



Co-Designing Mobile Technology and Care Delivery to Improve Family Integrated Care in NICUs

Linda Franck | mFiCare Principal Investigator
Sharon Sossaman & Brittany Lothe | mFiCare Parent Partners
Linda.franck@ucsf.edu

11/6/18



Objectives

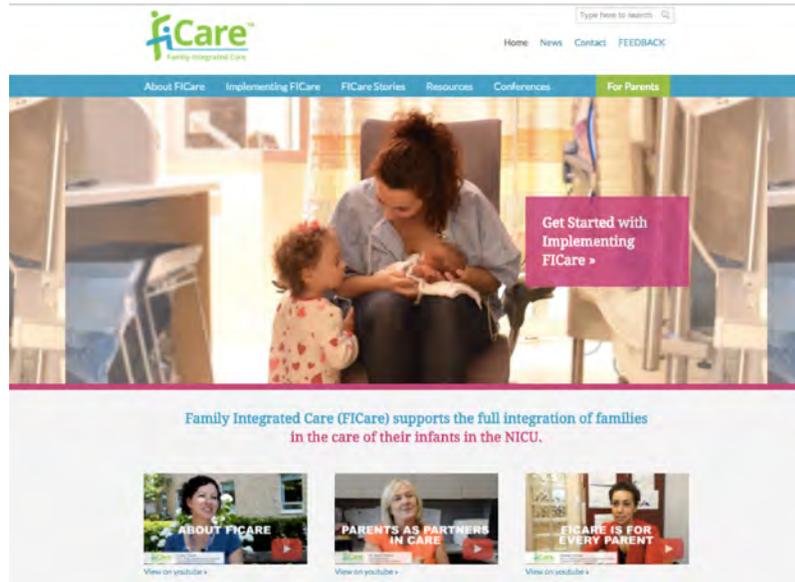
- ...describe the main features of mobile-enhanced family integrated care (mFiCare)
- ...describe the main processes of co-design
- ...discuss examples from the mFiCare project of parent and health professional co-design
- ...discuss the associated challenges and opportunities

11/6/18



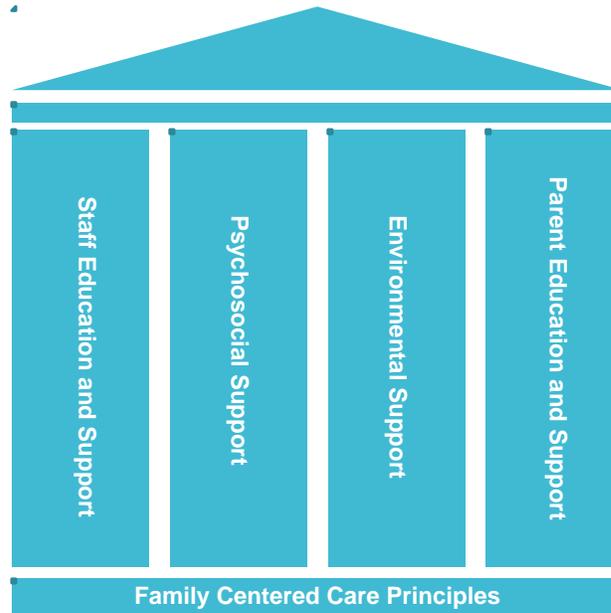
Family Integrated Care

www.familyintegratedcare.com
11/6/18



Pillars of FiCare

11/6/18



m4Care USA We3 Health WELLS WAY FOUNDATION UCR Benioff Children's Hospital UCsf

Evidence for FICare Effectiveness

O'Brien et al. BMC Pediatrics (2015) 15:210
DOI 10.1186/s12887-015-0527-0

BMC Pediatrics

STUDY PROTOCOL
Open Access

Evaluation of the Family Integrated Care model of neonatal intensive care: a cluster randomized controlled trial in Canada and Australia

Karel O'Brien^{1,2,3*}, Marianne Bracht⁴, Kate Robson¹, Xiang Y. Ye¹, Lucia Mirea^{1,5}, Melinda Cruz⁶, Eugene Ng^{2,4}, Luis Monterrosa⁷, Amuchou Soraisham⁸, Ruben Alvaro⁹, Michael Narvey⁹, Orlando Da Silva¹⁰, Kei Lui¹¹, William Tamow Mordt^{12,13} and Shoo K. Lee^{1,2,3}

FICare units had:

- Better weight gain (11%)
- Fewer exclusive formula feeding babies at discharge (14% vs 31%)
- Less parental stress and anxiety at discharge
- ALL FICare units continued with FICare after the trial

11/6/18

SPOILER ALERT!

- FICare cRCT refusal rate was approx 43% *because of the time commitment required*
- US parents may face (more?) barriers to involvement in their infant's NICU care
- Can FICare be *made more accessible* to parents who can't be in the NICU daily?
- Feasibility and acceptability of the FICare program in US NICUs must be tested

11/6/18

SPOILER ALERT!

- FICare cRCT refusal rate was approx 43% *because of the time commitment required*
- US parents may face (more?) barriers to involvement in their infant's NICU care
- Can FICare be *made more accessible* to parents who can't be in the NICU daily?
- Feasibility and acceptability of the FICare program in US NICUs must be tested

11/6/18



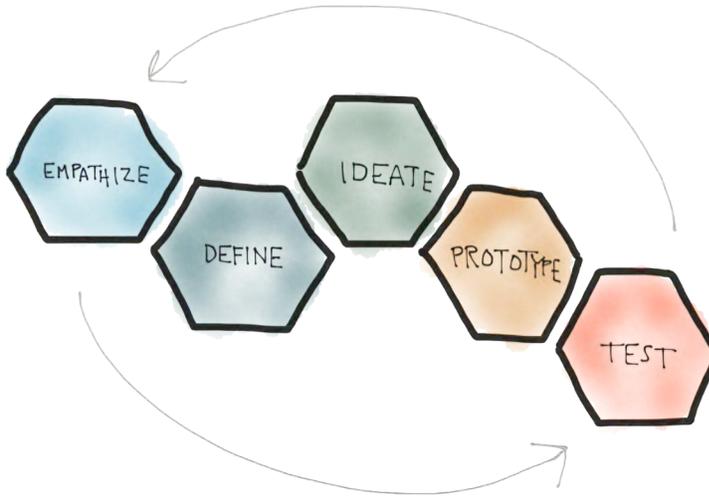
Amazing Parent Partners!



11/6/18



Principles and methods of co-design



11/6/18



And now a few words from Brittany Lothe



Click this link to hear Brittany explain the principles of Design Thinking

<https://willswayfoundation2.box.com/s/pm3a4ogy6tl16mphafu866i5q8wgk6ge>

11/6/18



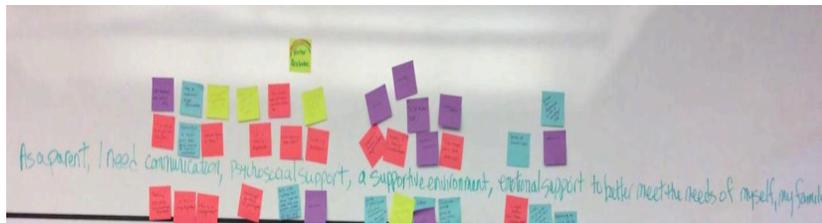
Parent/Clinician NICU Co-design



11/6/18



Insights from co-design sessions - NICU 'pain points'



1. Consider **emotional state of the parent**
2. Many parents in the NICU have **multiples**
3. The **right information at the right time** is critical so as not to overwhelm parents
4. **Add value** – not work – for clinical team
5. **Parents want mobile app technology to support their involvement in their baby's care**

11/6/18



User testing Round 1

"It has encouraged me to sit in on the rounds,, where as I would ask the nurse before what was going on."



"Just having all those questions to answer and stuff to fill in, kinda made me ask a little more."

"It just leads you into things you didn't know you needed to know about..."

11/6/18






User testing Round 2

"Using the journal took some getting used to, but now I like"



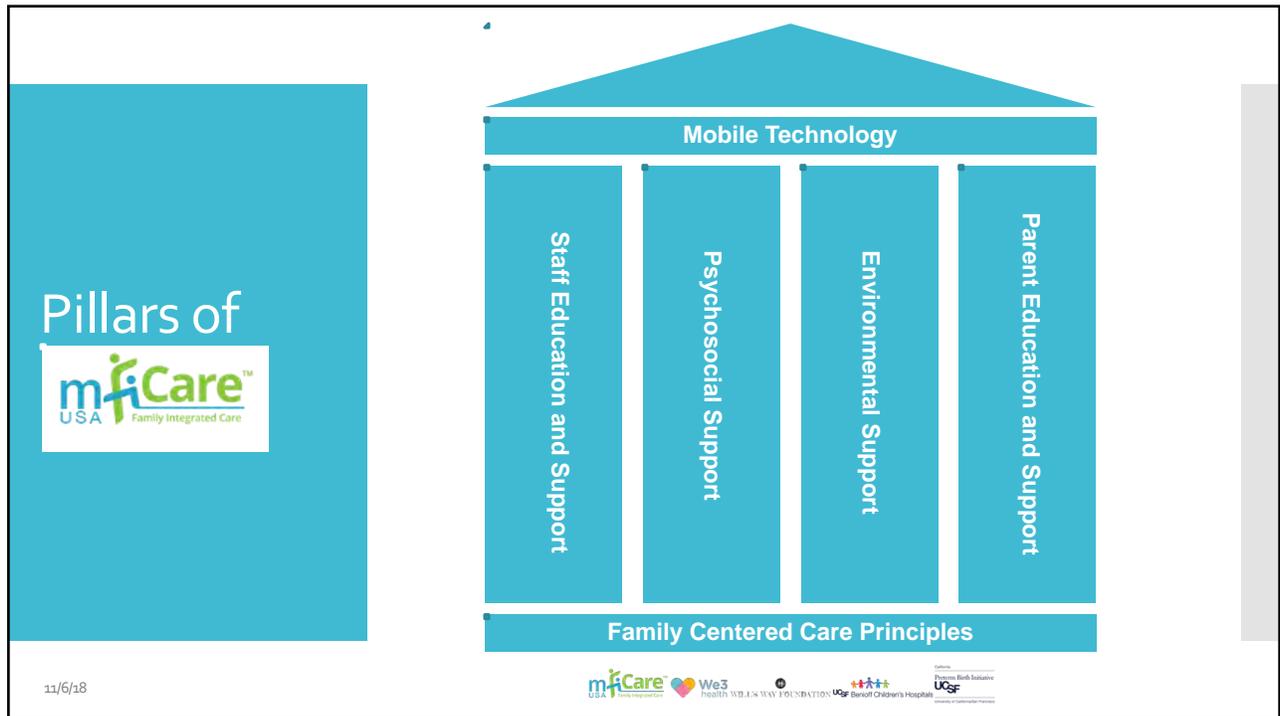
"Seeing the time I spend here in a graph makes me feel guilty or sad – can we track other things like when my baby got to 1kg or had her first bath?"

*"I'm having trouble figuring out how to record skin-to-skin time."
"I can't remember my password..."*

11/6/18





Parent Mentor Program co-design

Read more about the Canadian FICare Veteran Parent Program

<http://familyintegratedcare.com/toolkit/#tab-2>

Mt. Sinai NICU Social Worker and FICare Veteran Parent/Parent Buddy

11/6/18

mfiCare USA Family Integrated Care | We3 Health WILLAWAY FOUNDATION | UCF Benef Children's Hospital | University of Central Florida | Pediatric Birth Initiative | UCF

The need is similar across NICUs

”
I WAS IMPRESSED WITH OUR SOCIAL WORKER....OUR DOCTORS AND NURSES WERE EXCEPTIONAL...BUT I FOUND MYSELF IN DESPERATE NEED TO SOMEONE TO TALK TO WHO HAD BEEN IN MY SHOES...
 “
 NICU MOM

11/6/18



What is a Parent Mentor?



A parent of a former NICU preterm baby who can:

- Actively and empathetically listen to parent without trying to solve problems or give advice
- Provides emotional and informational support
- Helps parent identify and use their own personal strengths and support systems
- Empowers parent to participate in their baby's care as an essential member of the care team
- Knows when to ask for help

11/6/18



Parent mentor support happens in different ways

PARENT MENTOR 101



"I was thinking of your e-mail in the middle of this crisis... It's always good to know there is support that understands how hard this road is."

• An NICU dad

11/6/18



What support do Parent Mentors need to be successful?

PARENT MENTOR 101



11/6/18



In progress:
The US mobile-enhanced FICare clinical trial

Trial comparing FCC and mFI-Care (N=350)

BCH-SF BCH-O UCLA Kaiser SC CRMC Fresno UCSD

Phase 1: FCC (n=175 families and 175 NICU staff)

Phase 2: mFI-Care (n=175 families and 175 NICU staff)

11/6/18



So far...

- 68 parents from 3 sites in phase 1 (FCC) used the We3health™ app to report kangaroo (KC)/skin-to-skin care

Parent-generated data on their contributions to their baby's caregiving

11/6/18



Summary of what we've learned so far



1. Parents have amazing insights that substantially improve research design and implementation
2. True co-creation requires give-and-take
3. Parents are impatient for change - and that's good - and challenging - for traditional research

11/6/18



The next step in the research co-design journey



11/6/18



Co-Creating the Research Agenda and Strategy

Read more about the California Preterm Birth Initiative Parent-Clinician Advisory Board

- <https://pretermbirthca.ucsf.edu/interventions-across-reproductive-lifecourse-postnatal-care>

11/6/18



Co-design is the future

How you can be a co-design champion

- Lift the voices of diverse families
- Create opportunity/remove barriers to families to be 'at the table'
- Support parents to participate
 - Clear purpose
 - Practical support
 - Compensation, meeting flexibility
 - Learning the language, public speaking
- Pay attention to the principles of partnership and shared decision-making
- Question the status quo

11/6/18



US FiCare Sites

Parent Partners
Sharon and Jeramy
Sossaman
Anne Shamiyeh
Meredith Azeem
Elvira Pereda
Alejandra Sanchez
Emily and Sean Noonan
Iesha Scott Grant

UCSF– Benioff Children’s San Francisco
Linda Franck, Yao Sun, Robin Bisgaard, Rebecca Kriz, Katie Millar, Nadia Tsado

Will’s Way Foundation
Scott Bolick and Brittany Lothe, Preemie Parents and Co-Founders; Will Bolick, Chief Inspiration Officer

UCLA
Valencia Walker, Heather Hackett, Denise Ribero, Stephanie Hines, Juliet Sasinski, Pamela Miller

Benioff Children’s Hospital Oakland
Priscilla Joe, Holly Christensen, Samantha Ngo, Teresa Proctor, Joanne Kuller, Bette Flushmann

Community Regional Medical Center Fresno
Diana Cormier, Donna Wyman, Donna McCloudy, Drs. Rajani

Kaiser Permanente Santa Clara
Carol Lin, Lawrence Dong, Jennifer Mora

UCSD
Jae Kim, Mary Ekno, Judy Davidson

11/6/18



Resources

- Brown T. Design thinking. *Harvard Business Review* Jun 2008: 84-92.
- <https://dschool.stanford.edu/resources/>
- www.familyintegratedcare.com
- Contacts:
 - Linda.Franck@ucsf.edu
 - Brittany@willswayfoundation.us

11/6/18

