Marybeth Fry MEd  
Lead Family Advisor  
VON NICQ Next: Innovations in Newborn Care  
NICU Family Care Coordinator  
Akron Children’s Hospital  
Akron, OH  

The 2004 birth of Marybeth’s daughter at 28 weeks gestation and subsequent three month NICQ stay introduced her to a world she never knew existed and she wanted other NICU families to know they weren’t alone. In January of 2008, Marybeth became an Akron Children’s Hospital Parent Mentor and Volunteer and began visiting NICU families each week as a graduate parent. She also became involved in NICU FACT (Family Action Collaborative Team), a group of NICU graduate families and staff working together to support NICU families and promote family-centered care in the unit. Marybeth attended her first VON Conference with the Akron Children’s Team in spring of 2010 and has been fortunate enough to attend every meeting with the team. In the fall of 2010, she became co-chair of NICU FACT and began working more closely with hospital staff on our group’s initiatives. She began attending QuIP (Quality Improvement Council) meetings monthly and participated on NICQ8 conference calls weekly.  

In January 2013, Marybeth secured a paid parent position at Akron Children’s Hospital as the NICU Family Care Coordinator. This amazing opportunity has allowed her to be even more actively involved in furthering family-centered care and to see many of her volunteer projects come to fruition.

Kate Robson Med  
Parent Coordinator, NICU  
Sunnybrook Health Sciences Center  
Director, Canadian Premature Babies Foundation  
Toronto, Ontario, Canada  

Kate Robson’s first daughter was born in 2005 at 25 weeks, weighing 500 grams. Her second daughter was a slightly more robust 32-weeker born in 2007. She has spent time as a patient and as a parent in four different hospitals and three different NICUs. She now works in one of those NICUs as a Parent Coordinator, offering support to families and helping the unit deliver family centered care. Her background in Adult Education (MEd OISE/UT 1999) and Community Mediation (Diploma in Alternative Dispute Resolution, York University, 2003), when combined with her personal experiences, helps her bring families and staff together as collaborators. She is co-chair of the Canadian Family Advisory Network, is one of the Directors of the Canadian Premature Babies Foundation, and has had the opportunity to present at conferences such as the Canadian Association of Neonatal Nurses Annual Conference, the Gravens Conference on the Physical and Developmental Environment of the High Risk Infant, the Advanced Practice Nursing Forum, and the Annual Conference of the Australian College of Neonatal Nurses. She is also a family faculty resource for the Vermont Oxford Network.

NICQ Symposium Plenary Session, Friday, October 2, 2015  
Parent Perspectives  
Objective: Promote family involvement in quality improvement work.
Purposeful Engagement, Powerful Teams
Potentially Better Practices for Inviting and Integrating Family Members into Quality Improvement Work
Marybeth Fry and Kate Robson, VON Family Faculty

Disclosure & Thanks
Marybeth Fry and Kate Robson do not have any financial arrangement or affiliations with a commercial entity. They will not be discussing the unlabelled use of a commercial product in this presentation. A sincere thank you to Amy Nyberg, Ginny Shaffer and Joanna Celenza for sharing their wisdom and helping with this presentation.

Match the mechanism to the project
Do you need …
- A survey?
- An in-person focus group?
- An online focus group?
- A family advisory council?
- A parent panel?
- Family faculty?
- Parent representatives for committees?
- A short-term volunteer?
- A long-term volunteer?
- A parent on staff?

“Don’t assume that you know when/how family advisors can assist with a project, policy or initiative – being open to their wisdom at any moment might bring some perspective that otherwise would be missed.”
Joanna Celenza

Learn more about what kinds of projects family advisors can help with at the Institute of Patient and Family-Centered Care, and the Powerful Partnerships Handbook (NICH).

Match the person to the role
Would you hire this person for another job?
Does s/he have other skills to bring to the table?
Is this person emotionally ready to take on this particular role?
Can this person bring a unique voice or perspective?
Do you have a way to assess readiness on the part of the parent?
Do you have a way to assess readiness on the part of your staff?

Match the person to a mentor
Who on your staff can …
- Meet with parents before and after meetings to debrief?
- Check in regularly with parents to see how projects are going?
- Give parents orientation to the unit “from the other side”?
- Be a champion for parent involvement in your unit?
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And be ready to …

Share your successes widely! Success breeds success. Don’t let your family representatives be your best-kept secret.

Keep staff educated and involved. They can be great leads for finding family representatives, and can help integrate advisors into unit activities.

Maintain support of your parent advisors. These roles can be extremely emotionally challenging and isolating. Let them know they’re not alone.

Food for thought

Excerpted from Powerful Partnerships: a Handbook for Families and Providers Working Together to Improve Care

Don’t worry about exposing the system’s weaknesses to families. They already know about them.

Patient and family-centered care is about doing things with families, not to or for them.

Whether it is a quality improvement project or some other work, involving families from the very beginning is the best way to get it right.

Just get started.

Recommended Reading

Powerful Partnerships: http://www.nichq.org/how-we-improve/resources/powerful-partnerships


The Institute for Patient and Family Centered Care: http://www.ipfcc.org

The Canadian Foundation for Healthcare Improvement: http://www.cfhi-fcass.ca/WhatWeDo/PatientEngagement.aspx