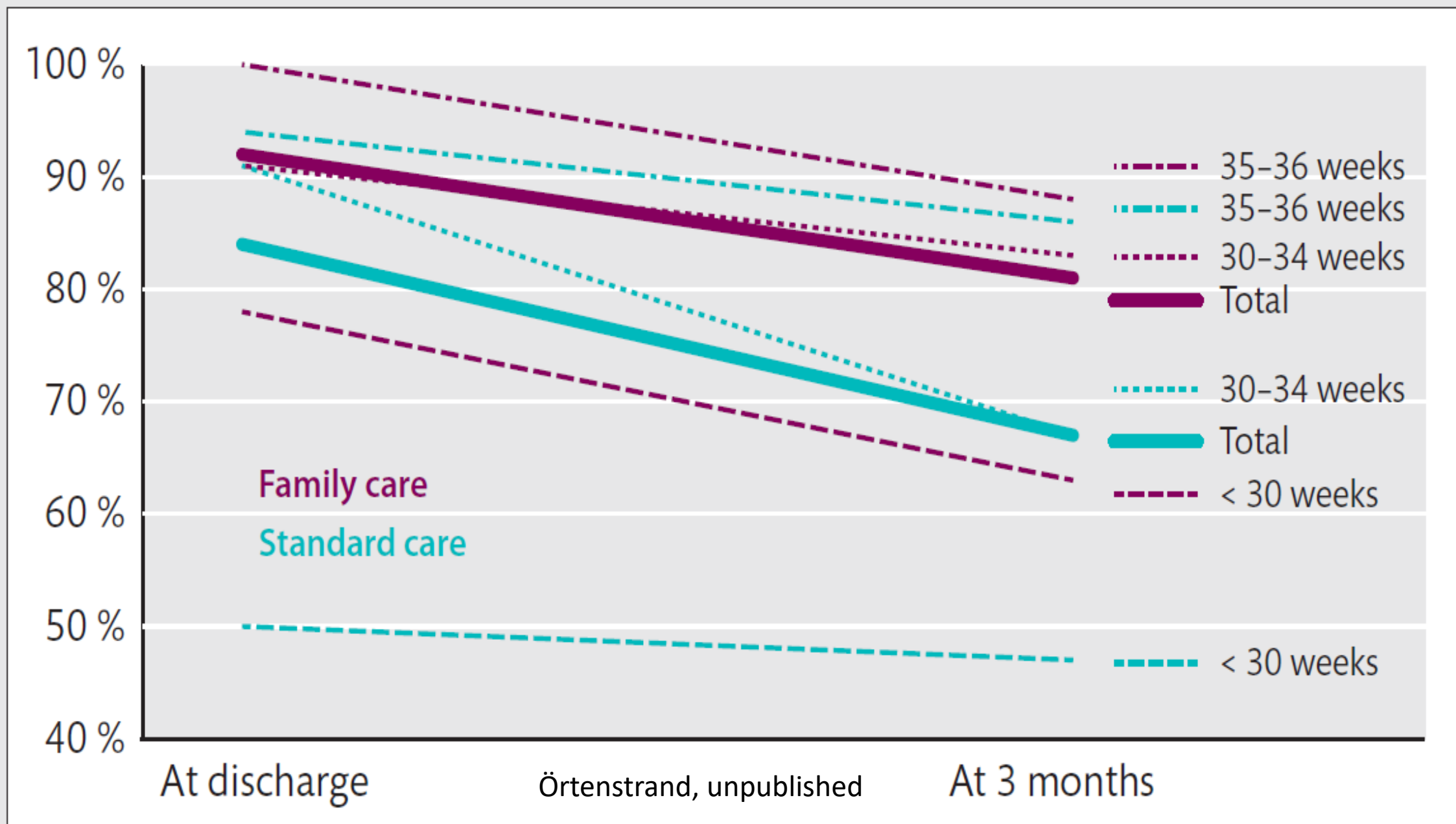
	Family care n = 183	Standard care n = 182	OR (95% CI) <sup>A</sup>
Verified Sepsis, %	7.1	9.8	0.68 (0.3-1.6)
Verified NEC, %	2.7	3.3	0.83 (0.2-2.8)
Diagnosed. PDA, %	15.3	16.9	0.90 (0.4-1.9)
IVH grade II-III, %	3.3	3.8	0.95 (0.3-3.2)
ROP stage II-V, %	2.7	6.6	0.34 (0.1-1.1)
<b>BPD moderate-severe, %</b>	1.6	6.0	<b>0.18</b> (0.04-0.8)

# Mothers' mental distress

at discharge and at 3 months of infant's corrected age

<u>Mothers</u>	Family care	Standard care	p
Anxiety, discharge (STAI), mean	35.4*	39.0	0.03
Parenting stress, 3 m (SPSQ), mean	2.41	2.52	0.29
Anxiety, 3 months (EPDS), mean	2.88*	3.68	0.04
Depressive symptoms (EPDS), %	14.9%	17.3%	0.72

# Exclusive or partial breastfeeding at discharge and at 3 months



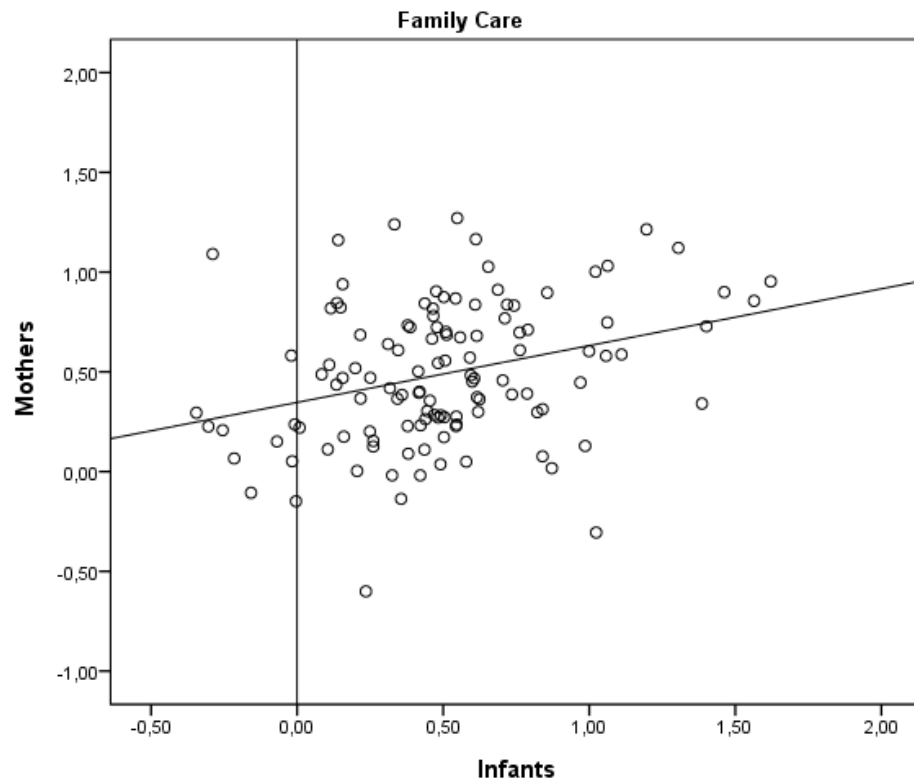
# Stockholm Family Centered Care Study

Mörelus et al 2012, Örténstrand et al 2010

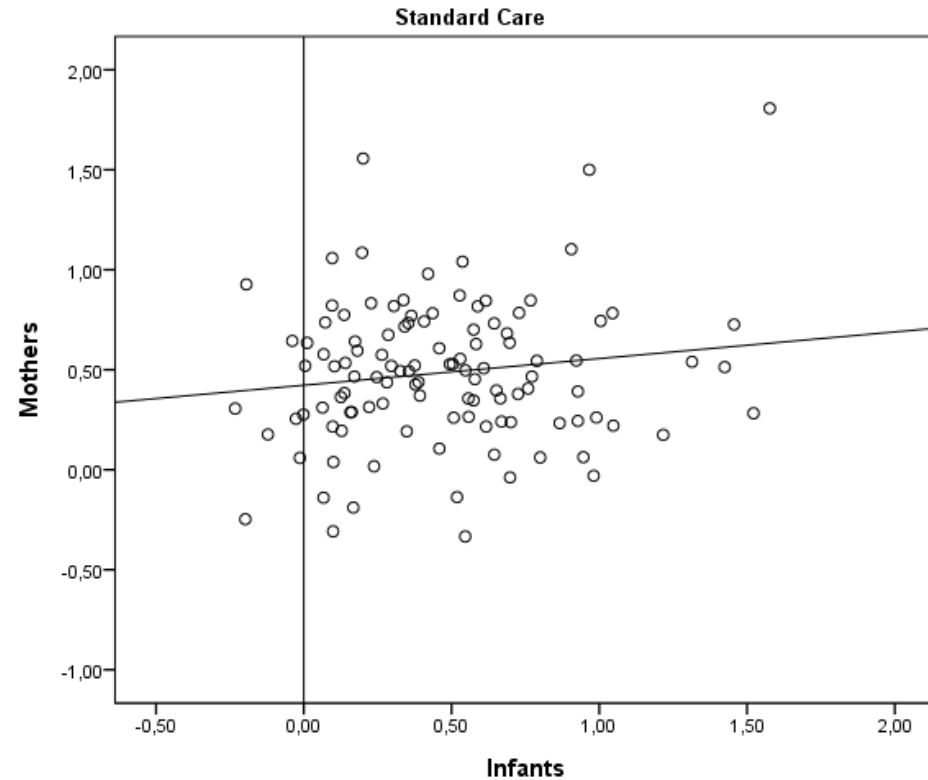
## Methods: *a nappy change*

- Salivary cortisol before (baseline) and 30 minutes after (response) a nappy change
- The nappy change was performed by the mother at the time of discharge from the hospital  
Median 36 (31-43) wks PMA

# Mothers' and infants' baseline salivary cortisol



FAMILY PARTICIPATION 24/7  
 $r = 0.31$   $p = 0.001$  ( $n=152$ )



REGULAR VISITS (approx. 10 hours)  
 $r = 0.14$   $p = 0.14$  ( $n=137$ )



# Continuous SSC after Preterm Birth

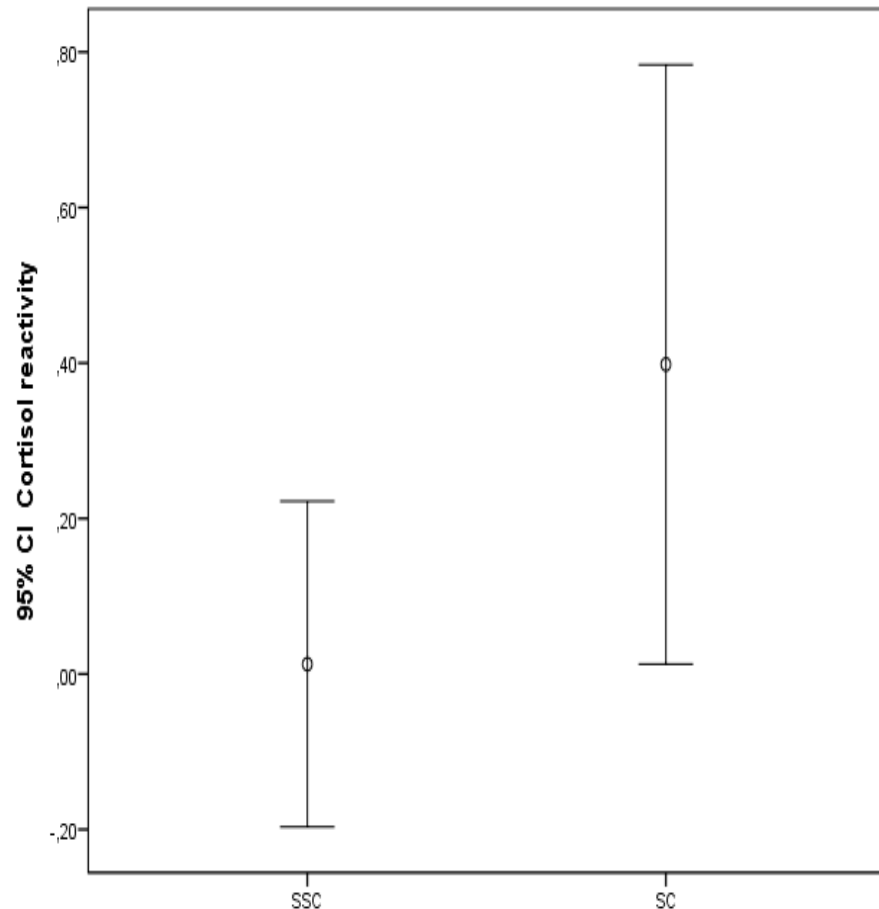
Mörelus E et al, Acta Paed 2015

**Table 2**

Mean hours (SD) spent in skin-to-skin contact per day for the SSC group and SC group, respectively.

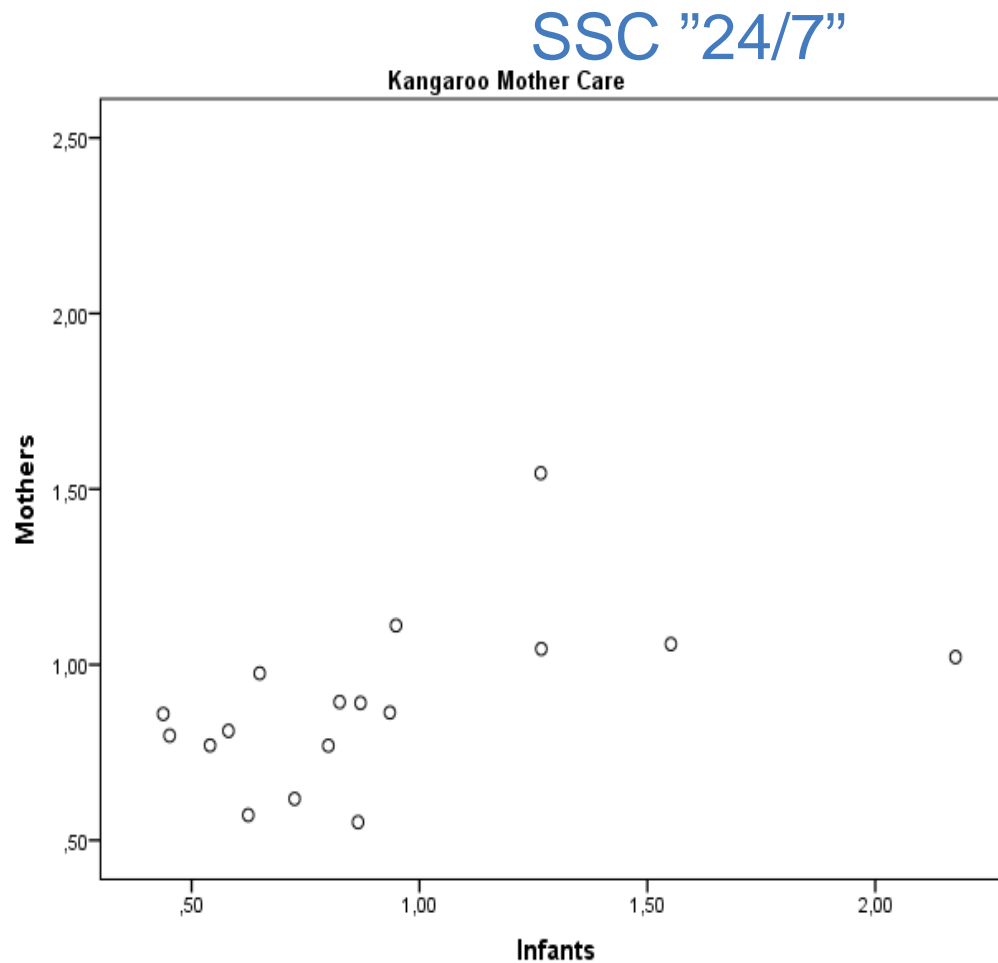
	Skin-to-skin contact		Standard care		p-Value
	n	Hours/day Mean (SD)	n	Hours/day Mean (SD)	
Day 2	18	21.25 (5.25)	19	7.75 (5.50)	<0.001
Day 3	18	19.50 (5.50)	19	7.25 (5.00)	<0.001
Day 4	17	19.75 (5.50)	19	7.75 (4.75)	<0.001
Day 5	17	20.50 (5.75)	18	6.75 (5.00)	<0.001
Day 6	16	20.00 (5.00)	17	6.00 (3.25)	<0.001
Day 7	15	16.75 (8.00)	16	7.00 (3.50)	<0.01
Day 8	12	18.00 (6.25)	14	6.50 (5.00)	<0.001
Day 9	7	16.25 (7.75)	12	5.75 (4.00)	<0.05
Day 10	4	13.25 (10.0)	7	4.00 (3.00)	
Day 11	1	21.50	5	6.00 (4.25)	
Day 12	1	18.50	4	5.75 (4.50)	

# Salivary cortisol reactivity during *nappy change* at one month Kangaroo Mother Care vs Standard care

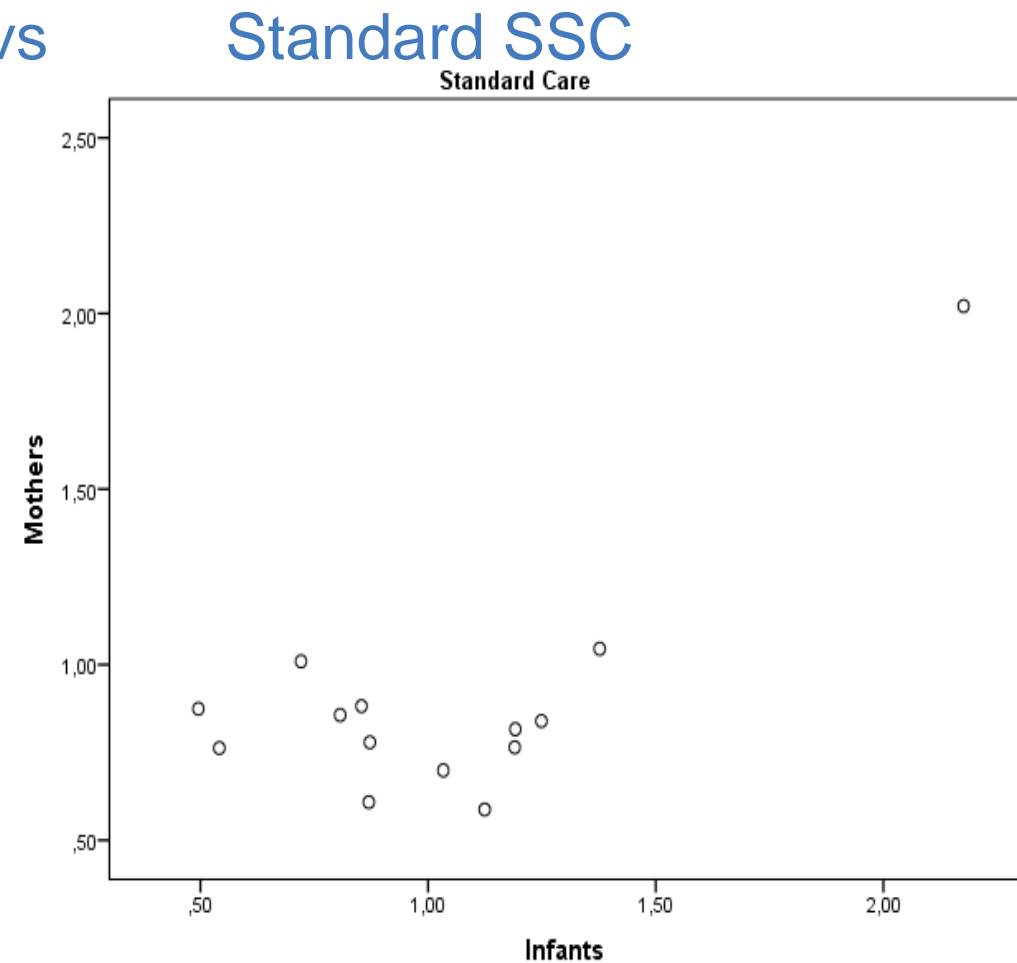


Lower stress reactivity at one month corrected age ( $p=0.01$ ) if practicing Kangaroo Mother Care. The results indicate that KMC including close parental contact and human touch, have a buffering effect on the infant's stress reactivity during handling (diaper change).

# Mother-infant salivary cortisol correlation at four months PMA - Still face as a stressor



$\rho=0.65$ ,  $p=0.005$  (n=17)



$\rho=0.14$ ,  $p=0.63$  (n=15)

## Methods (Measures)

### **DURING THE 1<sup>st</sup> WEEK POSTPARTUM AND AT DISCHARGE**

Cotton buds, at least 1 h after food intake.

- After collection, the saliva was centrifuged, frozen at  $-20^{\circ}\text{C}$ , and stored at  $-70^{\circ}\text{C}$ . A radioimmunoassay for cortisol was used to analyze cortisol concentrations in the saliva (Orion Diagnostica, Turku, Finland) . Samples were run in duplicate, and all samples from each individual were run in the same assay.
- Just shielded from sun light and shipped to the lab for analysis, at the latest within two weeks.

### **COSTS & FEASIBILITY**

- Approx 50 USD / sample

# Conclusions

This model of IFCDC

- Reduces the total length of stay for infants born prematurely, especially during need of intensive care.
- Reduces the incidence of BPD
- Reduces mothers' anxiety and may have a positive effect on their feelings of competence as a parent.
- Enhances the mother-infant coherence in stress regulation
- Enhances breastfeeding 3 months post discharge



# Couplet Care in Safdarjang Hospital, New Delhi, India

Mother, infant and grandmother/surrogate



## Couplet Care in Safdarjang Hospital, New Delhi, India

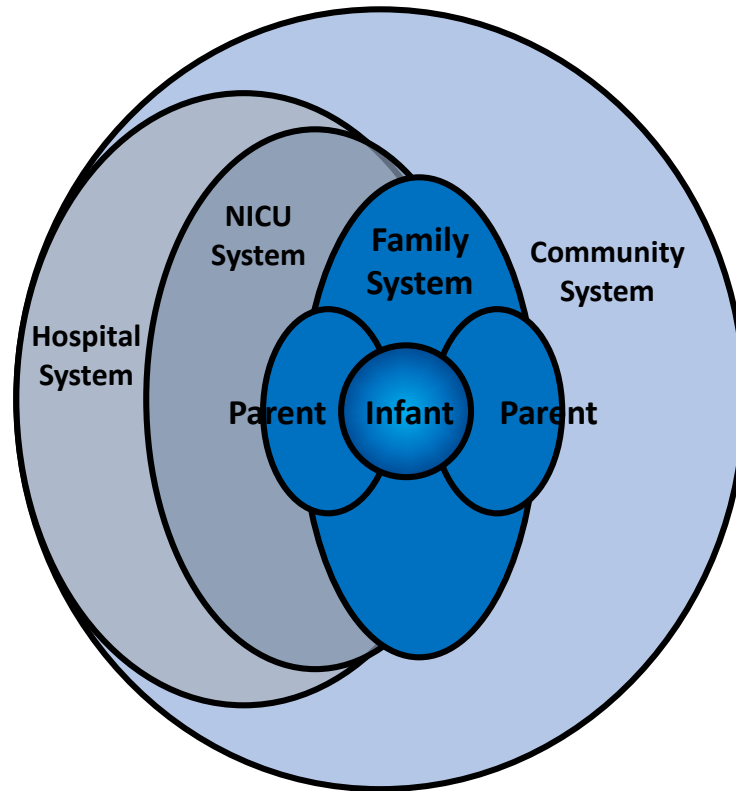


Medical Round of infant  
by neonatal team



Medical Round of mother  
by obstetric team

# Synactive Model of systems perspective



H. Als (1992)

## Indian *Guidance Note* on revised Special Nursery Care Units / SNCU:s configuration

There is a lot of scope for improving quality of care provided for the 900.000 *infants yearly* cared for in SNCUs.

- dissemination of Kangaroo Mother Care (KMC)
- *Family Participatory Care (FPC)* guidelines
  - empowered the mother to stay with the newborn
  - provide *developmentally supportive care (IFCDC?)*

Indian Guidance Note on revised  
Special Nursery Care Units SNCU:s configuration

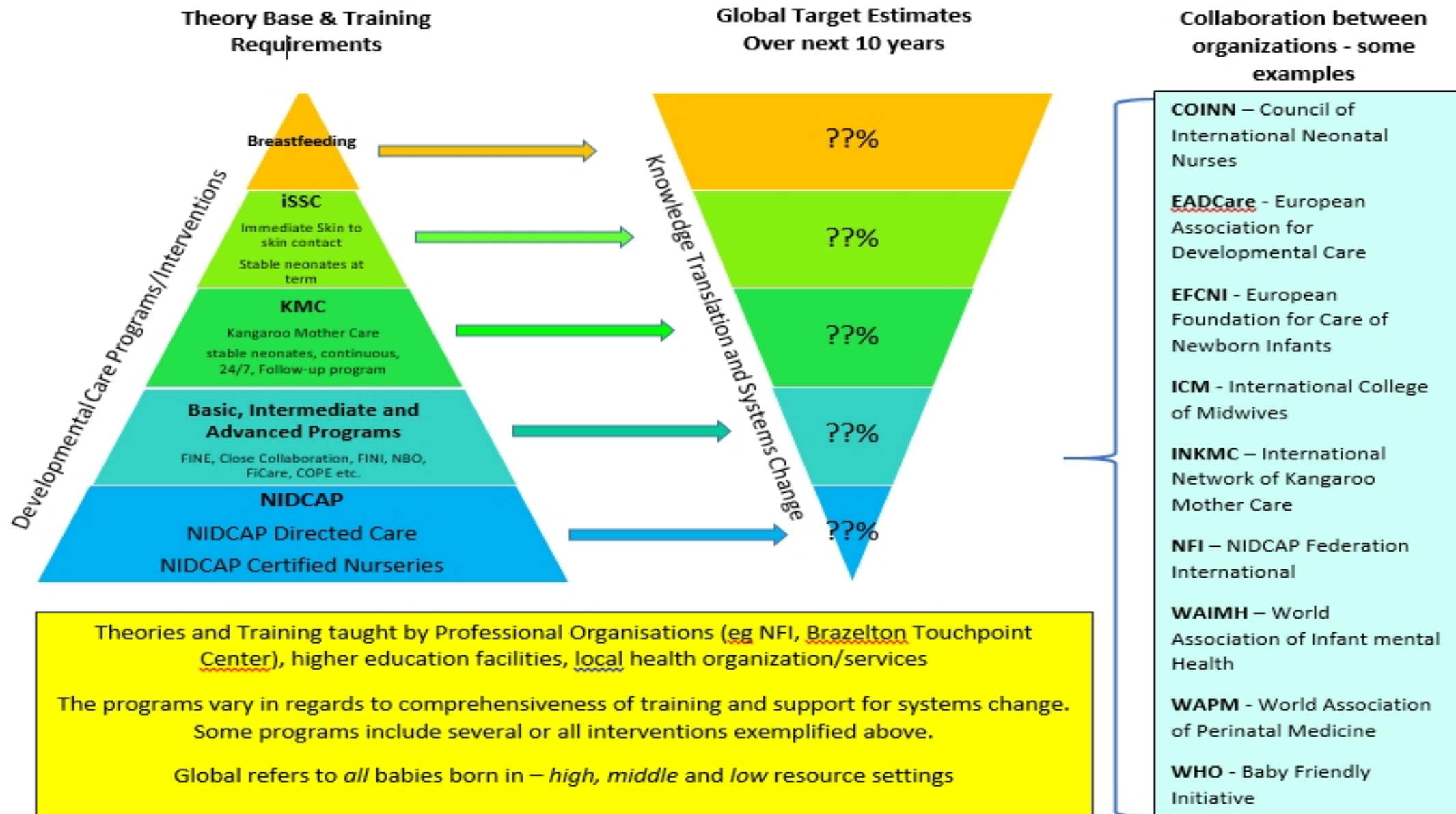
Step down/ KMC unit is to be renovated or merged as

*Mother Newborn Care Unit (MNCU)*

Preferably as a part of SNCU complex to keep the mother-baby dyad together to fulfill the following objectives

- observational care for *newborns* who do not require intensive care in SNCU.
- Making provisions for the *mothers of SNCU* admissions  
(Bed, diet and *treatment*)
- *COUPLET CARE for all of India!*
- (in xx? years)

# Global Perspective of Infant and Family Centered Developmental Care





# Other initiatives / programs for developmental care

FiCare

Little Steps

Individual unit  
programs





# Family and Infant Neurodevelopmental Education

(FINE)

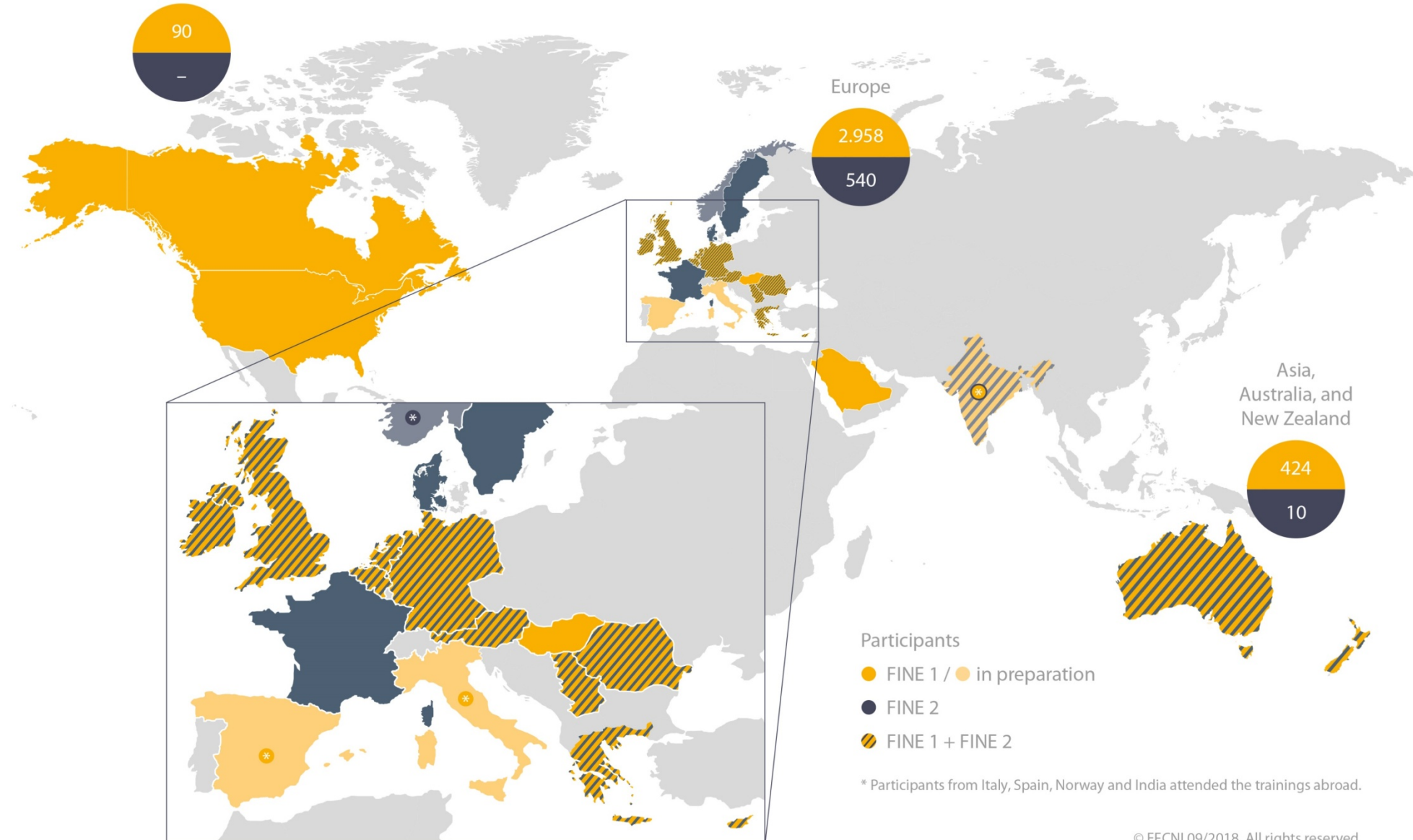
Foundation toolkit for IFCDC

endorsed by NIDCAP Federation International

Copyright: Inga Warren and Erasmus MC.

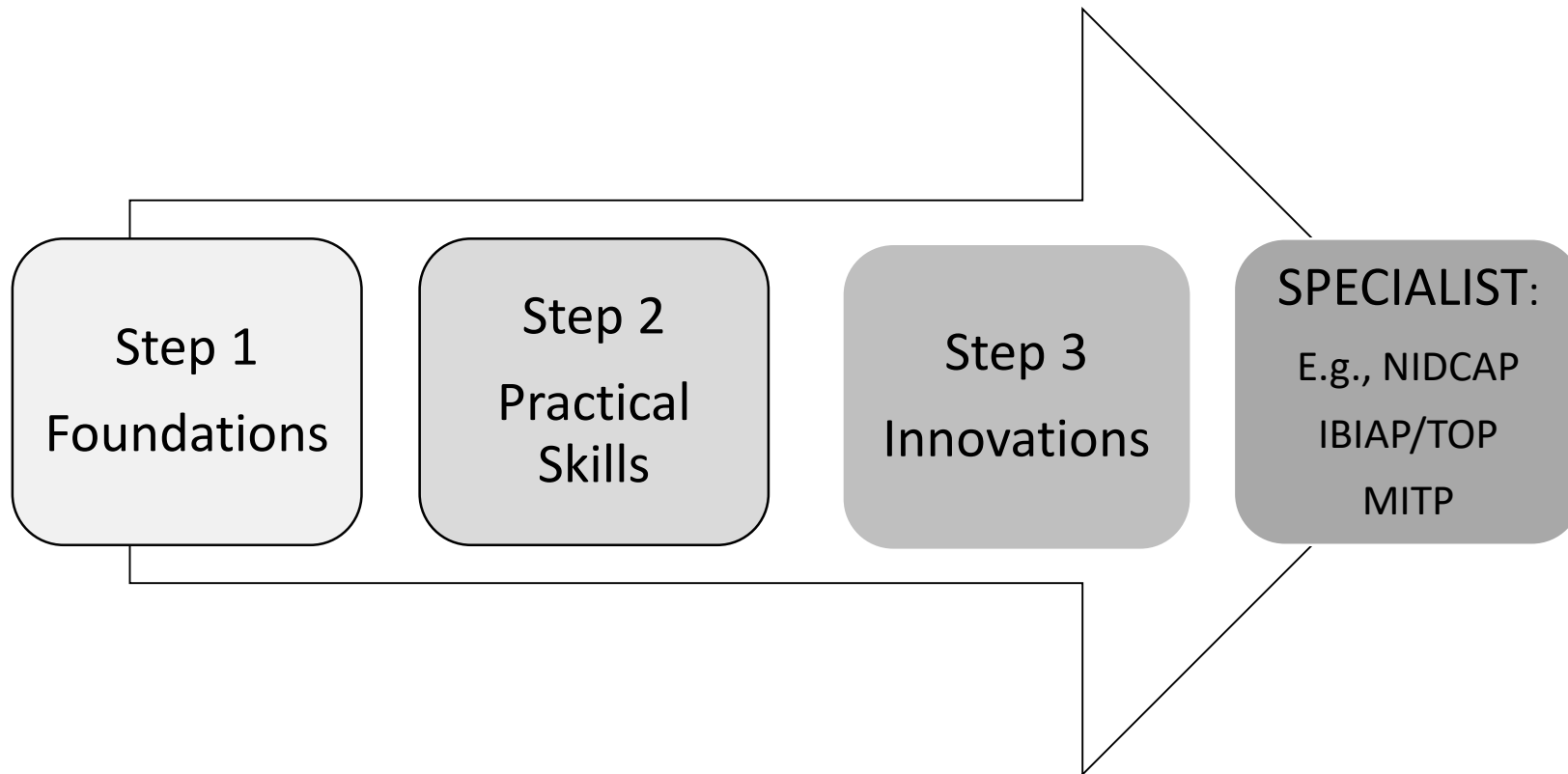
# FINE – Family and Infant Neurodevelopmental Education

(North)-America:



# FINE:

a pathway for infant- & family-centred developmental care education



# Essential themes

## INFANT DEVELOPMENT

- Brain
- Neurobehavioural
- Sensory
- Motor

## OBSERVATION

(based on synactive  
theory, Als 1982)

- Autonomic / Motor /State  
/ Attention
- Self regulation

## FAMILY

- Attachment / attunement
- Engagement
- Partnership
- LOVE

## Essential themes cont

### REFLECTION

- Thinking about what we do and how we feel
- Learning from experience

### EVIDENCE

- Best practice
- Direct evidence
- Supporting evidence
- Consensus

### SYSTEMS

- Openness
- NICU culture and organisation
- Learning styles
- Change management



## 2. PRACTICAL SKILLS: groups < 8, 12 weeks

### Objectives

Aware of and ready to change own practice

- Reflection
- Mentoring

Sees infant as an active communicator  
Individualises care.

- Observation
- Reflection

Partners with and learns from parents

- Active listening
- Parent participation

Identifies strengths and challenges in team

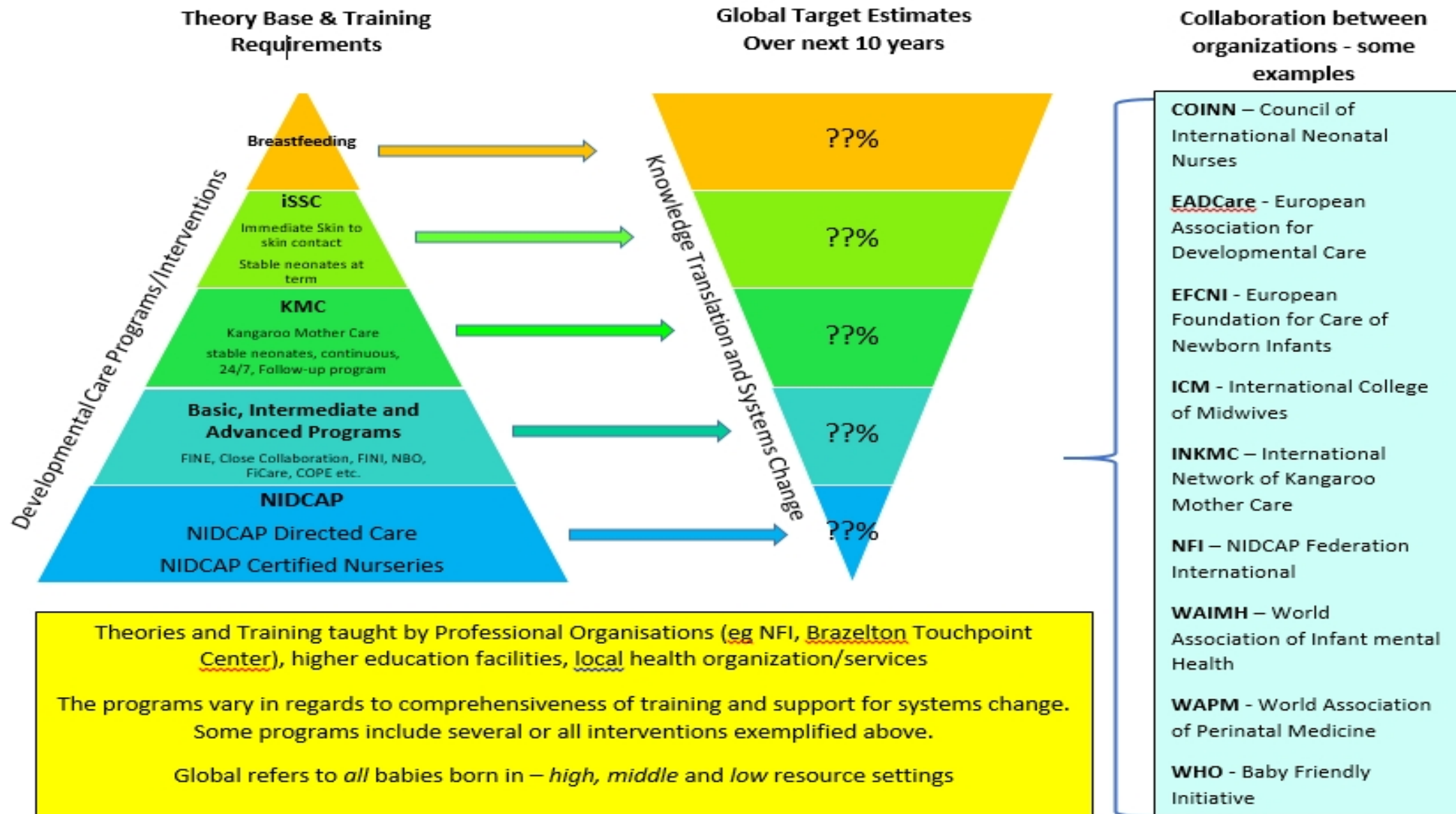
- Tools to evaluate practice
- Site assessment

# Bridging the gap

1. Between theory and practice
2. Between professionals, family and infant



# Global Perspective of Infant and Family Centered Developmental Care





NIDCAP Training Centers



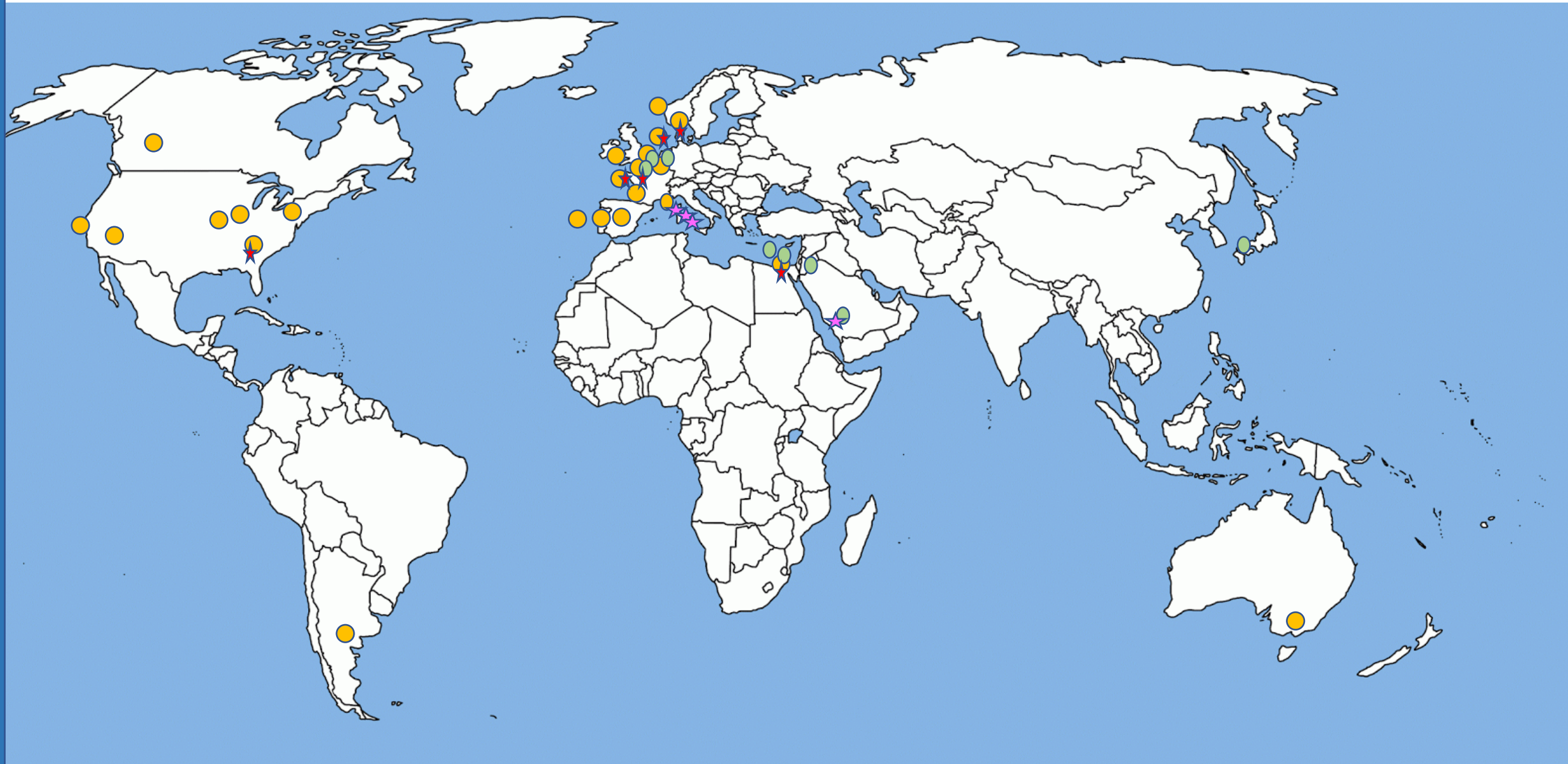
NIDCAP Training



NIDCAP Nursery

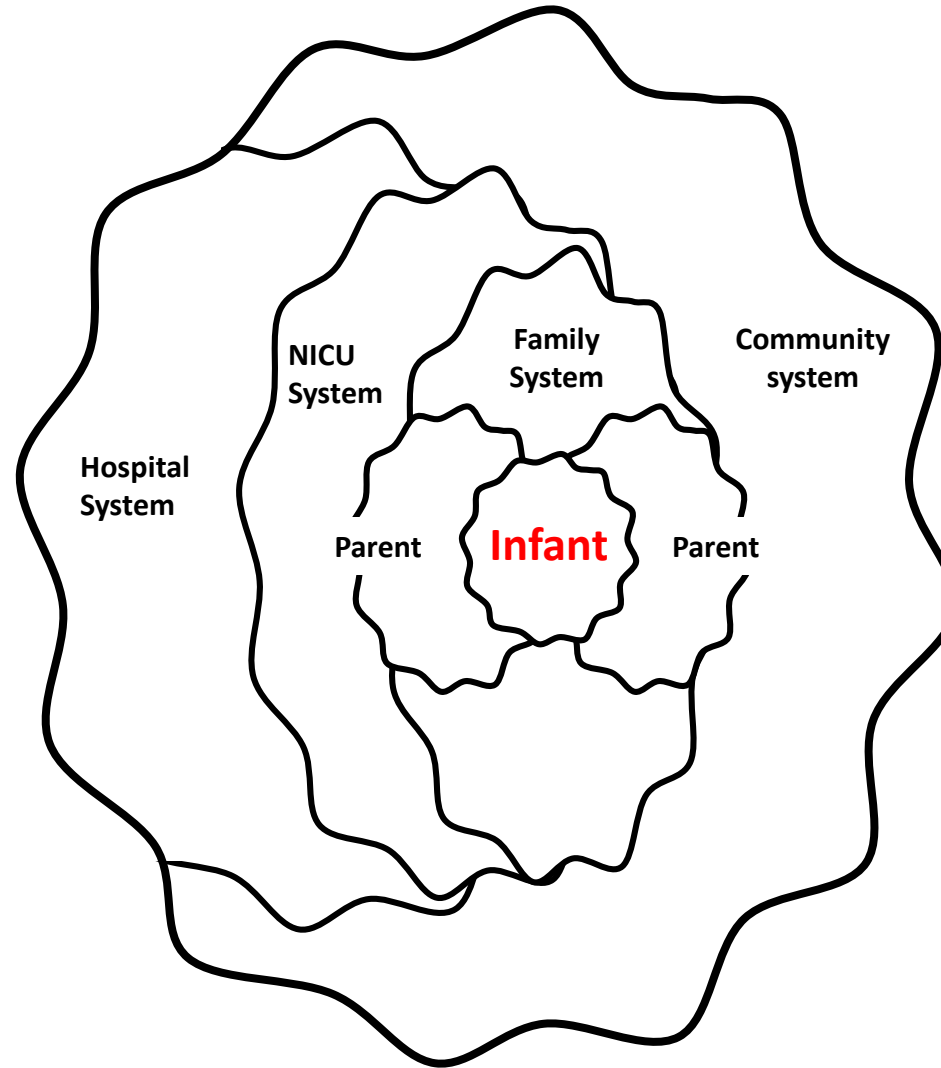


NIDCAP Nursery in  
Development





## Synactive Model of systems perspective



Political decisions

Hosp Admin decisions

Structural changes

Shortage of beds

Shortage of nurses



# Discussion Points



- Global spread of IFCDC
  - Start from the top? => Breastfeeding, KMC, iKMC ...
- Collaborations for the global spread
- Measurement of the global spread