



**Nurses and families
side by side**
today, tomorrow, together

Kate Robson





Today ...

- Our story
 - Meeting Maggie, going for Grace: our transformation
- The Parent Coordinator Position
 - Description, inspirations, possibilities
- The NICU as a transformational environment
 - How adults learn --> how parents become parents
 - How nurses teach --> how nursing care transforms families
- A big thank you from the families you help!



Our story





The description

- Acts as a liaison between NICU families and all members of the health care team
- Develops and coordinates support to families in the NICU and Neonatal Fellow Clinic
- Is the co-chair of the Sunnybrook NICU Family Advisory Council
- Provides individualized support to current NICU families as desired. Families may choose not to be involved with the Parent Coordinator
- Provides information to families about community resources that are available and updates this information as needed
- Participates in the design, implementation and evaluation of services, programs or systems that enhance services to infants and families
- Participates in improving organizational performance through recommending areas or approaches for improvement activities
- Provides education for families and staff based on input from families using strategies that facilitate learning and open communication
- Provides education to all new staff, students and trainees on principles of Patient & Family Centred Care
- Participates in NICU committees



The value is in the grey areas ...

- Outsider / insider
- Staff member / friend
- Voice of experience / Open mind
- Public representative of an institution / Squeaky wheel

These areas of apparent contradiction are where we find both the risks and the real opportunities of this position.



Building narratives

- Families will construct a narrative based on whatever they can find around them
- Experiences of other families, body language of staff, Internet-based searches
- Is their narrative accurate? Will it lead to disappointment?
- Helping families build their narratives is one of the best parts of my job



Challenges

- Part time = hard to knit yourself into the fabric, hard to manage time
- Risk of ego interfering. My story is one story
- Emotional demands of the work are exhausting
- Not a lot of time for “thinking work”



The Great Work

- Fostering resilience in families. Helping them find their confidence and build the best life they can
- Examining how we address the big issues: living with disability, living with uncertainty, living with societal inequities, facing death
- Working together to improve care and outcomes for everyone
- Working with my heroes (ie you)



Inspiration





The Opportunity in the NICU

- NICU metaphors: rollercoaster, minefield, gladiator's arena
- It's also the first learning environment for many parents
- Parents are surrounded by capable teachers (ie you)
- Helping parents find their confidence is a gift that will last a lifetime



What do you see?





What we were thinking

- Did we make the right decision? What kind of life will she have?
- I don't feel like a mother. She doesn't look like a baby.
- I feel helpless. I don't know what to do. The machines matter more than I do.
- I don't trust my body any more. There have been too many reversals. I don't trust statistics.
- At the same time, we both feel strangely elated. Is that normal?



What do you see?





What we were thinking

- Her first feed! I'm so proud that it's my milk!
- I finally did something for her! I feel capable!
- That nurse was right - those first few drops did matter. Now I don't feel like an idiot for collecting them all.



What do you see?





What we were thinking

- Here I am, breastfeeding my 2nd baby! I finally got to the point where it felt natural and good.
- I'm glad my nurses showed me what to do and encouraged me. Without their consistent support I never would have ended up here.



Our nurses were ...

- cheerleaders
- experts
- champions
- support team
- source of strength

- our **TEACHERS**



How do adults learn?

- What inhibits adult learning?
 - Stress, fatigue (Brundage & Mackeracher: 1980)
- What promotes adult learning?
 - Opportunities to practice, atmosphere of acceptance, hands-on practical opportunities (Gresh, 1995)
- Hands-on learning helps most adults learn, regardless of individual learning style
 - OIT, skin-to-skin care, baby care = learning tools
 - Skin-to-skin helps with stress response (Legault & Goulet, 1995; Neu, 2004)



How do adults learn? (cont)

- Learning is encouraged by ideas of self-benefit or benefit to others
- Different models than in conventional child-centred education: Ladders & chunks
- Taking time to find out what people already know and then build from that is time well spent



Patience is required

- Your daily environment is familiar to you but overwhelming to families
- Even experienced parents are inexperienced in the NICU
- Parents may need the same info over & over again
- We are not at our most rational. Most of us are engaged in “magical thinking.”
- Parents don't know the other demands on you
 - Patient load
 - Scheduled events



Teaching parents to be advocates

- Skin to skin holding, doing baby care, being involved in care plans: all powerful educational moments for parents.
- The experience of doing these teaches us about being parents.
- The experience of asking about them and seeking involvement teaches us about positive advocacy.
- These are life-long lessons.



On behalf of the thousands of families
you help, the people you've saved, the
transformations you've inspired ...

thank you