FAMILY INTEGRATED CARE AND
FAMILY INTEGRATED QUALITY IMPROVEMENT (FI-C-QI) ASSESSMENT

Background:

The **purpose** is to assess the level of family integrated care and family integrated quality improvement in the eleven NWIPA NICUs sites in order to: 1) understand baseline findings across the NWIPA sites and within each NWIPA site, 2) identify sites and areas of excellence and 3) shared areas where improvement efforts may be valuable.

Why are you being asked to complete the assessment? The Oregon Pediatric Improvement Partnership (OPIP), Northwest Neonatal Improvement Priority Alliance (NWIPA) and the Oregon Perinatal Collaborative (OPC) have formed an informal collaboration focused on improving care for prenatal to adolescents. As part of this collaboration we submitted and were awarded a subcontract to Oregon Perinatal Collaborative's Center for Disease Control grant to **develop and implement a baseline assessmen**t of the Family Integrated Care and Family Integrated Quality Improvement (FI-C-QI) in the NWIPA NICUs. For brevity purposes, the tool will be referred to as FI-C-QI so that Family Integrated is not repeated two times in the title and acronym. This assessment tool is **voluntary** and is **not a research study per review and designation of the OHSU Institutional Review Board (IRB)**. An overview of how this tool was developed and the important sections in the tool can be found in **Appendix A**.

How will the results be used and shared? Given the purpose is to gather information to inform each NICU site and the improvement collaborative on the current state and on potential future quality improvement opportunities, the results will be used in three ways:

- **Each NICU site will receive a summary** of their findings and a **de-identified** summary of the findings across the 11 NICU sites in the NWIPA.
- Secondly, informed by the data findings, a **site visit to the NICU site with the highest level of family centered care and family engagement** will be conducted by OPIP in order to understand the NICU site's processes and key parts of their efforts that can be shared with the other NICU sites in their quality improvement efforts. This site visit will include interviews with the NICU staff and with parents who are engaged in their quality improvement efforts.
- OPIP staff will **summarize the learnings across the 11 sites** and **from the site visit** and will **present the findings at the September 2019 NWIPA annual meeting.** NICU sites will be asked to share on systems and processes highlighted in this assessment**.** At this meeting, a working session will be focused on how to use the findings and specific strategies and tools that may be considered.

There are 7 sections in this Family Integrated Care and Quality Improvement (FI-C-QI) Assessment Tool:

1. NICU and Contact Information
2. Staff Education and Support
3. Parent Education
4. Parent as Care Provider
5. NICU Environment
6. Psychosocial Support
7. Family Integrated Quality Improvement

INSTRUCTIONS for Completing the FI-C-QI Assessment:

STEP 1: **Identify your team that will complete the F-IC-QI assessment**	**Identify a multidisciplinary team** that will work together to answer the questions in this assessment, on paper. This team should include at least one of the following (*it's okay if there is overlap of a person in these roles or more than one in each category that you want to include on this team*): • Nurse • Neonatologist/Neonatal Nurse Practitioner • Staff education point person • NICU Manager, administrator or other appropriate operations team member • Parent advisor/former NICU parent (Where possible and if part of your team) • Any other team members that you think should participate
STEP 2: **Have your team meet & start collecting responses**	✓**Pick a date** that your team can meet. Length of Time Estimate for this Step: 1 Hour ✓**Send the team the FI-C-QI assessme**nt before your group- level meeting so that each person can think through their responses. ✓**Convene your team** for a meeting to review the FI-C-QI assessment together and decide how to get all the responses necessary. Length of Time Estimate for this Step: 1 Hour. ✓At this meeting, you may be able to go through and answer many of the questions. There likely will be questions that will require further investigation before answering, such as asking other team members who are not a part of your respondent team. For those that cannot be answered together in your first meeting, assign who will be getting the information necessary in order to answer the remaining questions and a timeline for doing so. ✓ Schedule a follow up meeting OR email based review to be prepared for Step 3.
STEP 3: **Finalize Your Team Response**	✓ Have your **team review the completed** FI-C-QI assessment together. ✓ Length of Time Estimate for this Step: 1 hour. ✓ **Identify a team member** to enter the responses on the paper copy and complete Step 4 below.
STEP 4: **Enter your responses into the online assessment tool**	✓Go to [survey monkey] and **enter your team responses** ✓Please scan and email or mail a copy of your paper assessment tool to the OPIP team at the contact info below. ✓Length of Time Estimate for this Step: 25 Minutes. ✓Please enter your responses by **XX Date**.

Have questions or have a completed paper assessment tool to send to us? Here is our contact info:

Email: opip@ohsu.edu **Telephone:** (503) 494-6998 **Address:** Address: 707 SW Gaines Road, Mailcode: CDRC-P, Portland, OR 97239

Section 1: NICU Information

1.1 What is the name of your NICU?

_____

1.2. Please list the name of your team members who helped complete this assessment and their title or role in your NICU:

Name:_____ Title/Role:_____
Name:_____ Title/Role:_____
Name:_____ Title/Role:_____
Name:_____ Title/Role:_____
Name:_____ Title/Role:_____
Name:_____ Title/Role:_____
Name:_____ Title/Role:_____
Name:_____ Title/Role:_____
Name:_____ Title/Role:_____

1.3 Main Point of Contact:

Name:_____ Title/Role:_____ Phone Number:_____

Email Address:_____ Date completed:_____

Section 2: Staff Education & Support

The first pillar of the Family Integrated Care (FIC) model is to provide **staff with the skills** that enable them to educate, mentor and support parents in caring for their infant in the NICU and in ultimately being the primary caregiver. Note that "families" in this assessment = one or both parents and/or those individuals identified as the primary caregivers or guardians of the infant.

2.1 Please indicate whether your NICU staff receive standardized education and training as appropriate to their role in the care team on the following:

	Yes	No
a) Engaging and teaching families how to care for their child[i]	○	○
b) Engaging and teaching families to increasingly take on enhanced responsibilities for care of their child in the NICU for activities such as feedings and diaper changes	○	○
c) Lactation support	○	○
d) Trauma-informed care*	○	○
e) Social determinants of health and impact on health and health care use**	○	○

Definitions:

*Trauma Informed Care: Trauma-informed care (TIC) is a concept that acknowledges the lasting effects of trauma. TIC education should aim to help nurses understand that poor coping mechanisms, such as smoking, substance abuse, overeating, and high-risk sexual behavior, may be related to trauma history and how to engage with patients in a collaborative, non-judgmental manner when discussing health behavior change (Source). This includes recognizing pre-existing trauma, addressing acute traumatic stress reactions associated with the current traumatic event, minimizing potentially traumatic aspects of treatment, and identifying families who need additional monitoring or referrals for more help (Source).

**Social Determinants of Health (SDH): The conditions in which people are born, grow, live, work, and age, and the wider set of forces and systems shaping the conditions of daily life (World Health Organization). SDH includes factors such as socioeconomic status, environment (including air and water quality), food insecurity and food safety, education, employment, social networks, homelessness, and racism. Research has begun to show how SDH affects health outcomes. Nursing has always had a strong focus on SDH. SDH should be routinely assessed for families in the NICU. (Source)

2.2 Please indicate your level of agreement to the following:

"Hospital and NICU leadership strongly support efforts to embrace and implement staff education and training that supports Family Integrated Care"

○ Strongly Agree ○ Agree ○ Neither Agree Nor Disagree ○ Disagree ○ Strongly Disagree

2.3 Please indicate whether the following supports for family-integrated staff education and training exist within your NICU:

	Yes	No
a) There is an unpaid position(s) for a family leader to facilitate the development of patient and family education and support materials and initiatives[ii]	○	○
b) There is a paid position(s) for a family leader to facilitate the development of patient and family education and support materials and initiatives[iii]	○	○
c) Designated staff member or dedicated staff member FTE to oversee engagement from families and/or family advisors[iv]	○	○
d) Families are asked for their input on what topics should be the priorities for staff education and training	○	○
e) Families are involved the review and development of the staff education and training that is implemented	○	○
f) Families are involved in delivering staff education to provide the family perspective and experience	○	○

Section 3: Parent Education

Parent education goes hand-in-hand with all other aspects of parental involvement in the care of their infant. A comprehensive parent education program is necessary to provide parents with the skills and tools they need to confidently and safely care for their infant in the NICU and to be truly integrated in their child's care (Source).

This section aims to assess your NICU's parent education materials and the modalities by which parent education is provided. The topics are anchored to literature central to Family Integrated Care. The different modalities are anchored to literature findings about the value of and impact of education that is provided through different mediums in order to address health literacy and the benefits of different methods by which information is provided.

3.1 Please indicate your level of agreement with the following:

Hospital and NICU leadership strongly support efforts focused on parent education materials and curriculums that are provided through various modalities, including through printed materials, one-to-one education, group sessions, online information, etc.

○ Strongly Agree ○ Agree ○ Neither Agree Nor Disagree ○ Disagree ○ Strongly Disagree

3.2 Please indicate if your NICU has *standardized* parent education materials and/or curriculum about the following topics:

			If YES, Please check all that apply			
	No	**YES →**	**Printed Material**	**One-to-One Education**	**Group Education**	**Online or Smart Phone/ Tablet App**
a) For antepartum families who anticipate having an infant in the NICU due to prematurity or an identified health condition, information is provided on what to expect in the NICU and understanding prematurity	○	○	○	○	○	○
b) Understanding the impacts of prematurity on infant development for families new to NICU	○	○	○	○	○	○
c) The importance of and methods to prevent infection	○	○	○	○	○	○
d) Proper hand hygiene	○	○	○	○	○	○
e) Medications provided to infant	○	○	○	○	○	○
f) Pain and pain management	○	○	○	○	○	○
g) Respiratory care provided to infant	○	○	○	○	○	○
h) Neonatal feeding and nutrition	○	○	○	○	○	○
i) Lactation support	○	○	○	○	○	○
j) Resources for addressing family stress	○	○	○	○	○	○
k) Discharge planning (anticipatory guidance, appointments scheduled, etc)	○	○	○	○	○	○

3.3 Please indicate if your NICU has *standardized* parent education materials and/or curriculum about the following topics:

Neonatal Contact	No	YES →	If YES, Please check all that apply: Printed Material	One-to-One Education	Group Education	Online or Smart Phone/Tablet App
a) Neonatal contact: Safe ways for families to touch and hold the child and the importance of physical contact	○	○	○	○	○	○
b) Skin to skin contact	○	○	○	○	○	○
c) Infant massage	○	○	○	○	○	○

3.4 Please indicate if your NICU has *standardized* parent education materials and/or curriculum about the following topics:

Parenting in the NICU	No	YES →	If YES, Please check all that apply: Printed Material	One-to-One Education	Group Education	Online or Smart Phone/Tablet App
a) Parent role in caring for baby and how baby should grow over time (e.g. diaper changes, feeding, etc)	○	○	○	○	○	○
b) Staff role in caring for baby (e.g. teaching parents to care for baby, respiratory care, administering medications, etc)	○	○	○	○	○	○
c) Talking, singing and reading to baby	○	○	○	○	○	○

Section 4: Parent as Care Provider

The overarching goal of FIC is to support parents in becoming members of the NICU team and provide active care for their infant. To achieve this:

- Parents are invited to become collaborators in their infant's care
- The family is supported to participate to the best of their ability
- Multidisciplinary teams enable families to be integrated into their infant's care
- Parents participate in rounds to facilitate information sharing
- Parents are provided education and peer-to-peer support (Source)

This section aims to assess how your NICU involves **families as care providers in the NICU**.

4.1 Please indicate your level of agreement to the following:

"Hospital and NICU leadership strongly support the value of and encourage efforts to integrate families as equal members of the NICU team in providing active care for their infant."

○ Strongly Agree ○ Agree ○ Neither Agree Nor Disagree ○ Disagree ○ Strongly Disagree

4.2 Please indicate whether the following systems and processes exist within your NICU.

	Yes	No
a) Families can remain with their infant during rounds[v]	○	○
b) Families are active participants in rounds and provide information about their child[vi]	○	○
c) Families can remain with their infant during nurse shift change[vii]	○	○
d) Families can be present during procedures, codes and admission	○	○
e) There is a standardized process by which families define their family or other care partners who will be involved in care and decision-making	○	○
f) Policies and practices require family involvement in decision-making regarding their child's health care[viii]	○	○
g) Families assume most of the care of medically-stable infants such as temperature taking, administering some oral medications, decision making around skin to skin, diaper changes and feeding (excludes care such as intravenous meds, respiratory support & investigations (i.e. blood tests, lab tests, x-rays, etc))	○	○
h) Families participate in the discharge planning process, including discharge planning meetings[ix]	○	○

4.2.a. Comments about "gray areas" on any of the above, if applicable:

_____

Section 5: NICU Environment

One of the pillars of FIC is a welcoming and comfortable environment that meets the needs of parents and encourages them to participate in the care of their baby. The environment of the NICU includes the policies and procedures of the NICU, as well as the physical characteristics of the unit (Source). The goal of this section is to assess how your NICU provides best practices for NICU environment and FIC.

	Each baby has his or her own private room	NICU ONLY has shared patient rooms	It's a Mix of Both: Private Rooms AND Shared Rooms
5.1 Please indicate what type(s) of patient rooms your NICU has. Check all that apply.	○	○	○

Please indicate whether the following exists within your NICU:	Yes	No
5.2 Does your NICU have Family Care Suites where a mother and baby who are both patients can be cared for in the same room?	○	○

Please indicate whether the following exists within your NICU:	Yes	No
5.3 What types of sleep/rest accommodations are available for families in your NICU?		
a) Rest/sleep accommodations accessible to all families within private patient rooms	○	○
b) Shared use rest/sleep accommodations accessible to all families regardless of residence proximity to NICU	○	○
c) Shared use rest/sleep accommodations accessible only to families traveling from beyond a certain distance (e.g. Ronald McDonald House)	○	○

Please indicate whether the following exists within your NICU:	Yes	No
5.4 Meals for Families		
a) Meals and snacks are allowed at the bedside	○	○
b) Meals are provided to breastfeeding mothers, free of charge	○	○
c) Meals are provided are provided to both parents, free of charge	○	○
d) Meals are provided on a needs basis to both parents, free of charge (e.g. vouchers or pre-loaded cards)	○	○

Please indicate whether the following exists within your NICU:	Yes	No
5.5 24 hour family presence policy		
a) Family members are considered part of the care team, not visitors, with 24/7 access[x]	○	○

Please indicate whether the following exists within your NICU:	Yes	No
5.6 Celebrations and plans to recognize developmental milestones		
a) Developmental are recognized (e.g. signs with monthly birth anniversary, "today I weigh", I'm off the ventilator, no more feeding tubes, mom/dad's first holding, etc)	○	○
b) NICU milestones are recognized (e.g. discharge day)	○	○
c) Holidays are recognized (e.g. 4th of July, Easter, Hanukah, etc)	○	○

5.7 Please indicate whether the NICU has the following supportive spaces that are accessible to all families:	Yes	No
d) Signage and entrance policies that are welcoming to families there to see their child	O	O
e) Parent lounge	O	O
f) Kitchen area	O	O
g) Washer and dryer	O	O
h) Shower and locker facilities for families	O	O
i) Books and baby toys are provided to families to interact with their baby	O	O
j) Playroom for siblings	O	O
k) Childcare for siblings	O	O
l) Free parking	O	O
m) Parking that is in close proximity to the NICU	O	O

Section 6: Psychosocial Support

Parents in the NICU often feel lost and overwhelmed. Psychosocial support for families is necessary to enable them to overcome their fears and engage as a partner in the NICU care of their infant. Psychosocial support can be provided in many different ways. Most units provide some professional support for families, either through social workers or mental health workers. In addition, within FIC, opportunities need to be provided for peer-to-peer support (Source). This section aims to assess how your NICU provides best practices around psychosocial support for families.

6.1 Please indicate whether the NICU has the following:	Yes	No
a) Veteran parent peer-to-peer support for current NICU families	○	○
b) Parent support groups	○	○
c) Medical Legal Partnership* program	○	○

*Medical Legal Partnership: Medical-legal partnerships embed lawyers as specialists in health care settings. When some of the most complex and intractable problems—like an illegal eviction—are detected, clinical staff can refer patients directly for legal services. And like other members of the health care team, legal staff are available to consult with clinical and non-clinical staff about system and policy barriers to care. (Source)

6.2 Does your **NICU perform *standardized and systematic* screening of families for social determinants of health (*including food insecurity, transportation needs, living situation, financial stress)* either at the time of admission or at designated time periods during the child's NICU stay?**

○ Yes, proceed to 6.2a and 6.2b ○ No, proceed to 6.3

6.2a. If yes, what is the name of the screening tool(s) you are using?

6.2b. Are you documenting results in the child electronic medical record?

○ Yes ○ No

6.3 Does your NICU perform standardized and systematic screening of families for postpartum maternal depression?

○ Yes, proceed to 6.3a and 6.3b ○ No, proceed to 6.4

6.3a. If yes, what is the name of the postpartum maternal depression screening tool(s) you are using?

6.3b. Are you documenting results in the child electronic medical record?

○ Yes ○ No

6.4 Please indicate whether the following staff provide support services for families and staff in the NICU, and if Yes, whether you feel satisfied that the staffing is adequate to meet your institution's needs:	NO	YES →	IF YES, please rate the adequacy of staffing needs for your institution:		
			Staffing if adequate for the need	Staffing is somewhat adequate for the need	Staffing is not at all adequate for the need
a) Social Worker	O	O	O	O	O
b) Psychologist/Counselor	O	O	O	O	O
c) Nurse Educator	O	O	O	O	O
d) Spiritual Support Staff	O	O	O	O	O
e) Other staff that provide psychosocial support to families	O	O	O	O	O

6.5 Please list any other efforts or initiatives you might have in your NICU to advance Family Integrated Care that were not captured in this assessment:

_____

Section 7: Family Integrated Quality Improvement

Families and healthcare professionals bring complementary expertise to the quality improvement process (Source: NICHQ). We want to understand better your NICU's general quality improvement (QI) environment and the extent to which families are involved in your QI efforts.

7.1 Please indicate your level of agreement to the following:

Hospital and NICU leadership strongly support the value of and efforts focused on **quality improvement** in the NICU.

○ Strongly Agree ○ Agree ○ Neither Agree Nor Disagree ○ Disagree ○ Strongly Disagree

7.2 Please indicate your level of agreement to the following:

Hospital and NICU leadership strongly support the value of and efforts focused on **ensuring that families are engaged in and inform the quality improvement activities**.

○ Strongly Agree ○ Agree ○ Neither Agree Nor Disagree ○ Disagree ○ Strongly Disagree

7.3 Please indicate whether the following systems or processes are a component of your NICUs quality improvement efforts:	**Yes**	**No**
a) Family-derived data (such a surveys, parent interviews, etc) is collected and used to g**uide and inform quality improvement priorities**	○	○
b) Family-derived data is **used evaluate the impact of the quality improvement efforts**	○	○
c) **Family advisory councils** serve as a resource to QI team (e.g. review projects, documents)	○	○
d) Families participate as **occasional reviewers and consultants** during an improvement project	○	○
e) **Family input is obtained on specific changes strategies** or **tools** that are the focus for each quality improvement effort	○	○
f) **Family engagement, education, and integration** is a component of every quality improvement project	○	○
g) Families participate as **active members of improvement teams** and/or may serve on unit-based task forces and committees and faculty for staff and clinician education	○	○
h) Families are **paid to be on the QI team or involved in the QI efforts**	○	○
i) Parent advisory group **guides and informs quality improvement priorities** for the NICU	○	○
j) **Family focus groups** held on quality improvement priorities and family input used to prioritize which activities are focused on	○	○
k) Families **partner in the development** of NICU priorities, goals, policies and procedures	○	○
l) Families are **co-leaders of improvement initiatives**	○	○

7.4 Please list any other efforts or initiatives you might have in your NICU to advance Family Integrated Quality Improvement that were not captured in this assessment:

_____

THE END!

[i] Adapted from IPFCC Hospital Self-Assessment Inventory
[ii] Adapted from IPFCC Hospital Self-Assessment Inventory
[iii] Adapted from IPFCC Hospital Self-Assessment Inventory
[iv] Adapted from IPFCC Hospital Self-Assessment Inventory
[v] Adapted from Institute for Healthcare Improvement Self-Assessment
[vi] Adapted from Institute for Healthcare Improvement Self-Assessment
[vii] Adapted from IPFCC Hospital Self-Assessment Inventory
[viii] Adapted from PFCC Organizational Self-Assessment
[ix] Service User Involvement in Mental Health Scale
[x] Adapted from Institute for Healthcare Improvement Self-Assessment

APPENDIX A: BACKGROUND AND OVERVIEW OF FI-C-QI ASSESSMENT DEVELOPMENT

Summary of Literature Review to Inform the Development of an
Assessment of Family Integrated Care and Family Integrated Quality Improvement in NW IPA NICUs

Background on Project Funded Through the Oregon Perinatal Collaborative' s Funding:

The Oregon Pediatric Improvement Partnership (OPIP), Northwest Neonatal Improvement Priority Alliance (NWIPA) and the Oregon Perinatal Collaborative (OPC) are an informal collaboration focused on improving care prenatal-adolescents.

NWIPA members identified the need to focus future quality improvement efforts on enhancing the degree to which care in the NICU is family-integrated **(FIC)** and the degree to which families are integrated in the NICU's quality improvement efforts. Incorporating the patient and family voice into quality efforts is a core component of the Oregon Pediatric Improvement Partnership (OPIP) mission and they have experience with measuring family-centered care and family involvement in quality improvement efforts.

A component of the Oregon Perinatal Collaborative (OPC) grant from the Center for Disease Control supported OPIP to work with the NWIPA to:

1. Develop a **baseline assessment tool** of the level of family integrated care and quality improvement that will be completed by each of the teams in 11 NICUs participating in the NWIPA.
2. **Conduct a site visit to the NICU site with the highest quality of FIC and FIQI** so that we can understand how they developed their processes and key parts of their efforts that can be shared with the other NICU sites in their quality improvement efforts. This site visit will include interviews with the NICU staff and with parents who are engaged in their quality improvement efforts.
3. **Summarize the learnings from the assessment and site visit** to the NWIPA leadership and at the annual meeting of the NWIPA to guide and inform future quality improvement efforts focused on improving family integrated care and quality improvement processes.
4. Summarize the **process** with the **Oregon Perinatal Collaborative** to guide and inform their future efforts with their member partners focused on collecting baseline information about FIC and FIQI across member sites.

Design Parameters for the Family Integrated Care & Quality Improvement (FI-C-QI) Assessment

It is important to note who will be completing the assessment and how it will be completed as that impacts which items are best asked and potential limitations. The tool will be completed by the 11 multi-disciplinary teams from each of the sites that participate in the NWIPA efforts. We will ask each site to meet as a team to come to consensus on their answer. We will not be able to standardize that consensus process or ensure that each member of the multi-disciplinary team's input was equally valued. The teams will then enter their responses into the assessment tool. The goal for the tool is to capture breadth across the domains of FIC and FIQI and not depth about specific processes. We are also aiming for a parsimonious tool that relatively short so that it is feasible for the team complete.

Literature & Project Review Conducted to Inform Development of the Family Integrated Care & Quality Improvement (FIC-QI)

OPIP conducted a literature review for articles and online search for projects citing family centered care, family integrated care, and family involvement in quality improvement. OPIP also received many articles from Dr. Cohen. Overall 80 articles or tools were reviewed. Lastly, OPIP has included assessments of the degree to which quality improvement efforts are family-centered in their efforts focused in ambulatory care settings. OPIP identified relevant team-reported items from these projects that could be considered applicable in this project, which is team reported for NICU teams in a hospital-based setting.

Part 1: High-Level Summary of Literature Findings Family Centered Care & Family Integrated Care in NICUs

A) Definitions and Constructs:

The literature describes two terms that are sometimes distinct from each other and sometimes overlap. Overall, the literature describes Family Centered-Care as described below and that Family Integrated Care includes and builds upon Family Centered Care.

Family-Centered Care:

- The American Academy of Pediatrics[1i] defines family**-centered care (FCC) i**s an approach to health care that shapes health care policies, programs, facility design, and day-to-day interactions among patients, families, physicians, and other health care professionals. Health care professionals who practice family-centered care **recognize the vital role that families play in ensuring the health and well-being of children and family members of all ages**. These practitioners acknowledge that emotional, social, and developmental support are integral components of health care. They **respect each child and family's innate strengths** and view the health care experience as an **opportunity to build on these strengths and support families** in their caregiving and decision-making roles.
- FCC is characterized by four core principles: the family is **treated with dignity and respect**; healthcare providers **share unbiased information** with parents in a way that is accessible; parents **build on their strengths through** participation in various experiences that **enhances control and independence; families and providers collaborate** in policy, program development and education as well as the delivery of care[ii] (Johnson, 2000).

Family Integrated Care (FIC)

- FIC extends FCC in that the parents and family become integrated as **equal partners** in the neonatal team. In order for FIC to become the standard of care within a neonatal unit the basic principles of FCC should already be in place.
- Family integrated care involves providing parents with **sufficient education, support and tools** so that they are able to become co**nfident and independent primary caregiver**s of their infant in partnership with the rest of the caregivers.
- Parents are empowered to become **equal partners in the team** caring for their infants in collaboration with medical, nursing and allied health professionals. They participate actively in ward rounds, discuss management plans and share decision making. **Nurses' role shifts to teacher and facilitator from** the role of do-er. Parents gain knowledge, confidence and control through intensive competency based training as part of the FIC program. Parents assume much of the care of their medically stable infants except intravenous medications, respiratory support and investigations[iii].

- FIC empowers parents to sequentially **build their knowledge, skill, and confidence** so that they are **well-prepared to care for their infant long before discharge**. This model is dynamic whereby parents and HCP use relational communication skills to negotiate mutually equitable roles during the infant's NICU stay. Thus, roles change dynamically with the infants' progress and as parents learn to provide care. For example, at admission nurses may provide 90% of the infant's care and parents provide 10%; nearer to the time of discharge, parents provide 90% of the care and nurses provides 10%[iv].
- In the FIC model, **the family is encouraged to stay and be coached to be the newborn's primary caregivers**. This care model provides for Skin to Skin Contact (SSC) and nonseparation of the family unit, especially just after birth; care by parents early in the hospital stay; and coaching for parents to be the primary caregivers of their newborns. This model has been shown to decrease LOS and lower risk for morbidities for newborns at greater risk[v]. NICUs with strong FIC and a NICU environments that enable it have goals to minimize or eliminate family separation in the hospital[vi].
- An exemplary program in FIC called "FICare" comes out of Mt Sinai Hospital, Sinai Health System, Joseph & Wolf Lebovic Health Complex in Toronto, Ontario, Canada. Led by parents, health care provider staff and researchers, this program identifies **4 pillars of FIC: Staff Education & Support, Parent Education, NICU Environment and Psychosocial Support[vii].** Our team teases out another pillar around "Parent as Caregiver". These pillars are consistent with literature for other studied FIC/FCC NICUs and serve as a basis for formulating high level categories for an assessment in NWIPA NICUs.
- **Key Components of FiCare.** FICare integrates parents as active caregivers, shared decision makers and advocates for their infant. It "catalyzes partnerships between families and allied health professionals and facilitates the incorporation of parents into the NICU care team."[1] The model includes four essential components. Parents are provided with information to learn how to become integrated into their baby's care and to learn about their baby. Staff are educated and supported with information and practice so they develop the knowledge and skills needed to fully partner with families and integrate them into the care team. The NICU environment is changed to be more accessible and welcoming of whoever comes, comfortable, and supportive of families' needs. Families are included on rounds and policies support family presence. Celebrations and marking milestones is encouraged. Parents are gradually incorporated into bedside care and rounds. Psychosocial support is provided, both one-on-one and via groups.
- Change ideas in the literature represent practices that have been tested in the various studies through implementation of parent and staff education, psychosocial support and environmental support. It should be recognized that successful implementation of this PBP requires active and sustained engagement and support for staff as well as close partnership with parents.
- As part of providing psychological and social support for families and to assure the best health outcome, we need to address **social complexity of NICU families** as well as the medical care needed by their baby. The World Health Organization defines **social determinants of health (SDOH)** as "the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at the global, national, and local levels. Examples of resources include employment, housing, education, health care, public safety, and food access".[39]

Family-Integrated Quality Improvement (FIQI)

Most of the literature refers to family involvement in quality improvement as "family-centered quality improvement." However, for purposes of simplicity and given this assessment will focus on the family engagement in all aspects of quality improvement, we will incorporate and use the term "family-integrated quality improvement"

***FCQI Models in Ambulatory Settings*:** A key part of OPIP's mission is "*Incorporating the patient and family voice into quality efforts*". Therefore as an organization and within our specific projects we have focused on ways in which parents or youth (if the project is focused on adolescent care) can be a partner in the improvement efforts.

Through our efforts we identified several different ways that families can be engaged in quality improvement efforts to ensure that they are authentic partners:

- Parent advisory group that guide and inform quality improvement priorities, Parent focus group on quality improvement priorities identified
- Parents serve on quality improvement teams
- Parent input and review of specific changes strategies or tools that are focus in quality improvement efforts.
- Parent-derived data is collected and used to guide and inform quality improvement priorities OR to evaluate the impact of the quality improvement efforts
- Parent engagement, education is a component of every quality improvement project.

It should be noted that many of the tools and strategies that OPIP has used in previous projects are based on projects in an ambulatory care setting.

Institute for Patient and Family-Centered Care (IPFCC): IPFCC also has a framework that looks at five different levels for family integration:

- Level 1: families complete surveys or engage in other evaluative activities as respondents (e.g. focus groups).
- Level 2: Family advisory councils serve as a resource to QI team (e.g. review projects, documents)
- Level 3: families participate as occasional reviewers and consultants during an improvement project
- Level 4: Families participate as active members of improvement teams and/or may serve on unit based task forces and committees and faculty for staff and clinician education
- Level 5: families are coleaders of improvement initiatives.

Given the overlap in concept and theme, OPIP will create sections of the tools to merge related to concepts and that key unique concepts in each set of tools.

B) Categories of FIC and QI Proposed For the Baseline Assessment

Proposed Sections and Items of the Baseline Assessment
COMPONENT 1: Team Report of Family Integrated Care Processes and System
1A) Staff Education & Support 1. **Nurses become teachers and facilitators, education programs aimed at involving parent in delivering care to infant** 2. **Communication with parents, especially regarding Trauma Informed Care and Social Determinants of Health** 3. **Parents involvement in staff education**
1B) Parent Education: Provided through parent handouts, one-on-one education, small group work, veteran parents training existing NICU parents. 4. **NICU anticipatory guidance, do you have a standard process for communicating information about the following to parents:** **i. Orientation binder—admit info/ education for parents** **ii. Preventing Infection** **iii. Hand Hygiene** **iv. Specific care plan for baby/family** 5. **Neonatal feeding and nutrition** 6. **Lactation support** 7. **Neonatal contact/interacting with preterm infant/other NICU patients (the importance of contact and how its done)** 8. **Maternal and family stress** 9. **"Parenting in the NICU", Roles, Involvement of care: diapers, bathing, other basic care** 10. **Understanding Prematurity, Preterm infant development** 11. **Developmental care (infant massage, SSC, smell clothes, talking, reading to baby)** 12. **Medications, pain, respiratory care** 13. **Discharge planning (Anticipatory Guidance, appointments made, etc)**
1C) Parent as Care Provider (provided through policies, procedures, standard work) 14. **Parent attendance to and/or participation in rounds** 15. **Parents at shift change (does shift change handoff happen at bedside)** 16. **Parents at procedures, codes, admission** 17. **Family Care plan (preferences for who is involved in care, decision making, what care they want to do, support needs)** 18. **Parent discusses management plans with team, shared decision making** 19. **Performs diaper changes and feedings** 20. **Parents assume most of the care of medically stable infants except intravenous meds, respiratory support & investigations (i.e. blood tests, lab tests, xrays, etc)**
1D) NICU Environment physical and human 21. **Family care suite - room for two parents to sleep, fridge for breast milk, TV, or shared rooms—how many, bathroom?, shower? Etc.** 22. **Screens & breast pumps at bedside** 23. **Meals support (provided, allowed at bedside, vouchers…all parents or just breast feeding parents)** 24. **Family friendly visiting hours—open, 24 hours/day, some restrictions, family differentiated from others** 25. **Rest/sleep room—how many, where** 26. **Parent lounge and/or kitchen area** 27. **Washer and dryer**

28. **Parking/transit—parking vouchers, support** 29. **Access to hospital/NICU** 30. **Playroom for siblings and/or childcare** 31. **Welcoming signage and feeling** 32. **Baby/family celebrations (milestones, holidays)** 33. **Rules (i.e. barriers to being in the NICU such as flu season rules, shift change rules, when baby can be held, what visitors can be there without the parents what others could there be that parents identify, what are rules that have been barriers to family integration?)**
1E) Psychosocial Support 34. **Veteran Parent peer to peer support** 35. **Parent support groups** 36. **Support staff: social worker, psychologist/counselor, nurse educator** 37. **Systematic Screening (SDOH, PPMD, other?)** 38. **Medical Legal Partnership**

COMPONENT 2: Team Report of Family –Integrated Quality Improvement	
2A) Data derived from Families Evaluates Impact of Improvement Efforts	39. Parent-derived data is collected and used to guide and inform quality improvement priorities 40. Parent-derived data is used evaluate the impact of the quality improvement efforts
2B) Families Are Engaged Periodically	41. Family advisory councils serve as a resource to QI team (e.g. review projects, documents) 42. Families participate as occasional reviewers and consultants during an improvement project
2C) Families Provide Input Guidance on the QI Tools/Processes	43. Parent input is obtained on specific changes strategies or tools that are focus in for each quality improvement effort. 44. Parent engagement, education, and integration is a component of every quality improvement project
2D) Families Are Integrated as Part of the QI Team	45. Families participate as active members of improvement teams and/or may serve on unit based task forces and committees and faculty for staff and clinician education 46. Families are paid to be on the QI team
2E) Families Inform Quality Improvement Priorities and Their Input is Prioritized	47. Parent advisory group guide and inform quality improvement priorities for the NICU 48. Parent focus group held on quality improvement priorities and family input used to prioritize which activities are focused on 49. Families are coleaders of improvement initiatives

* Parent is used to indicate the parents/caregivers of the child.

[i] [i] American Academy of Pediatrics. Policy statement: family-centered care and the pediatrician's role. Pediatrics. 2003;112; 691–696.
[ii] Johnson, B.H., 2000. Family-centered care: facing the new millennium. Interview by Elizabeth Ahmann. Pediatr. Nurs. 26 (1), 87e90.

[iii] 17-family centered care and family delivered care article.pdf
[iv] 33-Family Integrated Care (FICare) in Level II Neonatal Intensive Care Units: study protocol for a cluster randomized controlled trial
[v] Örtenstrand, A., Westrup, B., Broström, E. B., Sarman, I., Åkerström, S., Brune, T., . . . Waldenstrom, U. (2010). - e Stockholm Neonatal Family Centered Care Study: E ects on length of stay and infant morbidity. Pediatrics, 125(2), e278–e285. doi:10.1542/peds.2009-1511
[vi] 12-design implementation and early outcome indicators.pdf
[vii] http://familyintegratedcare.com/about-ficare/