

**Family Integrated
Care: where we are
now?**



Learning objectives

- To understand what are the essential components of Family Integrated Care (FICare)
- To comprehend the long-term impact of FICare on infant and family health
- To identify the steps involved in the dissemination of this knowledge and opportunities in medical practice to support parent engagement in care



Where my journey began: Estonia

- *“The mother and infant should be considered as a closed psychosomatic system.*
- *Everyday ward rounds should focus not only on the infant but also on the needs of the mothers.”*

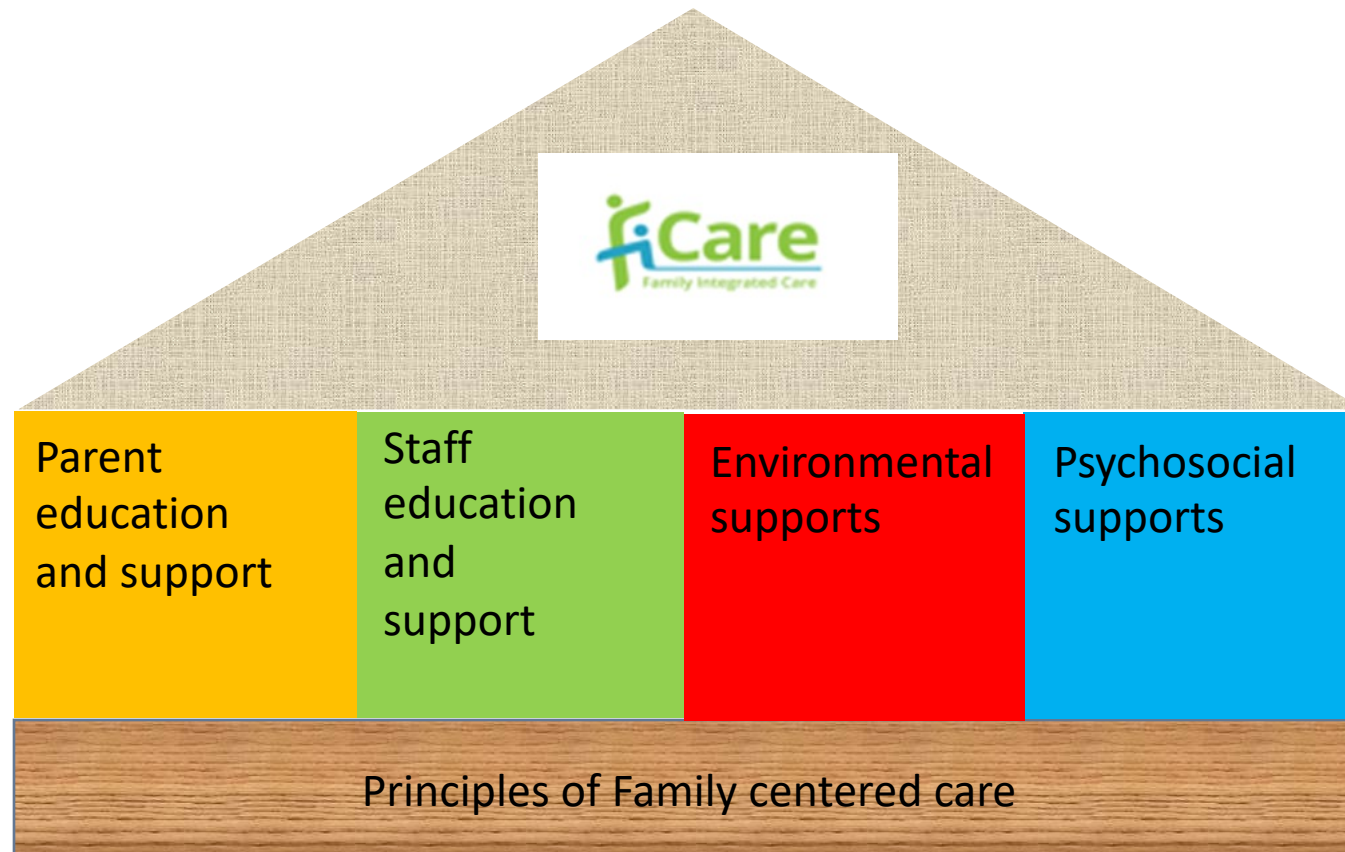
Dr. Adik Levin



From idea to making it happen: Parents and nurses on the journey



Family Integrated Care



Models of parent-partnered care

- **Family Integrated Care**
- Close Collaboration with Parents
- Family-Centered Care
- Primary nursing
- Care by parent
- Kangaroo mother care

Parent-delivered interventions

- Infant behavioral assessments
- Massage
- Skin-to-skin care (immediate and sustained)
- Infant feeding
- Developmentally supportive care
- Talking, reading, singing
- Comfort measures
- Family Nurture Intervention

Parent support interventions

- Parent-clinician communication
- Parent psychological support
- Parent education (individual and group)
- Supportive physical environments
- Supportive institutional and social policies
- Support after discharge

Philosophy of FICare

Parents parenting in the NICU!

The ideal healing environment for an infant is in the arms of their parent

Parents should be recognized as collaborators in their infant's medical care

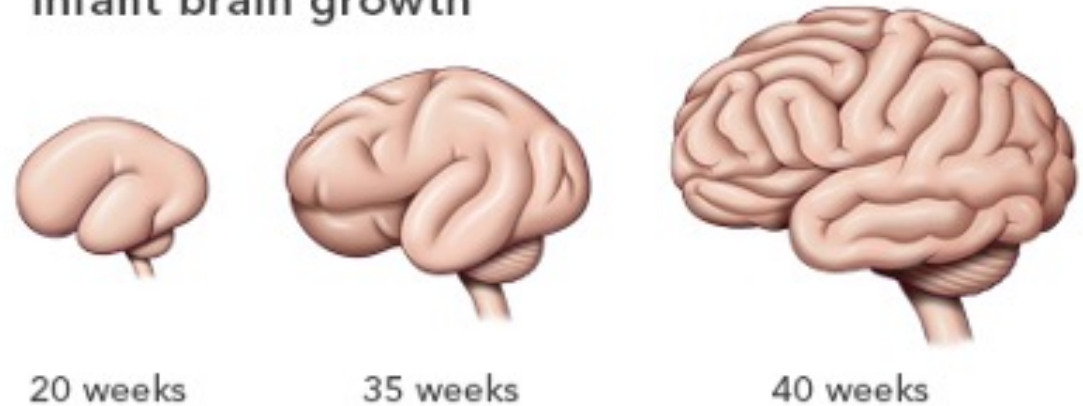
Parents have an important and unique role in decision making about the care of their infant



Impact of parental presence on infant neurodevelopment?

- Parent-infant interaction shapes the development of the infant
- Attuned parents provide developmentally responsive care which impacts the infant's nervous system & furthers normal brain development
- Parents regulate infant/toddler behaviour

Infant brain growth



Going home with empty arms

Parents are feeling lost

They need...

- Structure
- Education
- Purpose



Parent trauma in the NICU

Unexpected early delivery or complication, medical status, c/s

Seeing baby have traumatic medical procedures and life-threatening events

Witnessing other infants go through similar experiences

Continuously receiving bad news

Parent outcomes

- Parents in the NICU also suffer because of
Separation from their baby
Depression and anxiety
- The parents emotional state during the
NICU stay and beyond impacts their ability
to respond to their baby's cues and the
long-term health of the family unit



Parent education?

- Providing experiences that enhance the staff/parent partnership and supports parents independence as they grow into their role as caregivers in the NICU
 - Parent curriculum delivered in small group education sessions
 - Coaching by bedside nurses
 - Parent skill checklist/parent chart
 - Parents presenting on rounds
 - Parent engagement in care



Staff education: teaching staff to support families

- Staff education and Tools
 - Staff education modules
 - Staff/parent communication tools e.g. parent chart, communication white board, skills checklist, baby steps to discharge
- Parents/families are invited to collaborate in professional education of interdisciplinary team members
- Administrative/leadership and commitment with expectations around staff behaviours

Environmental supports

- Unit policies to support infant holding and parents being present at their baby's bedside
- Unit practices to support parent engagement
- Environmental support for prolonged parent/family presence at the bedside
e.g. chairs, breast pumps, parent rest space, food preparation area, parent meeting area. parent education space

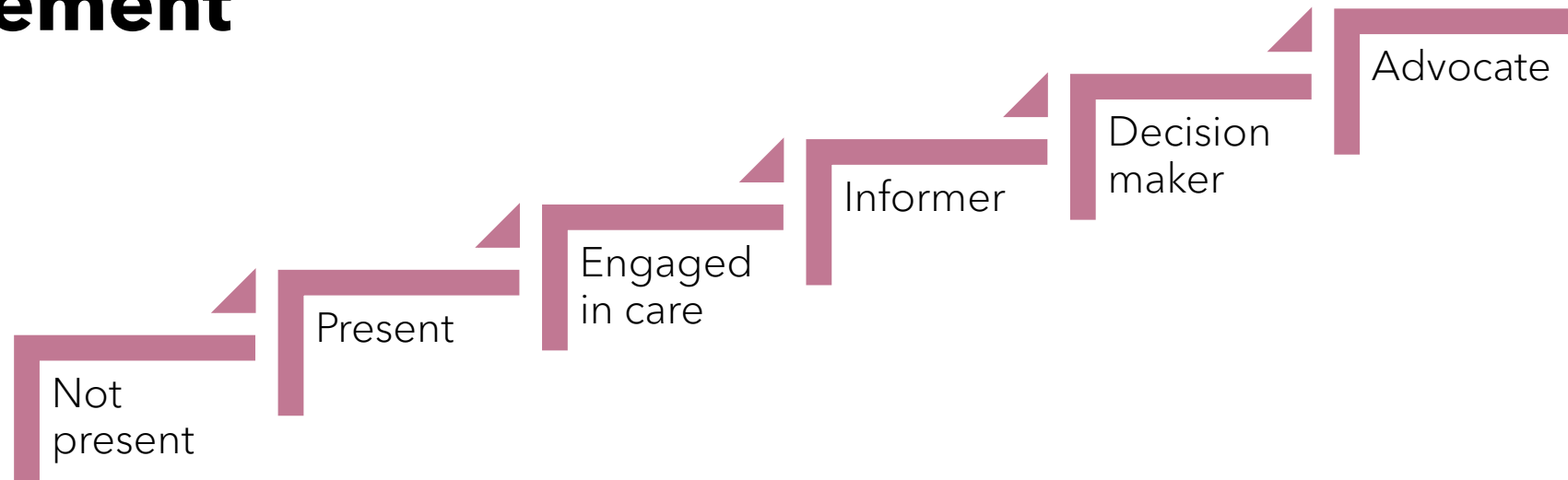


Psychosocial supports

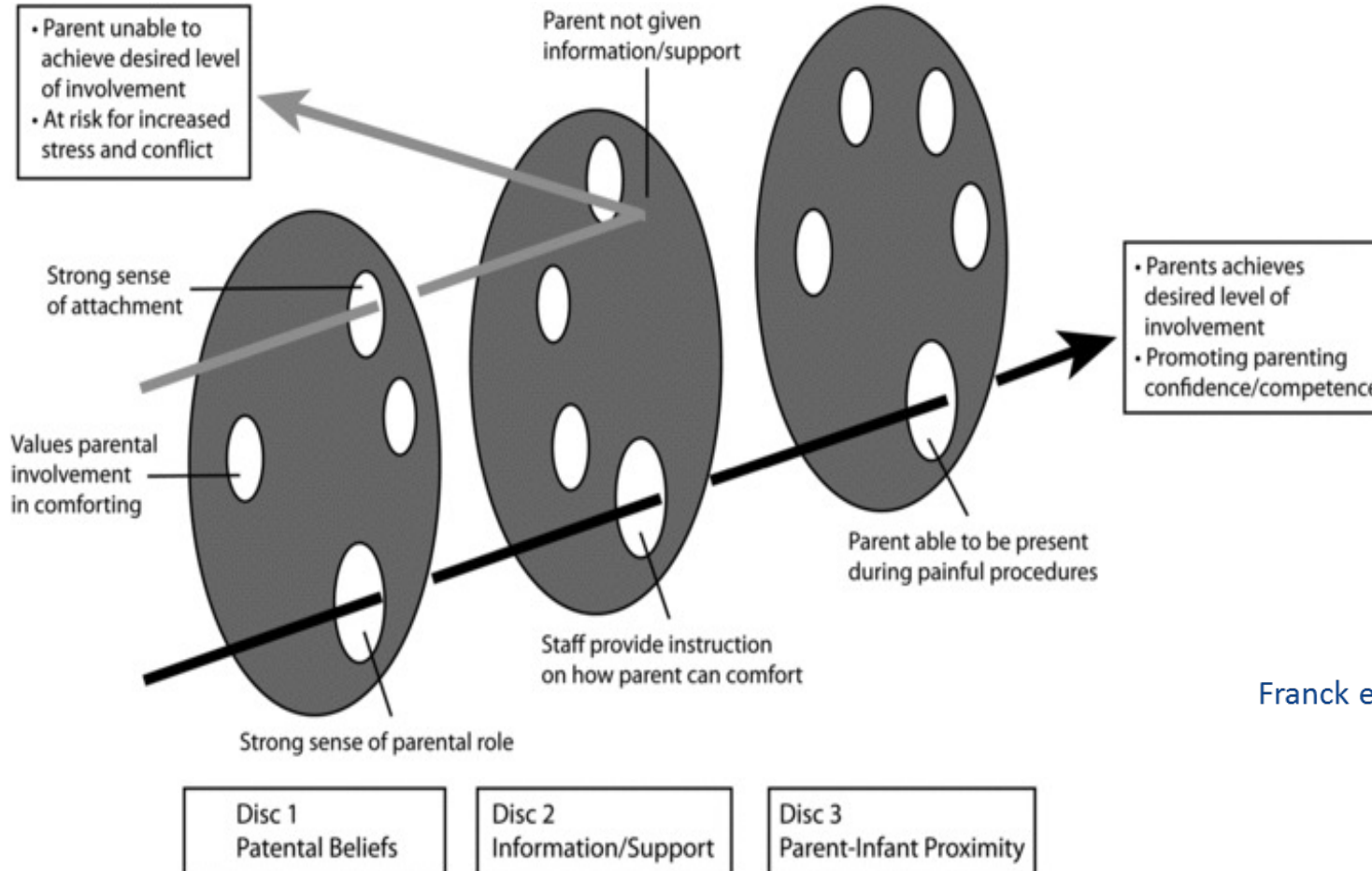
- Peer to peer support
- Veteran parent support
- Group support or one-on-one support
- Group social work and midwifery support



Parent Involvement



Parent engagement



Franck et al., JNS, 2012 44:1, 45–54

Impact on infants

Better growth in the NICU

More successful breastfeeding on discharge

Earlier discharge home, better weight gain and earlier suck achievement (UK and Canada)

Better self-regulation at 18 months corrected age

Better motor development

Better growth

Developmental outcomes of FICare

- Higher BMI
- Improved motor development scores

Family integrated care: very preterm neurodevelopmental outcomes at 18 months.

Synnes AR et al and the Canadian Neonatal Network Investigators; Canadian Neonatal Follow-Up Network Investigators.

Arch Dis Child Fetal Neonatal Ed. 2022 Jan;107(1):76-81.
doi: 10.1136/archdischild-2020-321055. Epub 2021 Jun 18



Improved self regulation

- Infants < 33 weeks gestation from the FICare cRCT
- Toddlers who received FICare demonstrated **better self regulation** indicated by lower Dysregulation scores, (T-score 41.7 vs 46.6, $p < 0.01$) at 18-21 months of age
- Parental stress was identified as a possible mediator of the impact of FICare on child behaviour

Family Integrated Care (FICare): Positive impact on behavioural outcomes at 18 months. Early Hum Dev. 151:105196, 2020 12.

Church PT; Grunau RE; Mirea L; Petrie J; Soraisham AS; Synnes A; Ye XY; O'Brien K

Impact on Parents

Developed hands on skills

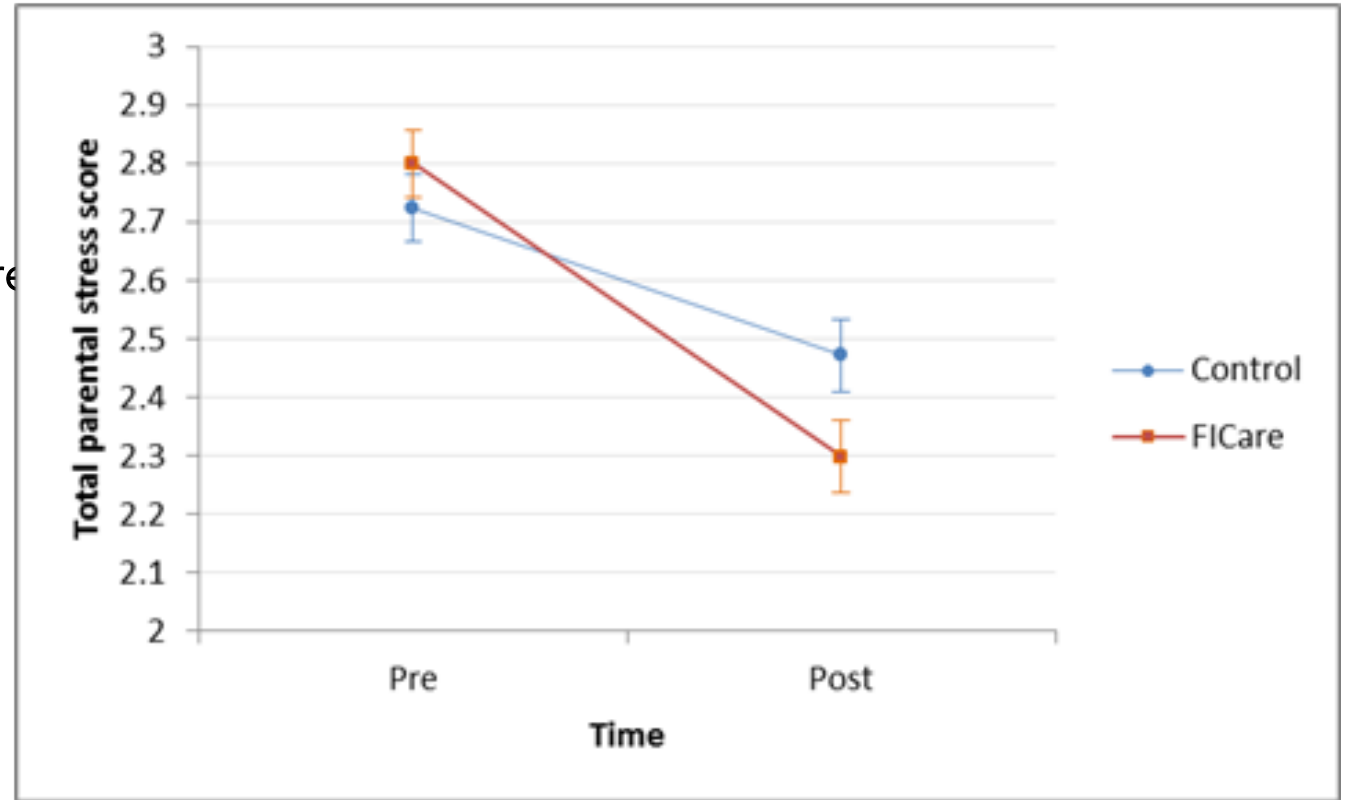
Developed a closer emotional bond with their infant

felt confident and competent taking care of their baby

valued the friendship and support of other parents

Decreased Parent stress

Even with 3 weeks of FICare we were able to demonstrate that Total parental stress and anxiety were reduced.



Sustained positive impact on maternal stress

- Maternal hair cortisol and cortisol/DHEA ratio at 18 months
- **Sustained improvement** in measures of maternal chronic stress
- **Lower maternal cortisol levels** were associated with **fewer child internalizing and externalizing behaviours** in FICare dyads
- For mothers reporting high parenting stress at 18 months, FICare was related to lower dysregulation T- scores via maternal cortisol

Lower Maternal Chronic Physiological Stress and Better Child Behavior at 18 Months:
Follow-up of a Cluster Randomized Trial of Neonatal Intensive Care Unit Family
Integrated Care
Mclean, Mia et al
The Journal of pediatrics, 2021-12-29;

What does FICare mean for staff



Effects on health care professionals

Build a better relationship with families
Satisfying to see parents become more
competent in communicating with staff and
taking care of their infants

**A qualitative study of families' and healthcare professionals' experiences in the Family Integrated
Care program in Australia, Xiangming Qiu, PAS Toronto 2018**

Effects on the health care professionals

"I felt that my workload was lessened by having parents in the FICare program,.... Although they are small, they are quite time consuming... I also really liked the amount of knowledge that the parents had about their babies. I thought it was much improved or greatly increased compared to other families."

- A RHW nurse



Why might FiCare be important long term?

Preterm infants have an increased risk of subtle challenges with learning, communication, moving and behaviour

The cause of behavioural problems are multifactorial including the effect of parent infant interactions

Behavioural problems impact the day to day function of the family and can have impact on school success



The FICare wave



Has grown



End of Study KT





Where are we now

- Publications with the search keyword “family integrated care” n >100
- Some Highlights
 - Adaptation and implementation of FICare in Level 2 NICU’s in Alberta; *led by Dr K Benzies*
 - Adaptation and implementation of FICare in China; *led by Dr Mingyan Hei China*
 - Adaptation and implementation of FICare across Europe and Zambia; *led by Dr Adelina Pellicer Madrid*
 - Adaptation and implementation in Netherlands; *led by Dr. Nicole Van Veenendaal*
 - Chez NICU in Halifax; *led by Dr Marsha Campbell Yeo*

FiCare effect on	Country of origin	Year of publication	Study design	Outcomes
Mortality	India	1983, 1986	Prospective ob study	Reduced mortality
Infection	India, Estonia, China	1986, 1994, 2020	Prospective cRCT	Decreased infection
Breastfeeding at discharge	India, Estonia, Canada, China, UK, China	1986, 1994, 2018, 2018, 2019, 2020	Prospective cRCT	Increased breast feeding initiation and sustained
Improved Weight gain	India, Estonia, Canada, China	1983, 1994, 2013, 2018, 2018	Prospective cRCT	Improved weight gain at 21 days
Parent mental health	Canada, Aus, NZ	2018	Prospective cRCT	Lower stress and Anxiety
Discharge/length of stay	India, Pakistan, Banerjee, China, Canada	1983,2004,2019,2020,2020	Prospective cRCT	Decreased length of stay
Readmission	Iran, China	2015,2019	Prospective cRCT	Reduced rehospitalisation
Improved behavioural outcomes	Canada	2020	Prospective cRCT	Improving self regulation

UK Neonatal Critical Care Transformation Review

- British Association of Perinatal Medicine have developed a "*Framework for Practice*" of *Family Integrated Care*
- Funded a team of Care Co-ordinators to facilitate the development of family integrated care practices in Neonatal units across the UK

Lindas work

Forming a relationship with parents (HEART)

- **H**ello
- **E**ye contact
- **A**sk and **A**nswer questions
- **R**emind parents how important they are in their baby's care
- **T**each parents how to be involved





6th International Family Integrated Care Conference

Moving Forward Together - Parents as Partners in Care

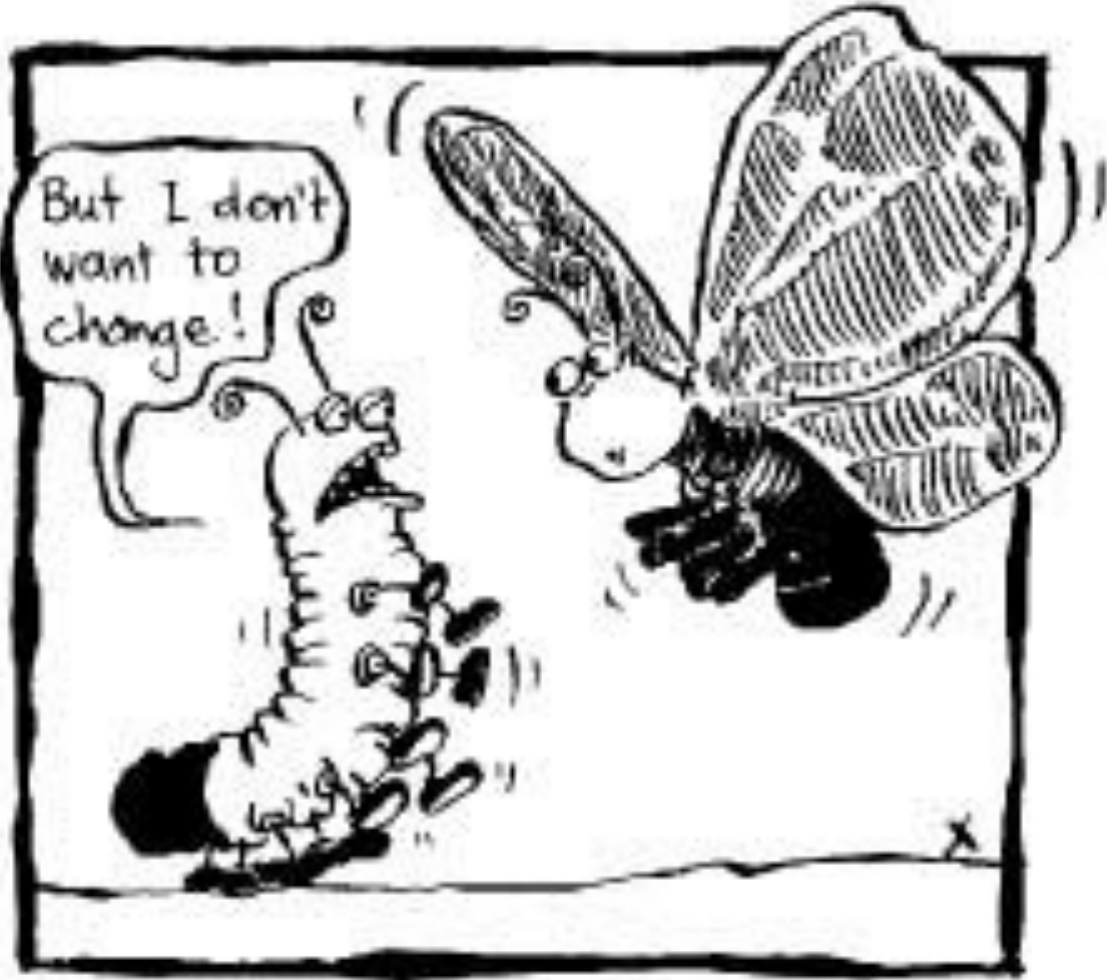
September 30, 2023 | Peter Gilgan Centre for Research and Learning

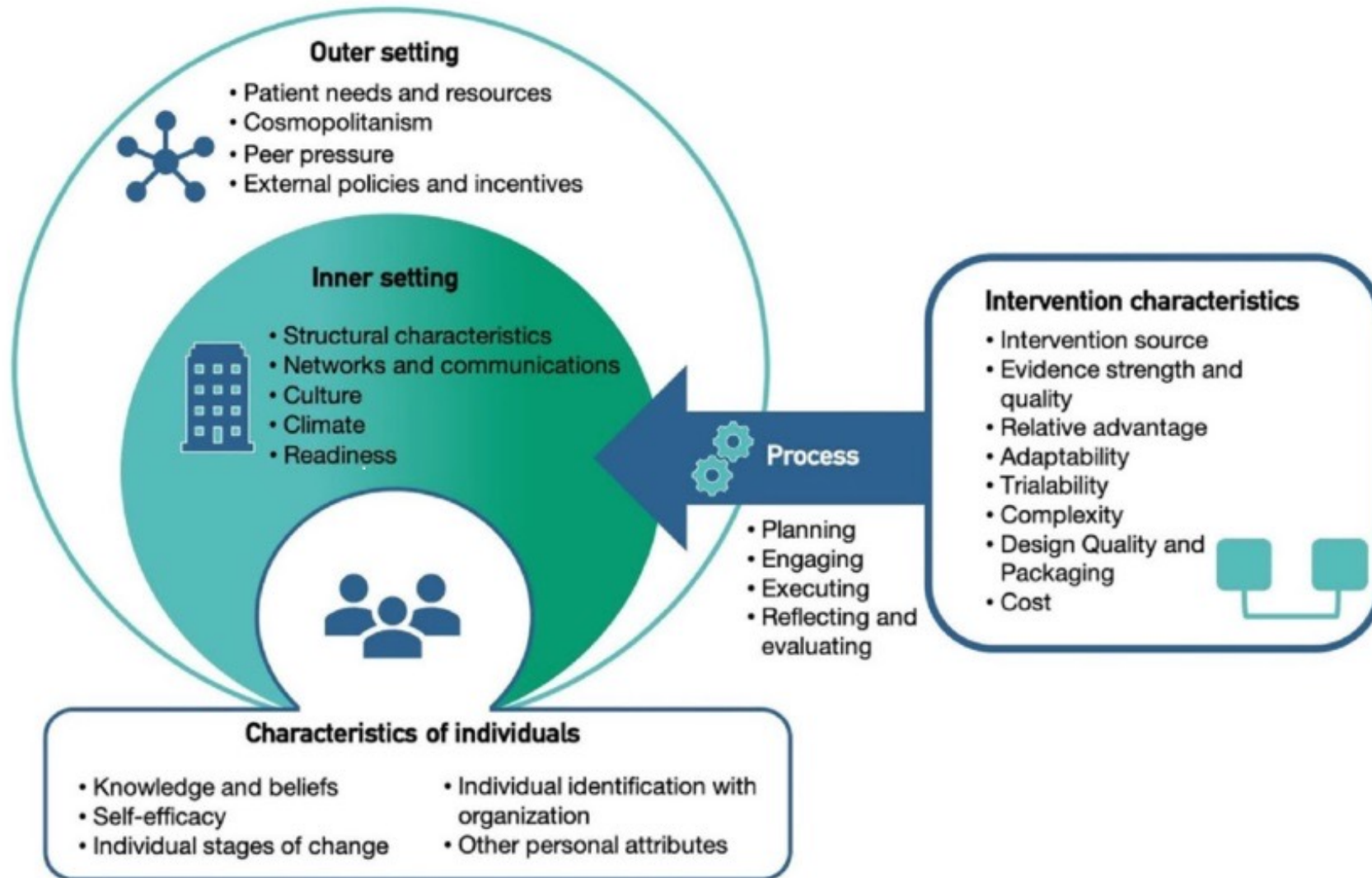
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FiCare supports the full integration of families in the care of their infants in the NICU

Change





Source: <https://thecenterforimplementation.com/implementation-in-action-bulletin/mar-2021>

Challenges

Knowledge and beliefs of staff and parents

Changing the role of nurses


- From doer to supporter
- From control to partnership
- Educator+++
- Champion/advocates

Changing the definition of good practice

Changing NICU culture

Implementation climate





Barriers to parental presence: Outer setting

- Health system level barriers
- Institutional Policies/procedures
- The NICU Environment

Barriers to parental presence: Social determinants





Barriers to parental presence:

Inner setting culture

- Body language: Shoulders keep out the parents not the walls
- Our words: Parents being referred to as visitors and asking to enter
- Control: Parents needing to ask to hold/touch

Barriers to parental presence: collaboration between staff and parents

- Parents have different needs
- Parents need to be invited to participate not forced
- Being prepared to ask and listen...are you ready to....
- Allow some negotiation of roles
- Growing the family as well as the infant

Make every hour count



How do you implement FICare

Guiding concept:

- Parents are true partners in their baby's care and should be supported to participate to the best of their ability

Create FICare steering committee

- Parents
- Administrators
- Physicians
- Bedside nurses
- other HCP

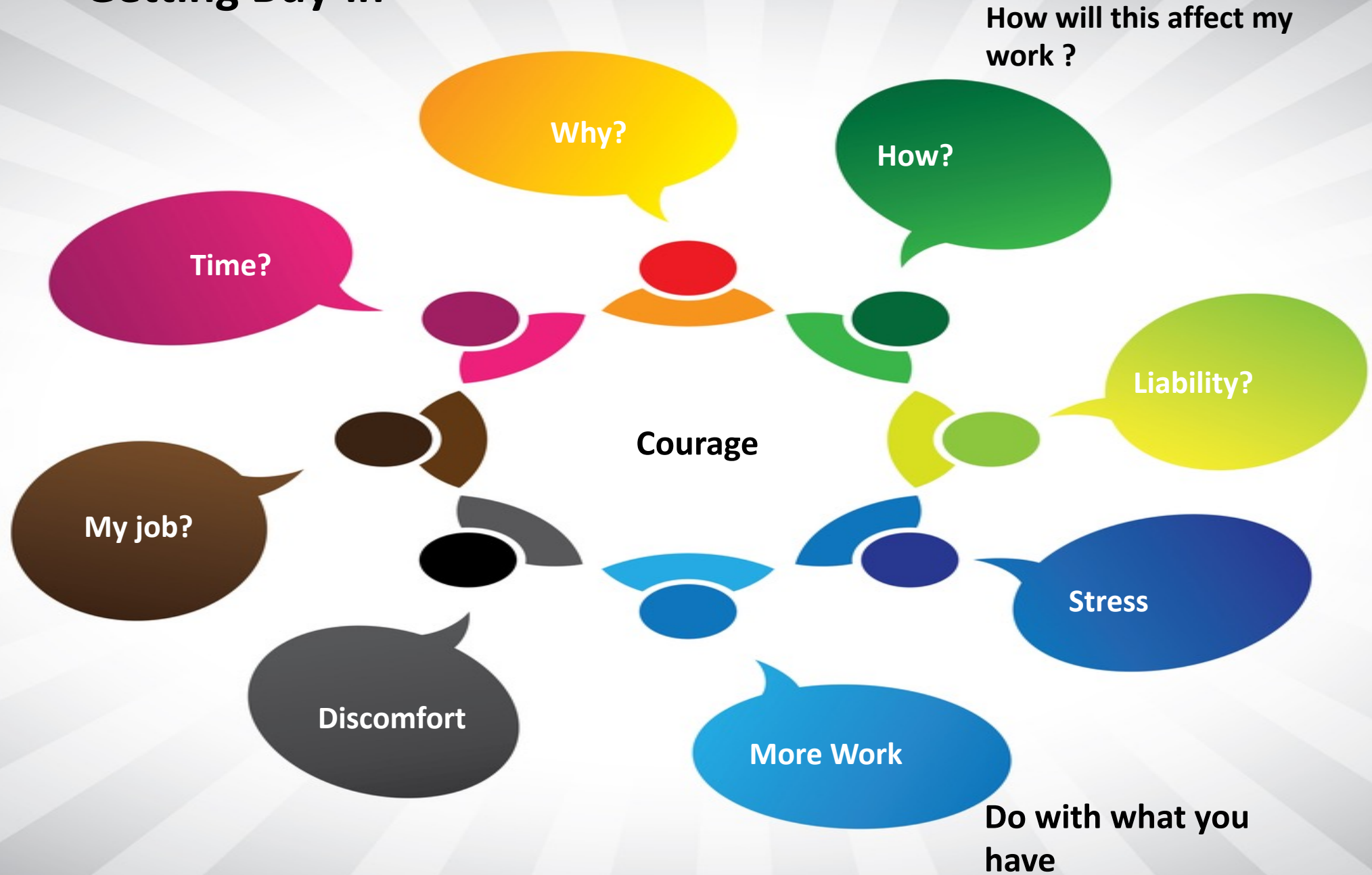
Planning

- Current state assessment
- Organisational and clinical leadership buy-in

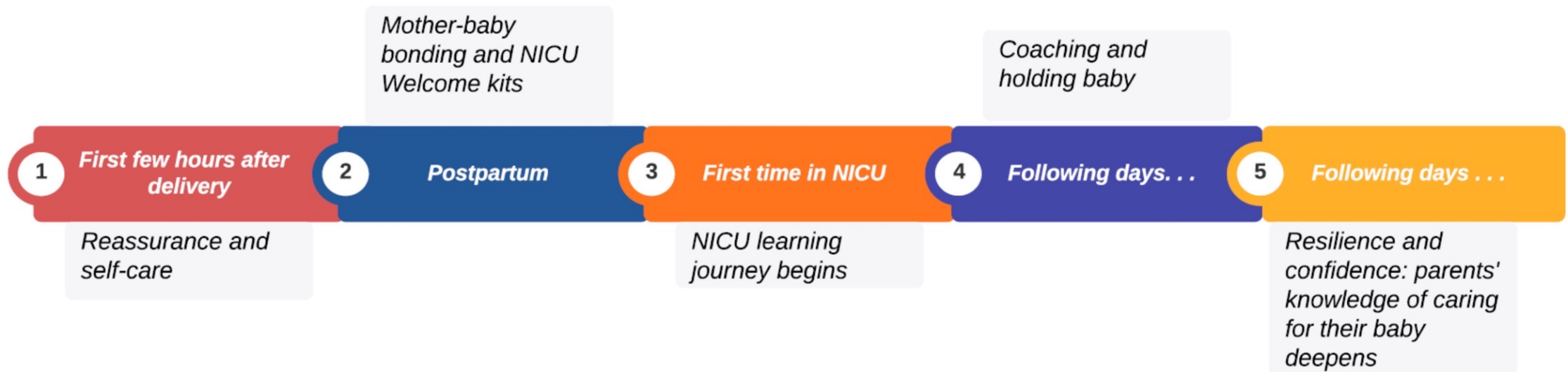
Engagement:

- Staff
- Families

Getting Buy-in



The Parent Journey: *critical beginnings*



Communication with families

01

Give families a voice to speak up

02

Understand the impact of small gestures of empowerment

03

Use strategies for engagement

Support parent learning

Listen

Listen to parent stories

Teach

Teach parents how to parent:

- Invite
- Teach
- Model

Understand

Understand health care needs in this complicated setting

How do you sustain FICare?

Engagement

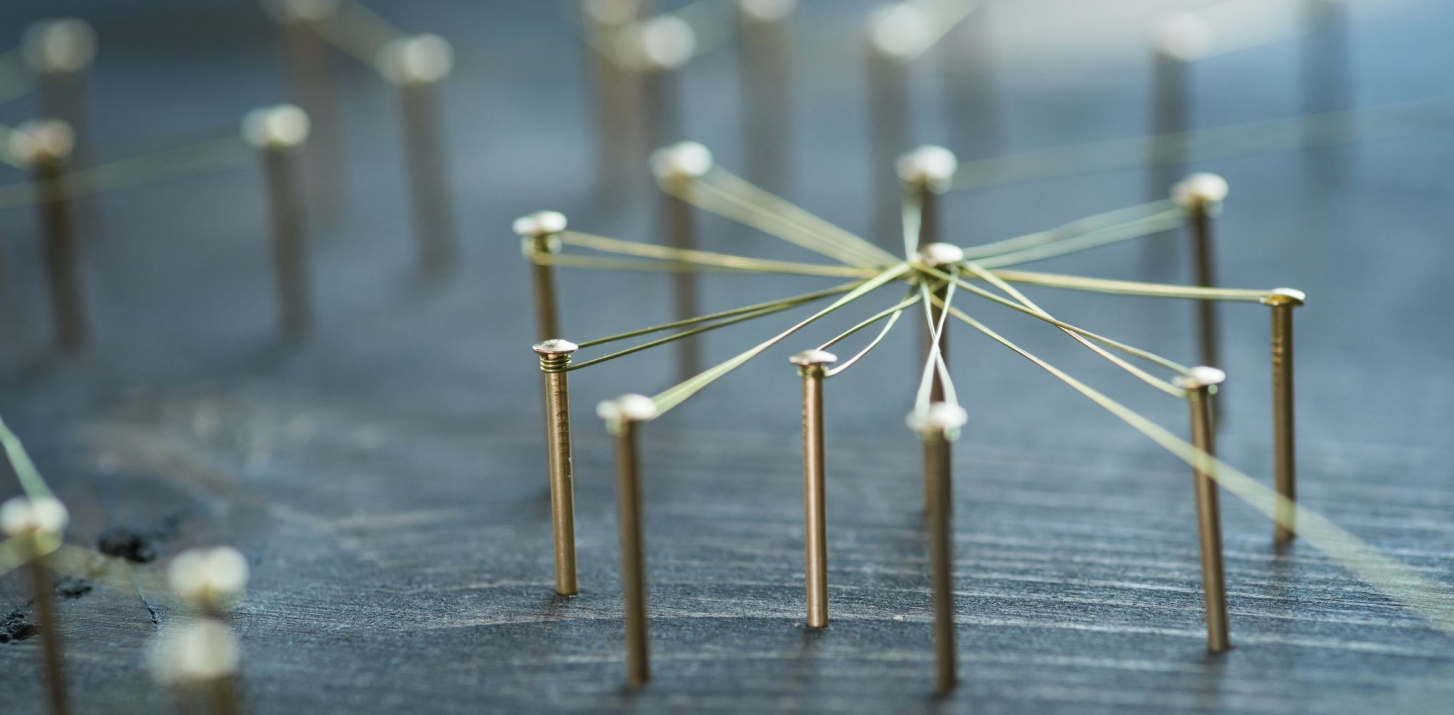
Communication

Formalize and
standardize
changes

Training

Measurement

Celebrate
success



Build parents resilience and confidence

“People will forget what you said, people will forget what you did , but people will never forget how you made them feel ”

Maya Angelou

FIcare GOAL:

.....through the dark I could be Gabriel's mom, I was taught touch, the feeling, the interaction, and how all that became Gabriel's "best medicine"





**Thank you to all the
nurses, families and my
collaborators around the
world who continue to
work to make FICare
possible**

Familyintegratedcare.com