



Improving Transition from NICU to Home for Infants Requiring Complex Care

NICU Graduates Change Package



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Executive Summary

In recent years, increasing numbers of children with special health care needs go home from the neonatal intensive care unit (NICU) requiring some form of supportive technology. For newborns, the main types of technological support needed are nutritional support and respiratory support.¹ The decision to discharge home is made primarily on the basis of the infant's medical status but is complicated by several factors, including family readiness for discharge, differing opinions about what forms of care can be provided at home, and pressures related to hospital costs and length of stay. It takes time for the family of a high-risk infant to prepare to care for their infant at home and to secure the necessary support services and community resources.

Infants often go home from the NICU requiring more care and closer follow-up than was typical in the past.² For technology-dependent infants, particularly those requiring tracheostomy and a ventilator, the time to discharge can be significantly delayed by months to even years.³ Barriers to discharge may include difficulty in finding home nursing, inability to obtain timely funding for home care, and lack of a suitable home environment. Best practices to help families and young children in the transition from the hospital NICU to home include optimizing caregiver involvement in an infant's care early on in the hospital stay, shared decision making between medical providers and families, and a standardized team-based

approach to prepare the home environment for a technology-dependent child. An appropriate discharge plan needs to be developed throughout, rather than at the conclusion, of the hospital stay in order to successfully identify community resources and prepare a clear path to transition home.⁴ Ideally, all of these plans will include input from and collaboration between parents/caregivers, care managers, and the NICU team, however there may be a disconnect between these stakeholders in this process. As more NICU babies with complex medical needs are discharged to home, recent studies have shown that readmission rates of premature infants are on the rise, leading to further increases in healthcare expenditures.⁵



¹ American Academy of Pediatrics, Section on Home Health Care. *Guidelines for Pediatric Home Health Care*. McConnell MS, Imaizumi SO, eds. Elk Grove Village, IL: American Academy of Pediatrics; 2002

² American Academy of Pediatrics Committee on Fetus and Newborn, *Hospital discharge of the high-risk neonate*. *Pediatrics*, 2008. 122(5): p. 1119-26.

³ Edwards EA, O'Toole M, Wallis C. *Sending children home on tracheostomy dependent ventilation: pitfalls and outcomes*. *Arch Dis Child*. 2004 Mar;89(3):251-5.

⁴ Baker CD, Martin S, Thrasher J, et al. *A Standardized Discharge Process Decreases Length of Stay for Ventilator-Dependent Children*. *Pediatrics*. 2016;137(4):e20150637

⁵ Boss, R. and Hobbs, J., "Continuity of Care for NICU graduates," *Contemporary Pediatrics*, 2013.

⁶ Kaplan HC, Lannon C, Walsh MC, Donovan EF; Ohio Perinatal Quality Collaborative. *Ohio statewide quality-improvement collaborative to reduce late-onset sepsis in preterm infants*. *Pediatrics*. 2011 Mar;127(3):427-35. Epub 2011 Feb 21.

Executive Summary

The Ohio Perinatal Quality Collaborative (OPQC) network has successfully implemented several quality improvement projects focused on improving prenatal and perinatal outcomes for women and children in the state of Ohio.⁶ In collaboration with the Ohio Department of Medicaid (ODM), OPQC began the NICU Graduates Project in July 2015 with the purpose of using quality improvement methods to improve care for infants with complex healthcare needs in the transition from a neonatal intensive care unit to home. A six month design phase included interviews with families/caregivers, clinical experts, and organizational stakeholders to learn what ideal care and transition home would look like in this population, and to help inform our key driver framework and change theory. Our goal was to work with NICU teams to develop better practices and standardization in the transition to home process which may ultimately lead to improved care coordination and reduced discharge delays. Overall, this project aimed to reduce avoidable unplanned readmissions and decrease length of stay for infants with tracheostomy with or without ventilator, and/or gastrostomy tube, as measured below:

AIM: Infants with complex needs will have optimal care and outcomes as a result of improved and sustained support for families during and after NICU stays, resulting in being successfully cared for at home. The teams worked to successfully transition NICU infants to care at home, as measured by:

- Decreased average time from initiation of medical intervention (trach/vent/g-tube) to care at home by 10%
 - *Decreased time from “physiologically ready for discharge*” to care at home*
 - *Decreased time from “medically ready for discharge*” to care at home*
- Decreased avoidable unplanned readmissions within 7 days of discharge by 10%



In order to achieve the aim, the project focused on the following key drivers:

- Early identification of need for medical intervention
- Strengthened family capacity to care for infant during transition to home and long term
- Earliest and standardized process for transition to home
- Enhanced coordination of care through a prepared medical home and needed community resources
- Available and adequately trained home nursing workforce
- Collaboration among families, clinicians, hospitals and insurers to identify & address system barriers

*For the purposes of this project, “*physiologically ready for discharge*” was defined as, at a minimum, an infant is: 1) Tolerating feeding regimen suitable for home; 2) Successfully transitioned to home ventilator on stable settings (if applicable); 3) Utilizing supplemental oxygen flow suitable for home; and 4) Off intravenous medications. *Medically ready for discharge* is defined as an infant being “*physiologically ready*” and when caregiver education is complete.

NICU Graduates Key Driver Diagram (KDD)

The following key driver diagram is the model used by NICU Graduates teams to develop and test process improvement work for improving the transition home for NICU infants with complex needs and technology dependence. The key drivers are the factors that contribute to achieving the aim. The interventions are change concepts that impact the key drivers.

SMART Aim

- By June 30, 2018, NICU infants with complex needs will successfully transition to care at home, as measured by:
- Decreased average time from initiation of medical intervention (trach/vent/g-tube) to care at home by 10%
 - Decreased time from "medically ready for discharge" to care at home by X% (hospital and system sensitive)
 - Decreased time from "physiologically ready for discharge" to care at home by X% (system sensitive)
 - Decreased avoidable unplanned readmissions within 7 days of discharge by 10%
 - Family/parent/caregiver measures TBD

Global Aim

Infants with complex needs will have optimal care and outcomes as a result of improved and sustained support for families during and after NICU stays, resulting in being successfully cared for at home.

Key Drivers

- Early identification of need for medical intervention (trach, vent, g-tube)
- Strengthened family capacity to care for infant during transition to home and long term
- Earliest and standardized process for transition to home
- Enhanced coordination of care through a prepared medical home and needed community resources
- Available and adequately trained home nursing workforce
- Collaboration among families, clinicians, hospitals and insurers to identify & address system barriers

Interventions

- Optimize decision to trach, including family readiness and infant's medical readiness
 - Utilize shared decision making tools
- Caregiver education during hospitalization
 - Early, repeated education based on learning style assessment
 - Use of simulation technology, teach-back method, journey board
 - Provision of red flag action plan
- Assessment of family's emotional needs
- Develop and activate peer social support and parent community
- Continuous support from sub-specialty team after transition to home
 - Plan for and utilize technology to connect families and providers after transition to home, consider e-mail and telemedicine
- Identify and communicate with Medicaid/payer Care Manager/Case Manager
- Standardize roles and responsibilities of discharge point person at Children's hospital and Medicaid/payer, and include family in communication
- Enhanced understanding of public resources
 - Create tools to guide appropriate resource utilization (DME, home nursing, community support, etc.)
- Identify eligibility for available resources (Managed Care Medicaid/payer, Waiver) and early triggers for application process
- Work with Medicaid/payer to ensure qualified home nursing
 - Develop guidelines for home nursing care with individualized patient red flags
- Create and standardize assessment/reassessment tools to match home nursing services to the child's needs
- Ensure seamless provision of Durable Medical Equipment and other emergency equipment
 - Standardize checklists for DME with best practices
 - Establish early contact with DME providers
- Standardize hand off between Children's Hospital and PCP, with standard communication including:
 - Phone call prior to transition home with entire team including current provider (pulmonologist/neonatologist), family caregivers/parents, and PCP
 - Discharge notes and red flag action plan provided to PCP in timely manner

How to Use This Change Package

A change package is a concise document that includes ideas and inspiration for teams seeking to apply quality improvement methods to increase the effectiveness and efficiency of their care processes and outcomes. Change packages focus on a specific condition, care process, or health system feature and generally include background material; a summary of evidence or best practices; and specific tools, strategies, and examples that can be applied to improvement work.

This change package outlines strategies for NICUs as they begin to improve the transition from NICU to home in a collaborative effort that include parents, caregivers, families, clinicians and insurers. Included in the following pages are resources and tools to improve transition home using the key drivers

employed in the NICU Graduates Project to assure that infants with complex needs will have a successful discharge process and care at home.

Forming Your Team and Understanding Your System

Forming a project team is the first step in beginning your improvement work. The following roles are suggestions for a NICU Graduates Project site team. This list is not exhaustive, and there may be other roles at your site involved in transition planning. You should feel free to include as many people and roles as you feel are necessary to your team. In addition, you may consider including other stakeholders, external to your site, who can contribute to your improvement work (e.g., DME, home nursing provider, payer).

Role	Responsibility
Neonatologist	A physician with experience caring for infants in the NICU, with specific involvement during transition to home. This person can also be the lead MD.
Pulmonologist	A physician with experience caring for infants with tracheostomy (with and without vent) and/or chronic complex pulmonary conditions. This person can also be the lead MD.
Nurse	A NICU nurse who is part of the care team, preferably has experience with transition to home, and can work to be an advocate for the NICU Grads Project within their site.
Care Manager	A team member who provides care coordination in the NICU for babies with complex needs.
Family Representative	A parent with experience with the site NICU and has had a baby with a tracheostomy (with or without a vent) and/or a g-tube.
Social Worker	This team member serves as a key leader in planning for transition to home and brings knowledge of available community resources to support the family in recovery.
Family Liaison	A hospital employee who connects with families on a regular basis. This person could also serve in another clinical role on your team.

How to Use This Change Package

Once your team is formed, it is useful to start by understanding the characteristics of your practice that support transition from NICU to home for infants with complex needs. It is recommended that your entire project team complete a Systems Inventory together, such as the one below. The Systems Inventory is informed by the key drivers and change strategies in

the Key Driver Diagram. Ideally each team member should take the inventory and then discuss the findings as a group. Did everyone have the same responses? It is helpful to come to consensus on your current practice first before moving onto the next step.

NICU Graduates Systems Inventory Tool

Instructions: For each of the following statements, indicate the response (yes, no, in process) that most accurately reflects your NICU's current state. Once you have completed each section, identify and prioritize *potential areas of focus for your improvement work*.

Section 1: Early identification of need for medical intervention

	Yes	No	In the process of implementing
1) Does your team have a process to support family readiness for decision to trach?			
2) Does your team have a process to support family readiness for decision to g-tube?			

Section 2: Strengthened family capacity for care through transition to home preparation

	Yes	No	In the process of implementing
3) We have a tool to assess families' learning styles during the hospital stay			
4) We have an educational curriculum that is specific for transition to home for infants with tracheostomy			
5) We have an educational curriculum that is specific for transition to home for infants with g-tubes			
6) Families of infants with tracheostomy room-in/have an overnight stay prior to transition to home			
7) We utilize journey boards (tool to help families understand what will happen throughout their stay) during parent education			
8) Upon transition home, families receive a red flag action plan (specific list of symptoms or reasons to call a healthcare provider) for their tracheostomy			
9) Upon transition home, families receive a red flag action plan (specific list of symptoms or reasons to call a healthcare provider) for their g-tube			
10) Families have an opportunity to help tailor red flag action plans to their individual situations			
11) We have a tool to assess parents' emotional needs			
12) We have services available to address emotional/psychological family needs			

How to Use This Change Package

Section 3: Early and standardized process for transition to home

	Yes	No	In the process of implementing
13) Our community has peer to peer support available to families after transition home			
14) Families can directly contact our team via e-mail after transition home			
15) Families can directly contact our team 24 hours/day after transition home			
16) We have a process to identify early triggers for the Medicaid waiver program			
17) We have a process to ensure qualified home nursing availability upon transition home			
18) We have a process to ensure access to Durable Medical Equipment support/resources upon transition home			

Section 4: Prepared Primary Care Providers and community to care for infants with complex needs

	Yes	No	In the process of implementing
19) We use a handoff tool with Primary Care Providers for infants with complex needs			
20) We have a joint phone call with caregivers and their PCP prior to transition to home			
21) We automatically send discharge notes to the PCP			
22) We provide the PCP with a copy of the family's red flag action plan			

Section 5: Enhanced coordination of care through an established medical home

	Yes	No	In the process of implementing
23) Our families are assigned one care coordinator/point person throughout their stay			
24) Family care coordinators continue to provide support to families after their transition home			

Improving Transition from NICU to Home for Infants Requiring Complex Care

How to Use This Change Package

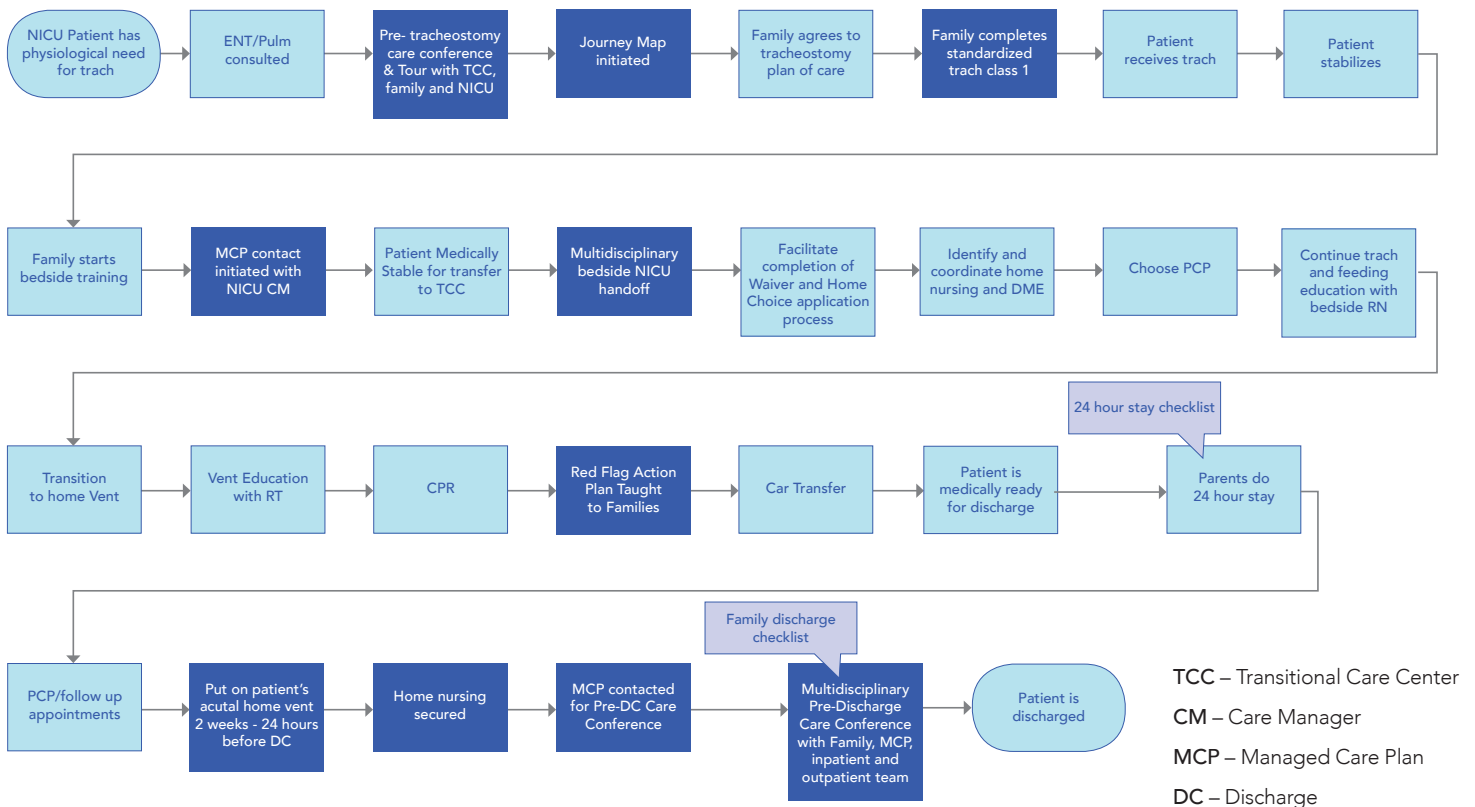
Mapping Your Transition to Home Process

A process map, or flow chart, is a diagram that shows each step in a process that a team wants to understand. The beginning and end points of the process are depicted by ovals; actions are described in rectangles connected by arrows pointing in the direction that the process should flow. When there are options to choose from, a diamond-shaped box indicates a decision step for which a "yes" or "no" answer may be chosen. Understanding your current process can help identify priority areas to test new interventions.

Some key questions to consider when creating your process map are:

- **What does the current state of your process look like?**
- **How are families and caregivers currently involved in the process?**
- **At what point in the process does planning for transition home begin?**
- **Where are the most common barriers to discharge?**

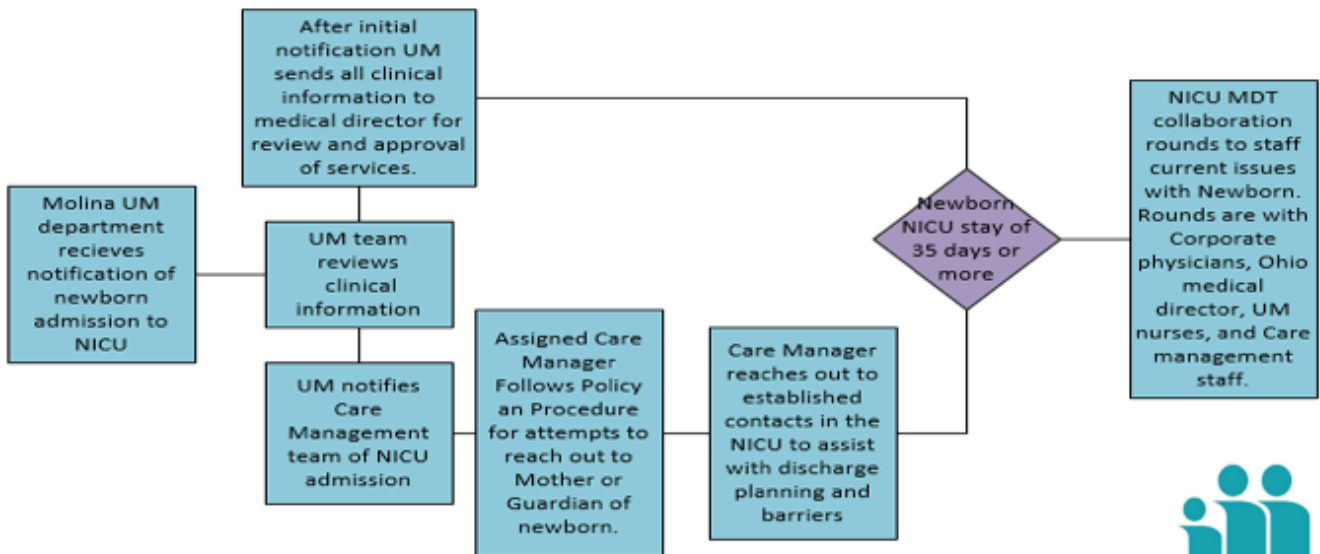
Below is an example of a process map from Cincinnati Children’s Hospital for NICU care and babies identified as requiring a tracheostomy. Dark blue process steps and call outs indicate components resulting from OPQC NICU Grads Work. To view larger, [click here](#).



How to Use This Change Package

Mapping the process from the perspective of various stakeholders, such as parents, patients or insurers, can be helpful in identifying areas for improvement and coming to consensus on where barriers exist in the system.

Below is an example of a process map from Molina Healthcare demonstrating the Managed Care Plan perspective for collaborating with NICU teams on transition home.



UM – Utilization Management



NICU Graduates Population

Identifying your target population, the action or activity you expect to change, and how you will measure this change are important steps in setting your project aim. In this project, the initial focus was on NICU infants with specific medical interventions including tracheostomy, ventilator, and/or gastrostomy tubes. However, many of the tools and strategies developed in this work can be applied to various neonatal populations.

Partnership and Culture Change

Family Engagement and Collaboration

Engaging parents and families as valued team members is critical to the change process. Both current and graduate parents provide unique perspectives and offer opportunities for your team to incorporate changes and improvements.

Family Liaison: Ideally, this role is filled by a paid parent on staff, who acts as the liaison between the hospital team and the graduate family representative(s), as well as current families on the unit. Professionally, this person may also be a social worker, patient advocate, patient experience professional or educator.

- The Family Liaison connects with the graduate family representative(s) on a monthly basis as their main point of contact.
- Provides guidance to the family representative(s), outlining the structure of the team and the purpose of the project goals.

Graduate Family Representative(s): This person is a graduate NICU/PICU parent who has experienced the transition to home process with a medically complex child, within the last 2 to 5 years. Ideally, there should be a two year period after the initial hospital discharge before they are invited to participate for this volunteer position to allow ample time for reflection on his/her experience.

- Ideally, there should be several graduate family representatives for a more diverse, broader view of experiences. Endeavor to create racial, cultural, socio-economical, and geographical diversity on your team.
- The graduate family representatives should be invited to attend monthly meetings, either in-person, via conference call or via a Facetime/Skype or other web-based opportunity. When setting team meeting times, consider alternating between day time and evening meeting times, if that would



Image used with permission from March of Dimes

- encourage the graduate family representatives to attend more often.
- If attending monthly meetings in-person, graduate family representatives should be provided a free parking voucher and a cafeteria meal voucher as a way of compensating this unpaid position.
- The graduate family representatives are considered experts and viewed as a valued team member; and asked for their recommendations and ideas frequently. Their role is to contribute to the development of educational tools, products and processes, rather than just be used as the final review after a tool, product, or process has been created.

“I was able to have everything ready and stable when he came home. He was very tiny, almost lifeless. I wanted him to be able to relax and be a normal child at home. I was able to use the [red flag action] plan so it wasn’t as scary. [The NICU team] was able to set everything up in the plan. The action plan was my lifesaver. I was able to go to it if I needed to.

– Lisa, Mother to NICU Graduate

Partnership and Culture Change

Current Families: Many current families are willing and excited to help provide real-time feedback on educational tools, products or processes. While they are still in the hospital, you have the unique opportunity to ask parents about the efficacy of discharge education, journey boards, red flag action plans and other transition to home tools.

Family Engagement Specialist: During the OPQC NICU Graduates Project, a Family Engagement Specialist was hired as part of the OPQC Team. Below are some of the role responsibilities of the Family Engagement Specialist:

- Attend weekly OPQC team huddle calls and provide the parent's voice and perspective (1 hour per week)
- Attend monthly OPQC Action Period calls and provide the parent's voice and perspective (1 hour per month)
- Attend two Learning Sessions per year, Spring and Fall (2 days per year)
 - Assist in developing a plan for parent participation during every Learning Session and coordinate their involvement
- Act as the staff connection between the OPQC Faculty and the Family Liaisons from each hospital team
- Either through group calls or one-on-one phone calls, connect with the graduate family representatives from each hospital team on a regular basis, as educational tools, products and processes are being developed
- Provide samples of educational tools, products and processes to graduate family representatives from each hospital via email and invite feedback, comments and suggestions
- Conduct family interviews for the purpose of acquiring quotations, stories, and experiences, in order to gain better understanding and knowledge of the families' experiences.

Collaboration with Medicaid and Managed Care Plans

One of the most beneficial aspects of this project was the opportunity for NICU teams, Medicaid and Managed Care Plans to collaborate together with families to improve the transition home and experience post-discharge. Managed Care Plan Care Managers were involved early on in design of tools and testing interventions, participating as engaged stakeholders who attended Action Period calls and in-person Learning Sessions. This collaboration was facilitated by Medicaid Bureau Chief for Clinical Operations, Kim DeDino, MS, RD, CSP, as a direct liaison between NICU teams and Care Managers. A special NICU Grads e-mail address at Medicaid was created specifically for concerns related to discharge barriers. This communication tool will remain available after the project ends.

"Partnering with the NICU teams on the NICU Grads projects has improved collaboration between the NICU and MCP care managers. Some NICUs now reach out for assistance on coordination of care for discharge and invite Molina to attend their Care Conferences. They provide collaboration when the Care managers contact the NICU."

– Marcia, Molina Care Manager

Change Strategies / Project Interventions

A change concept is a general notion or approach to change found to be useful in developing specific ideas that lead to improvement. These interventions were tested by NICU teams and parents and refined based on key learnings.



KEY DRIVER #1: EARLY IDENTIFICATION OF NEED FOR MEDICAL INTERVENTION

CHANGE STRATEGY:

Identify, develop and implement standards to optimize decision to trach, including family readiness and infant's medical readiness.

Although there is no national consensus (AAP, ATS) on standards to optimize decision to trach, hospitals in this project were asked to look at their individual policies and practices to come to an agreement locally on this important topic. *This standard should include not just making a medical decision, but also having a process in place to ensure clinical teams are talking with families about interventions and have the right people involved in the discussion early on.* An assessment of current practice, including collecting data on how long this part of the process takes, may reveal some systems that need to change to decide on a tracheostomy in a reasonable amount of time. The ultimate goal should be for each hospital to have a consistent plan regardless of which clinical provider is involved.

Many teams choose to utilize shared decision making tools to support the conversation between health care providers and family members when determining the most appropriate time for the next level of medical intervention in the NICU. Shared decision making tools such as decision aids can often lead to better understanding of complex processes and help families make more informed, confident decisions regarding care.

Change Strategies / Project Interventions

KEY DRIVER #2: STRENGTHENED FAMILY CAPACITY TO CARE FOR INFANT DURING TRANSITION TO HOME AND LONG TERM

CHANGE STRATEGY:

Caregiver education during hospitalization, including:

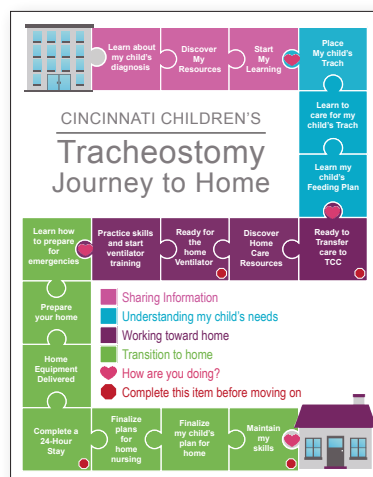
- Early, repeated education based on learning style assessment
- Use of simulation technology, teach-back method, journey board
- Provision of red flag action plan

Strengthening family capacity for care was a critical key driver in the NICU Graduates project. By educating families to be caregivers earlier in the hospitalization, babies can potentially go home sooner (parent/family education was a frequent barrier to discharge as reported by the OPQC NICU Grads teams). In our population, some key strategies which may be associated with reduction in readmissions included conducting a caregiver learning style assessment to tailor education, having a 24 hour rooming-in period for caregivers prior to discharge, and utilizing a journey board with families. In addition, our findings indicate that developing a red flag action plan throughout the transition to home process may reduce Emergency Department visits (learning style assessment may also impact ED visits). Some examples of these tools, in addition to other valuable change strategies are included below.

Journey Board

A journey board is a tool designed to help families understand the steps in the process during their NICU stay and transition to home. Journey boards often provide valuable prompts for health care providers and families to discuss important topics regarding care for a NICU baby. Journey boards should be able to communicate the pathway to discharge in family-friendly language and include milestones that can be referenced by families and clinicians throughout the hospital stay.

Example: Journey Boards



To view larger, click on the image.

Change Strategies / Project Interventions

Red Flag Action Plan

Another tool to prepare for care transition to home is the red flag action plan. This is a written plan for acting on clinical “red flags” once the baby is transitioned home. Due to the unique concerns for babies with respiratory conditions, our project teams created a separate Red Flag Action Plan for Tracheostomy, and G-Tubes.

Example: **G-Tube and Tracheostomy Tube Red Flag Action Plans**

To view larger, click on the image.

G-Tube Red Flag Action Plan
 Prepared for GIRL TST (DOB 2/28/2008) by Ashley Hays, RN CIS
 Administrator on 5/15/2018

GOOD.	CAUTION!	DANGER!!
If you observe: <ul style="list-style-type: none"> Tolerating Feeds No Leaking No signs of skin breakdown Gaining weight appropriately <p>THIS IS EXPECTED</p>	If you observe: <ul style="list-style-type: none"> Leaking <ul style="list-style-type: none"> Check balloon volume and *** Skin Breakdown <ul style="list-style-type: none"> Cover the site with *** Clogged Tube <ul style="list-style-type: none"> Instill *** Use push pull method Failure to gain weight <ul style="list-style-type: none"> *** 	If you observe: <ul style="list-style-type: none"> Tube dislodged <ul style="list-style-type: none"> If less than *** If greater than *** Distended abdomen <ul style="list-style-type: none"> Call doctor instructed Site looks inflamed <ul style="list-style-type: none"> Call doctor Other symptoms such as fever
<p>Tube Type/Size: ***</p> <p>Date of initial placement: ***</p> <p>Date of last tube change: ***</p> <p>Balloon Volume: ***</p> <p>G-tube feeding information: (CMC IP G-TUBE FEED:26923)</p> <p>Formula Type and Calories: ***</p>	<p>CALL DOCTOR IF NO IMPROVEMENT!</p> <p>Doctor's Name: ***</p> <p>Doctor's Number: ***</p> <p>If the doctor's office is closed, call Dayton Children's Hospital at 937-841-3000 and ask the operator to page your doctor or the doctor covering for your doctor.</p>	<p>GET HELP RIGHT AWAY!!</p>
<p>KEEP DOING WHAT YOU ARE DOING.</p> <p>Trach Size: ***</p> <p>Trach Cuffed: (CMC IP Trach cuffed:4414)</p> <p>Cuff filled with: (CMC IP Air or Sterile Water:4415)</p> <p>Volume: ***</p> <p>Suction Depth: ***</p>	<p>CALL YOUR DOCTOR!</p>	<p>GET HELP RIGHT AWAY!!</p> <p>Call 911 if any of these things happen;</p>

Tracheostomy Tube Red Flag Action Plan
 Prepared for SHELOB RXTTEST (DOB 11/1/2002) by Ashley Huelskamp, RN CIS Administrator on 5/12/2017

GOOD.	CAUTION!	DANGER!!
If you observe: <ul style="list-style-type: none"> Baseline oxygen Oxygen saturations are between *** and *** Baseline vent settings Secretions are thin, white/clear No increased suctioning required 	If you observe: <ul style="list-style-type: none"> Trach secretions: <ul style="list-style-type: none"> Are yellow, green or blood tinged Are thicker than usual Increased amount Are foul smelling Increased work of breathing <ul style="list-style-type: none"> Increased rate Intermittent desaturations Retractions Stoma site: <ul style="list-style-type: none"> Is red and/or Has new or unusual drainage Trach comes out and you cannot get it back in and child is not in distress Increased oxygen requirement Food or liquid coming through the trach 	If you observe: <ul style="list-style-type: none"> Frank blood from trach Difficulty breathing <ul style="list-style-type: none"> Pale skin Blue around mouth or nose Increased respiratory rate Retractions Child stops breathing <ul style="list-style-type: none"> Check pulse If no pulse, start CPR Oxygen saturation less than *** Unable to get trach in and child is in respiratory distress
<p>KEEP DOING WHAT YOU ARE DOING.</p>	<p>CALL YOUR DOCTOR!</p>	<p>GET HELP RIGHT AWAY!!</p> <p>Call 911 if any of these things happen;</p>

Additional Red Flag Action Plan examples from Rainbow Babies and Children's Hospital may be found here: [G-tube](#) and [Trach](#)

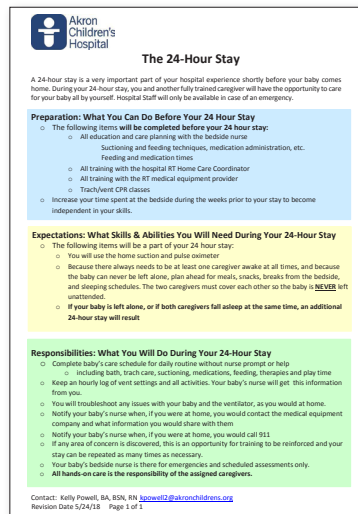
Change Strategies / Project Interventions

24-Hour Rooming-In

A 24-hour rooming-in period prior to discharge is critical in helping parents feel competent and confident to safely care for an infant with a tracheostomy at home. This opportunity can also aid in caregiver development of critical thinking skills to handle emergency situations at home.

Example: **24-Hour Rooming-In Guidelines**

To view larger, click on the image.



CHANGE STRATEGY:

Assessment of family's emotional needs

- Engage social work team to screen for various behavioral/mental health issues
- Use conversation starters, like "Tell me how you are doing" "Do you mind if I sit and talk with you for a while" "What's going on in your world today" "Some families have told me that this is very stressful. What are you do to help cope through all of this?"

CHANGE STRATEGY:

Develop and activate peer social support and parent community

- Hire a graduate parent as a staff person to help inform team of the parent and family perspective, and to act as the family-staff liaison
- Develop and nurture a cadre of graduate parent volunteers to support families in the hospital
- Create and monitor a closed-group social media presence (Facebook) for families to connect and exchange ideas, once they transition to home

CHANGE STRATEGY:

Continuous support from sub-specialty team after transition to home, including having a plan to utilize technology such as e-mail and telemedicine to connect families & providers after transition to home.

- Utilize technology (email, telemedicine, app, text capabilities) to connect families and providers after transition to home

Change Strategies / Project Interventions



KEY DRIVER #3: EARLIEST AND STANDARDIZED PROCESS FOR TRANSITION TO HOME

Example: **Transition Bundle**

The NICU Grads transition bundle of 9 key tools/strategies may aid in an effective transition from NICU to home. Examples of many of these tools may be found throughout this change package.

Transition Plan Bundle Elements (Discharge Preparation Activities)	Suggested Resources
1. Assign Discharge Coordinator	Trained and dedicated personnel
2. Create and discuss journey board for transition planning once determining medical intervention/procedure is to occur	Journey Board
3. Arrange for appropriate DME (assuring caregiver is competent in use), home nursing, and additional resources as needed	Trained and dedicated personnel
4. Provide red flag action plan for post-discharge care that is culturally and language appropriate and share with PCP and home nursing	Red Flag Action Plan Home Nursing Plan Home Vent Card
5. Provide a tool for caregivers and providers to reference available public resources relevant to this specific patient	Community Resource guide
6. Begin caregiver education within 7 days of medical intervention and complete training in infant CPR and relevant medical care for the patient before discharge	Education packet Use "Teach Back" methodology
7. Provide parents and baby rooming in at least 24 hours e.g. simulating home environment, with independent feeding and care for baby	Rooming In Checklist Use "Teach Back" methodology
8. Schedule follow up appointments convenient to family with relevant medical care for this patient	Trained and dedicated personnel
9. Schedule conference call with all pre and post discharge caregivers e.g. current provider (pulmonologist/neonatologist), caregiver(s)/parent(s), and future provider (PCP)	Conference call agenda and script

Change Strategies / Project Interventions

CHANGE STRATEGY:

Enhanced understanding of public resources, including tools to guide appropriate resource utilization (DME, home nursing, community support, etc.)

In our population, patients who had a reference tool of available public resources reviewed prior to discharge were found to have reduced readmissions. This Community Resource Guide template was developed as a foundation for teams to populate with local information and adapt categories to their individual patient needs. The document may be provided as handouts to families, or utilized and updated through an online platform.

Example: **Community Resource Guide**

COMMUNITY RESOURCE GUIDE		
Social Services	Website	Local Address & Phone Number (To be filled out by hospital)
Women Infants and Children (WIC)	www.odh.ohio.gov	
Healthy Start Healthy Families Medicaid	www.medicaid.ohio.gov/forohioans/GetCoverage	
Bureau for Children with Medical Handicaps (BCMH) – Ohio’s Title V Children with Special Health Care Needs Program	www.odh.ohio.gov/odhprograms/cmh/cwmh/bcmh1.aspx	
Help Me Grow Part C (IDEA) Early Intervention	www.helpmegrow.ohio.gov	
Help Me Grow Home Visiting	www.helpmegrow.ohio.gov	
Local/County/State Departments of Health	www.odh.ohio.gov	
Cribs for Kids	www.cribsforkids.org	
Financial Counseling		
Local Job and Family Services		
Medical	Contact Information	Tips for Parents
Primary Care Pediatric Provider		1st doctor’s appointment for baby: _____
Health Care Provider(s) for Mom/Caregiver (e.g., family planning, primary care)	List of each clinic/doctor’s name/ address	1st doctor’s appointment for mom/caregiver: _____ 2nd doctor’s appointment for mom/caregiver: _____
Emergency Department Provider	Children’s Hospital ER:	Closest ER: _____ Tips for Parents: • Contact your local police and fire departments prior to going home. Provide details about your child including oxygen needs, special equipment, etc.

Change Strategies / Project Interventions

COMMUNITY RESOURCE GUIDE (continued)

Medical	Contact Information	Tips for Parents
<p>Follow-up Specialty Clinic(s) (e.g., surgical, BPD, eye, ortho)</p>	<p>List of each clinic/doctor's name/ address</p>	<p>Tips for Parents:</p> <ul style="list-style-type: none"> • Keep appointments straight; use a calendar & reminder system • Develop system to communicate changes to home health care agency and durable medical equipment company • Request if any appointments can be handled virtually, utilizing a device with a camera
<p>Department of Public Health – Immunization Program</p>	<p>www.odh.ohio.gov/odhprograms/bid/immunization/immindex1.aspx</p>	<p>List of immunizations already given:</p> <hr/> <hr/> <hr/> <hr/> <hr/>
<p>Children's Dental Clinic</p>	<p>www.odh.ohio.gov/odhprograms/ohs/pap/find/find.aspx</p>	<p>Local Dental Clinic:</p> <hr/>
Agencies for At-Home Care	Contact Information	Tips for Parents
<p>Home Health Care Agency Options</p>	<p>Provide list of local HHC agencies</p>	<p>Tips for Parents:</p> <ul style="list-style-type: none"> • Boundaries/house rules • How to handle difficult conversations • How to handle difficult situations • Call outs, sick days, no shows • Ask for a single contact person (name/phone number)
<p>Durable Medical Equipment</p>	<p>Provide list of local equipment companies</p>	<p>Tips for Parents:</p> <ul style="list-style-type: none"> • Supply inventory management • Medical supply list and non-medical supply list; including order numbers, size, quantity • Room set-up • How to handle change in doctor's orders • Ask for a single contact person (name/phone number)

Change Strategies / Project Interventions

COMMUNITY RESOURCE GUIDE (continued)

Feeding	Contact Information	
La Leche League	www.llli.org	Local breast feeding support group: _____
Feeding Tube website	www.feedingtubeawareness.org	
Behavioral and Mental Health Services	Contact Information	
Local Alcohol and Drug Addiction Services	Ohio Association of County Behavioral Health Authorities www.oacbha.org	
Social Work		
Counseling		
Written information on signs and symptoms of PTSD or PPD		
Support Groups	Contact Information	
Respite Care		
Parent Mentor program		
Parent to Parent Support Groups		
Parent Match Opportunities		
Sibling Support		
Crisis Hotlines and Shelters	Contact Information	
Local Child Abuse Hotline		
Local Women and Children Safety Hotline		
Local Domestic Violence Hotline		
National Domestic Violence Hotline	800-799-7233 www.thehotline.org	
Local Shelter Services		
Poison Control		

Change Strategies / Project Interventions

COMMUNITY RESOURCE GUIDE (continued)

Educational Information	Contact Information	
Local Hospital website		
March of Dimes	www.marchofdimes.org www.marchofdimes.org/ohio	
Raising Special Kids	www.raisingpecialkids.org	
Food Assistance Programs	Contact Information	
Local Food Bank		
County/State Nutrition Assistance Program		
Emergency Food Assistance Program		
Local Salvation Army		
Women Infants and Children (WIC)	www.odh.ohio.gov	
Supplemental Nutrition Assistance Program (SNAP)		
Financial Assistance Programs	Contact Information	
Cash Assistance Program		
Utility Assistance Program		
Housing	Contact Information	
Ohio Housing Department (Section 8)		
US Department of Housing and Urban Development (HUD)		
Local Community Housing Division		
County Housing Authority		

Change Strategies / Project Interventions

COMMUNITY RESOURCE GUIDE (continued)

Legal Assistance	Contact Information	
Ohio Foundation for Legal Services and Education		
Local Legal Services		
Disability Rights Ohio	www.disabilityrightsohio.org	
Local / County Child Support Division		
Parenting Resources	Contact Information	
Local Child and Family Resources		
Single Parents Association	www.singleparents.org	
Raising Special Kids	www.raisingpecialkids.org	
Local Teen Parenting Outreach Services		
Online support groups	Contact Information	
Local Hospital Website and/or Facebook NICU Page		
March Of Dimes Parent Online Support Group	www.shareyourstory.org	
	www.globaltrach.org	
	www.pressuresupport.com	
	www.mommiesofmiracles.com	
	www.feedingtubeawareness.org	

Improving Transition from NICU to Home for Infants Requiring Complex Care

Change Strategies / Project Interventions



KEY DRIVER #4: ENHANCED COORDINATION OF CARE THROUGH A PREPARED MEDICAL HOME AND NEEDED COMMUNITY RESOURCES

CHANGE STRATEGY:

Standardize hand off between Children’s Hospital and PCP, with standard communication including:

- Phone call prior to transition home with entire team including current provider (pulmonologist/neonatologist), family caregivers/parents, and PCP
- Discharge notes and red flag action plan provided to PCP in timely manner

Example: Discharge Care Conference Script (Cincinnati Children’s Hospital)

Discharge Care Conference Script

Goal:
To arrange a meeting one to two weeks before discharge with inpatient and outpatient disciplines and caregivers. Communication during the meeting to assure caregivers are aware of their outpatient resources and determine what still needs to be completed prior to discharge.
APN and/or care manager to have an updated AVS and or discharge summary to go over at discharge meeting.

To be Invited:

Inpatient Pulmonary Team:

- Pulm APN
- Pulm attending/fellow
- Social work
- Care manager
- OT/PT/Speech/dietician
- Caregiver educator(s)
- Primary nurses

Outpatient Pulmonary Team:

- Pulm attending
- Pulm RN
- Social worker

Outpatient Resources:

- Durable medical equipment representative
- Private Duty Nursing representative
- Managed Care Plan case manager (as applicable)
- Home Choice representative (OH only as applicable)
- Primary Care Physician or Complex Care MD (as applicable)

What will be covered:

Inpatient Pulmonary Team:

- Medical updates
- Financial resource updates
- Equipment and nursing orders completed
- Follow appointments made/needed
- Therapy updates and outpatient recommendations
- Any education that still needs to be completed
- Home feeding plan/WIC performance

Outpatient Pulmonary Team:

- Recommended outpatient follow up
- Outpatient resources available
- Who to contact with needs?

Outpatient Resources:

- Equipment delivery and education
- When PDN starting
- Who to contact with questions about PDN or DME
- Home choice contact information
- MCP contact information and when to contact
- When to make first PCP appointment and when to contact with questions

Complex Care Doctors: Dr. XX, Dr. YY
Pulmonary Nurses: Nurse XX, Nurse YY
Care Source Contact: Jane Doe (team lead) – e-mail, phone

To view larger, click on the image.

Change Strategies / Project Interventions



KEY DRIVER #5: AVAILABLE AND ADEQUATELY TRAINED HOME NURSING WORKFORCE

Many of the change strategies in this key driver reflect a remaining need for continued work around increasing and supporting a trained home nursing workforce to meet the needs of NICU Graduates with technology dependence and other pediatric complex care patients. One strategy currently being tested by Cincinnati Children's Hospital is to partner directly with a healthcare staffing/home healthcare agency to provide in-hospital training for Private Duty Nursing (PDN) staff. The expectation is that this training model will result in more confident PDN staff and families, and a smoother transition to home for NICU babies.

CHANGE STRATEGY:

Identify eligibility for available resources (Managed Care Medicaid/payer, Waiver) and early triggers for application process

CHANGE STRATEGY:

Work with Medicaid/payer to ensure qualified home nursing, including to develop guidelines for home nursing care with individualized patient red flags

CHANGE STRATEGY:

Create and standardize assessment/reassessment tools to match home nursing services to the child's needs

Assessment tools for this population should include non-medical needs, as these needs contribute to complexity both for the family and for the entity involved in provision of Home Nursing services. Suggested assessment domains for non-medical needs are included in later discussion in this change package.

Change Strategies / Project Interventions

CHANGE STRATEGY:

Ensure seamless provision of Durable Medical Equipment and other emergency equipment, including:

- Standardize checklists for DME with best practices
- Establish early contact with DME providers

Example: **Checklists for Discharge Process** (Nationwide Children’s Hospital)

CCBPD Discharge Checklist	
	NNP Responsibilities
Initial	✓ Completed by: _____
	Immunization are up to date
	Saturation study is ordered 3-5 days prior to discharge
	Room air trial is ordered within 48 hours of discharge for oxygen qualifying
	CXR done within 7 days of discharge
	Asthma Action plan, if appropriate, is developed and reviewed with family by RT
	Hearing screen is completed
	Newborn screen results documented by NBS coordinator and follow-up complete
	BPD education with family is completed (in conjunction with the BPD clinic team)
	Coordinate with Case Manager regarding needed consults:
	- Cardiology _____
	- Endocrine _____
	- ENT _____
	- Surgery _____
	- ROP _____
	- Neurosurg/neurology _____
	• Lab and testing follow-up is clarified ex. ROP/BPD, Audiology, etc.
	• Education is completed by specialty ex. Endocrinology _____
	WIC prescription is signed
	Discharge summary/Hospital course is completed including a physical exam
	- Include fluid restrictions, Lasix/O2 weaning difficulties, feeding challenges, especially emesis
	Hand-off to BPD clinic
	RN Responsibilities
Initial	✓ Completed by: _____
	CPR: Class in BJR: Date _____
	Teaching/modeling of appropriate age care _____
	Well baby teaching/Discharge Class: Date _____
	Medication and inhaler review (Reinforce what pharmacy and RT teach)
	G-Tube class in BJR: Date _____

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To view larger, click on the image.

An additional Checklist for Discharge from Cincinnati Children’s Hospital may be found here:

[Discharge Checklist](#)

Change Strategies / Project Interventions



KEY DRIVER #6: COLLABORATION AMONG FAMILIES, CLINICIANS, HOSPITALS AND INSURERS TO IDENTIFY & ADDRESS SYSTEM BARRIERS

CHANGE STRATEGY:

Identify and communicate with Medicaid/payer Care Manager/Case Manager

Throughout the NICU Grads project, key strategies were tested to incorporate Managed Care Plans (MCPs) earlier in the discharge process and build a stronger relationship between payers, families/caregivers and NICU teams. These included identifying one contact at the MCP to liaison with the NICU team, educating parents/caregivers about the benefits of care management, and inviting MCPs to participate in the discharge care conference.

Example: Home Going Discharge Instructions (Akron Children's Hospital)

To view larger, click on the image.

CHANGE STRATEGY:

Standardize roles and responsibilities of discharge point person at Children's hospital and Medicaid/payer, and include family in communication

Measures

Key measures were identified at the start of this project to help guide the work and focus on important areas for improvement. Both process and outcome measures were utilized, as well as a variety of sub-outcomes that were important to our particular collaborative. One consideration for measurement was an interest in differentiating between which key drivers teams may be able to

impact at an individual hospital level, and which may need to be addressed through policy change at a system level. In addition to data collection for individual patients, teams completed a baseline and subsequent annual systems inventory survey to indicate their current practice for elements of the transition bundle ([See page 17](#)).

Below are a list of suggested elements for data collection. In general, institutions should tailor measurement strategies to address individual goals and specific areas for improvement:

1. Discharge date
2. Does this baby have a Tracheostomy at discharge?
 - If Yes, when was the initial consult for the tracheostomy ordered?
 - If Yes, provide the procedure date
 - If Yes, was the baby ventilator dependent at discharge?
3. Does this baby have a Gastrostomy Tube at discharge?
 - If Yes, when was the initial surgery consult ordered?
 - If Yes, provide the procedure date
4. Indicate date baby is determined to be physiologically ready for discharge
5. Date a journey board was started for this baby's discharge plan
6. Indicate date the Managed Care Plan was notified the baby was in your hospital (if applicable)
7. Date DME (durable medical equipment) provider was initially contacted
8. Caregiver(s) were given a formal learning style assessment (using an assessment tool)?
9. Date caregiver(s) post discharge medical care training was initiated
10. Date caregiver(s) post discharge medical care training was completed
11. Red Flag Action Plan was reviewed before discharge with caregiver(s)
12. Was a Discharge Coordinator identified prior to discharge?
13. Date home nurse was identified and assigned to baby (if applicable)
14. Caregiver(s) reviewed a reference tool of available public resources relevant to the care of this patient prior to discharge
15. Caregiver(s) had the opportunity to 'room-in' with the baby for at least 24 hours simulating their home environment
16. Caregiver(s) had a call with the discharge provider and primary care provider and/or post discharge provider where patient status and discharge plan was communicated
17. What is the caregiver(s) biggest worry about caring for the child at home?

Measures

If your team wishes to use the data collection elements listed above to replicate the outcome measures used by OPQC, please consider the following recommendations:

- Average time from date of medical intervention to care at home – This is defined as the date of discharge minus the procedure date. If the patient has both a Gastronomy Tube and a Tracheostomy, use the date of the first procedure date to calculate the result.
- Readmissions within 7 days or between 7 and 30 days – These measures only count the first readmission within 7 days or between 7 and 30 days for each patient to ensure these measures are done on a patient level rather than a readmission level.

Thinking About Care in the First Few Years after Discharge

Background

Both the population of, and hospitalizations for children with complex conditions are on the rise in US hospitals⁷ with attendant costs estimated to be \$50-110 billion annually⁸. In 2008, the American Academy of Pediatrics updated their Hospital Discharge guidelines for high-risk neonates, emphasizing the needs for well-coordinated care, individualized planning and physician judgement⁹. In addition to the varied and intensive medical needs of these children, there are significant non-medical, social and psychological needs for these children and their families to be evaluated in the course of establishing a sufficient and appropriate care plan, adjusting it as medical and non-medical needs evolve.

The initial focus of the NICU Graduates work was on the unique needs of infants and children that are discharged with Chronic Lung Disease of Prematurity and technology-dependence (e.g. tracheostomy, ventilator, and/or enteral feeding tubes), during the first three years of their lives. Central to our vision is the conviction that care in the child's home, with their family, is optimal, when the family has the resources to successfully care for the child at home. Following their hospital discharge, many families deliver care similar to hospital level in their own homes. Additional work is needed to address the larger population of children with medical complexity (CMC), who have multiple chronic conditions, high healthcare utilization and often technological dependence. AAP Discharge



Image used with permission from March of Dimes

Guidelines could be adapted for the heterogeneous conditions in CMC, including neurologic/neuromuscular conditions, congenital anomalies, cardiac disease, genetic/metabolic conditions, malignancies and transplants. Their ongoing support needs involve a lifespan trajectory and must support a broad array of activities of daily living.

From late 2016 through May 2017, Drs. Jennifer Lail, Garey Noritz and Dan Benscoter, and other subject matter experts from inpatient, outpatient, home health, ODM, and Medicaid Managed Care collaborated to determine the parameters and key factors for inclusion in tools to evaluate the changing medical and non-medical needs of these children with medical complexity. The aim for the tools was to ensure that the right levels of care are assigned and delivered to the child, at the right time and in the optimal setting.

⁷ *Pediatrics*. 2010 Oct;126(4):638-46. doi: 10.1542/peds.2009-1658. Epub 2010 Sep 20. Increasing prevalence of medically complex children in US hospitals. Burns KH1, Casey PH, Lyle RE, Bird TM, Fussell JJ, Robbins JM.

⁸ *Health Affairs*, 33, no.12 (2014):2199-2206. *Children with Medical Complexity and Medicaid: Spending And Cost Savings*. Dennis Kuo and Chris Feudtner, Jay G. Berry, Matt Hall, John Neff, Denise Goodman, Eyal Cohen, Rishi Agrawal.

⁹ 129(4):e1103 *Pediatrics*, November 2008, VOLUME 122 / ISSUE 5. *Hospital Discharge of the High Risk Neonate Committee on Fetus and Newborn*

Thinking About Care in the First Few Years after Discharge

The changing healthcare environment necessitates the standardization and coordination of care to support families in anticipating and adapting to their needs following discharge from an acute-care facility. In addition to managing high medical needs, services, therapies and equipment for survival, families require adjustment over time to their child's fluctuating health acuity. Families need empowerment, training, and support to have the capacity to respond to other medical and non-medical family needs, such as another illness in the family, a new sibling, or a family crisis. The cumulative costs, family stress, and potential work loss with a young child or youth with protracted illness must be considered in evaluating methods of support, including access to medical equipment, home nursing, and other therapies. Many of these topics are discussed in more detail in a supplement to *Pediatrics* entitled "Building Systems that Work for Children with Complex Health Care Needs."¹⁰

Objectives

- Develop, as an example, guidelines for the post-discharge and home care needs for children leaving the neonatal intensive care unit with technology dependence (birth – 30 months)
- Identify and anticipate the needs of children with technology dependence (birth – 30 months), including home nursing needs, needs for durable medical equipment, and other healthcare needs,



categorizing these according to the various professional roles (home nurse, care manager, primary and specialty providers, DME suppliers).

- Identify potential methods for more systemically capturing a family's "non-medical needs," with particular attention paid to how those needs affect caregiver capability or capacity to care for a child at home

Challenges and Considerations

To meet and adapt to the changing needs of children and families with tracheostomies, ventilators, enteral feeding tubes, and central vascular access outside of the hospital setting, a network of collaboration ("the Medical Neighborhood")¹¹ between families, insurers, primary care providers, pediatric specialists, home

¹⁰ Supplement to *Pediatrics*, March 2018, Vol 141, #3, "Building Systems that Work for Children with Complex Health Care Needs"

¹¹ *Coordinating Care in the Medical Neighborhood: Critical Components and Available Mechanisms*. US Dept of Health and Human Services; AHRQ Publication No. 11-0064, June 2011

Thinking About Care in the First Few Years after Discharge

health care personnel, medical equipment suppliers and communities is required. Based on the child's medical complexity, a fiscally viable care system must be constructed to keep the child safe and to support the family's ongoing or diminishing capacity for care within the home, while minimizing the need for hospitalizations and emergency department utilizations.



Inherent in the life of an infant with technological dependence is the increased risk imposed by intercurrent illness, however minor, which may acutely escalate the child's care and surveillance needs. The needs of the child's family care providers may also increase with job loss, family conflict, sibling instability, or funding stress.¹² Accordingly, our system demands

flexibility to increase services and support urgently in such events, hopefully avoiding deterioration or hospital re-admission. Equally important is regular assessment for opportunities to decrease support services or remove equipment as the child's clinical trajectory improves and clinical severity decreases.

The goal is safe transition of and ongoing care for all neonates, but specifically NICU graduates who are technologically dependent. Collaboration and advocacy across the state for systems and policies that optimally support our children requires input from each phase and site of their complex care journey. The presence of clinical "stability" is not necessarily an indicator that resources are no longer needed and can be removed; lack of hospitalization or ED utilization can indicate the family is self-managing only because of the critical supports of home nursing, respite care, equipment and supplies, and funding in place. Building a "medical neighborhood" that allies health care resources with those of schools, faith-based groups, non-profits, non-licensed support personnel, social and mental health services, housing authorities and legal aid will be essential to support our growing population of children with both complex and chronic conditions in the least restrictive and most fiscally viable environment.

¹² Parenting Stress among Caregivers of Children with Chronic Illness: A Systematic Review. Cousino and Hazen, J. *Pediatr.Psychol.* (2013), doi: 10.1093/jpepsy/jst049

Thinking About Care in the First Few Years after Discharge

Assessing Medical and Non-Medical Needs

Several nascent tools were developed intending to inform the care and identify the medical and non-medical needs for children with medical complexity. We believe that these materials would

be useful elements for medical education for families of children with medical complexity, residents, and other healthcare professionals responsible for addressing the many and varied needs for these children and their families.

Evaluation of Non-Medical Needs for Children with Medical Complexity – A Modified Self-Sufficiency Matrix^{13, 14, 15}

Administration

The Self Sufficiency Matrix is an assessment and outcome measurement tool that may be used to better understand how a client is doing and whether an intervention is appropriate for this client and family. Indicators on this tool show **what** information should be collected, but not how to collect it. The questions in red may help to guide your conversation, address difficult issues, and determine which indicators are being met. Information needed for this assessment should come from:

- The client/family – use this tool as a topic list during conversation and enter scores afterward or during interview.
- Colleagues, community supports, and clinicians who know the patient and family – use information from interactions that others may have had with the client. This supplementary information may help fill in the gaps and be relevant to the assessment.
- Administrative records – client medical record notes or discharge summaries can be informative, as well as other administrative records available.

Building Trust

Beginning the assessment as a conversation with open-ended questions may help build rapport to develop a trusted relationship and discuss these sensitive topics. For example, rather than asking if a client's housing is stable, you may ask "Tell me about your home. Is there something about your home situation that would help us know how we can help you more?"

Scoring

Scoring should start with the highest level of sufficiency, and you should decide whether a client meets indicators in the first cell "empowered" – if not, work backwards until you reach the level of self-sufficiency appropriate for each client. Consider whether a client would meet the majority of the criteria in a cell when making assessment. The levels within the domains are mutually exclusive, and only one may be selected. All scores must be entered as ordinal, whole numbers (there are no half-scores).

¹³ Fassaert T, Lauriks S, van de Weerd S, de Wit MAS, Buster M. (2013) *Ontwikkeling en betrouwbaarheid van de Zelfredzaamheid-Matrix*. Tsg, 91, 169 - 177.

¹⁴ *Self-Sufficiency-Matrix*, 2013, S.Lauriks, M.C.A. Buster, M.A.S. De Wit, S. van de Weerd, G. Tigchelaar, and T. Fassaert. <http://www.selfsufficiencymatrix.org/zrm-int.aspx>

¹⁵ *Arizona Self-Sufficiency Matrix*, Abt Associates Training

Evaluation of Non-Medical Needs for Children with Medical Complexity – A Modified Self-Sufficiency Matrix ^{13, 14, 15}

Domain	1 = In Crisis	2 = Vulnerable	3 = Safe	4 = Building Capacity	5 = Empowered	Score
Foster Care		Child is discharged into foster care				
Caregiver Availability/Quantity TRACH/VENT Only	No trained caregiver present and/or not awake observing child in home at all times. <i>Is one TRAINED caregiver present AND awake and observing the child in home at all times? (No) = 1</i>		One caregiver is present AND awake and observing the child in home at all times. <i>Does child have trach/vent? (Yes) AND Is one or more caregiver always awake and observing the child (Yes) = 3</i>	One or more trained caregiver is present in home at all times AND always awake and observing the child. Second caregiver is available part-time. <i>Does child have trach/vent? (Yes) AND Is one or more caregiver always awake and observing the child with a second caregiver available part-time (Yes) = 4</i>	Two or more trained adult caregivers are available in home at all times. One or more caregiver is always awake and observing the child. <i>Are two or more trained adult caregivers available in home at all times, with one always awake and observing the child? (Yes) = 5</i>	
Caregiver Availability/Quantity OTHER CMC	Lack of one trained caregiver who is present in home at all times that the child is present in the home. <i>Is one trained caregiver present in home at all times that the child is present? (No) = 1</i>		One trained caregiver is present in home at all times that the child is present in the home. <i>Is one trained caregiver present in home at all times that the child is present? (Yes) = 2</i>	One or more trained caregiver is present in home at all times. Second caregiver is available part-time. <i>Is one or more trained caregiver present in home at all times that the child is present? AND Is a second caregiver available part-time (Yes) = 2</i>	Two or more trained adult caregivers are available in home at all times. <i>Are two or more trained adult caregivers available in home at all times? (Yes) = 5</i>	
Family Size		Is the size of the family a potential risk or barrier to effective caregiving? <i>Do you have the help you need to care for the other members of your family (children)? (No) = 1</i>		Is the size of the family a potential risk or barrier to effective caregiving? <i>Do you have the help you need to care for the other members of your family (children)? (Yes) = 4</i>		

Evaluation of Non-Medical Needs for Children with Medical Complexity – A Modified Self-Sufficiency Matrix ^{13, 14, 15} (continued)

Domain	1 = In Crisis	2 = Vulnerable	3 = Safe	4 = Building Capacity	5 = Empowered	Score
Caregiver Health and Capability (as related to care provision for patient)	<p>One or more caregivers in the home has an acute health crisis (e.g. chronic disease, injury, recent surgery) or cognitive impairment that would prevent effective caregiving</p> <p><i>Are all caregivers in the home experiencing good health? (No) AND Is caregiver health preventing ability to care for children? (Yes) = 1</i></p>	<p>One or more caregivers in the home has an acute health crisis. Caregiving is minimally impacted.</p> <p><i>Are all caregivers in the home experiencing good health? (No) AND Is caregiver health preventing ability to care for children? (No) = 2</i></p>	<p>Caregiver has presence of chronic disease but it is well managed. Acute health crisis has occurred in past six months.</p> <p><i>Does one or more caregiver have well managed chronic disease? (Yes) AND Has the caregiver had an acute health crisis in the past six months? (Yes) = 3</i></p>	<p>Caregiver has presence of chronic disease but it is well managed.</p> <p><i>Does one or more caregiver have well managed chronic disease (Yes) AND Has the caregiver had an acute health crisis in the past six months? (No) = 4</i></p>	<p>No current active health issue of caregiver(s)</p> <p><i>Are all caregivers in the home experiencing good health? (Yes) = 5</i></p>	
Life Skills		<p>Unable to meet basic needs such as hygiene, food, and activities of daily living.</p> <p><i>Can client meet some basic living needs without assistance? (No) = 1</i></p>		<p>Able to meet all basic needs of daily living without assistance.</p> <p><i>Is client able to provide basic living needs to self (and family)? (Yes) = 4</i></p>		
Emotional Health –Caregiver	<p>Danger to self or others; recurring suicidal ideation; experiencing severe difficulty in day-to-day life due to psychological problems.</p> <p><i>Is the caregiver a danger to self or others? (Yes) = 1</i></p>	<p>Recurrent mental health symptoms that may affect behavior, but not a danger to self/others; persistent problems with functioning due to mental health symptoms.</p> <p><i>Is the caregiver a danger to self or others? (No) AND Does client have mild or no mental health symptoms? (No) = 2</i></p>	<p>Mild symptoms may be present but are transient; only moderate difficulty in functioning due to mental health problems.</p> <p><i>Does caregiver have mild or no mental health symptoms? (Yes) AND Do the symptoms impair functioning only slightly? (No) = 3</i></p>	<p>Minimal symptoms that are expectable responses to life stressors; only slight impairment in functioning.</p> <p><i>Do the symptoms impair functioning only slightly? (Yes) AND Are the symptoms rare and does the caregiver have good/superior functioning? (No) = 4</i></p>	<p>Symptoms are absent or rare; good or superior functioning in wide range of activities; no more than every day problems or concerns.</p> <p><i>Are the symptoms rare and does the caregiver have good/superior functioning? (Yes) = 5</i></p>	
Family Health	<p>One or more children in the home is experiencing acute health crisis that would prevent effective caregiving.</p> <p><i>Are all other children in the home experiencing good health? (No) AND Is health of other children preventing ability to care? (Yes) = 1</i></p>	<p>One or more child in the home is experiencing acute health crisis. Caregiving for client is minimally impacted.</p> <p><i>Are all other children in the home experiencing good physical and mental health? (No) AND Is health of other children preventing ability to care for client? (No) = 2</i></p>	<p>One or more children in the home has well managed chronic disease. Acute health crisis has occurred in past six months.</p> <p><i>Does one or more other child have well managed chronic disease? (Yes) AND Has the other child had an acute health crisis in the past six months? (Yes) = 3</i></p>	<p>One or more children in the home has well managed chronic disease.</p> <p><i>Does one or more other child have well managed chronic disease (Yes) AND Has the other child had an acute health crisis in the past six months? (No) = 4</i></p>	<p>No current active health issues of other children in home.</p> <p><i>Are all other children in the home experiencing good health? (Yes) = 5</i></p>	

Evaluation of Non-Medical Needs for Children with Medical Complexity – A Modified Self-Sufficiency Matrix ^{13, 14, 15} (continued)

	1 = In Crisis	2 = Vulnerable	3 = Safe	4 = Building Capacity	5 = Empowered	Score
Family or Social Relations		<p>Lack of necessary support from family or friends; abuse (DV, child) is present or there is child neglect.</p> <p><i>Does client have support from family/friends? (No) = 1</i></p>		<p>Strong support from family or friends. Household members support each other's efforts.</p> <p><i>Does client have strong support from family/friends and do family/friends support one another? (Yes) = 4</i></p>		
Emotional Health - Child		<p>Danger to self or others; recurring suicidal ideation; experiencing severe difficulty in day-to-day life due to psychological problems.</p> <p><i>Is the child a danger to self or others? (Yes) = 1</i></p>		<p>Minimal symptoms that are expectable responses to life stressors; only slight impairment in functioning.</p> <p><i>Do the symptoms impair functioning only slightly? (Yes) AND Are the symptoms rare and does the child have good/superior functioning? (No) = 4</i></p>		
Utility Needs	<p>Electric, gas, oil, or water is currently shut off in home.</p> <p><i>(Yes) = 1</i></p>	<p>Electric, gas, oil, or water company has threatened to shut off services in home in the past 12 months.</p> <p><i>(Yes) = 2</i></p>	<p>All utilities are currently on, working, and not at risk of being discontinued.</p> <p><i>(Yes) = 3</i></p>			
Housing	<p>Homeless or threatened with eviction.</p> <p><i>Is the client housed and not at imminent risk of losing that housing? (No) = 1</i></p>	<p>In transitional, temporary or substandard housing; and/or current rent/mortgage payment is unaffordable (over 30% of income).</p> <p><i>Is the housing stable and/or affordable? (No) = 2</i></p>	<p>In stable housing that is safe but only marginally adequate</p> <p><i>Is the housing adequate? (No) = 3</i></p>	<p>Household is in safe, adequate subsidized housing.</p> <p><i>Is the housing unsubsidized? (No) = 4</i></p>	<p>Household is safe, adequate, unsubsidized housing.</p> <p><i>Is the housing unsubsidized? (Yes) = 5</i></p>	

Evaluation of Non-Medical Needs for Children with Medical Complexity – A Modified Self-Sufficiency Matrix ^{13, 14, 15} (continued)

Domain	1 = In Crisis	2 = Vulnerable	3 = Safe	4 = Building Capacity	5 = Empowered	Score
Employment	No job. <i>Do you have a job? (No) = 1</i>	Temporary, part-time or seasonal; inadequate pay, no benefits. <i>Is the job full-time? (No) = 2</i>	Employed full time; inadequate pay; few or no benefits. <i>Does the full-time job pay adequately with benefits? (No) = 3</i>	Employed full time with adequate pay and benefits. <i>Is the full-time job permanent? (No) = 4</i>	Maintains permanent employment with adequate income and benefits. <i>Is the full-time job permanent? (Yes) = 5</i>	
Income	No income. <i>Does client have income? (No) = 1</i>	Inadequate income and/or spontaneous or inappropriate spending. <i>Is the income adequate to at least meet basic needs? (No) = 2</i>	Can meet basic needs with subsidy; appropriate spending. <i>Can client meet basic needs without assistance? (No) = 3</i>	Can meet basic needs and manage debt without assistance. <i>Does client have discretionary income and can save? (No) = 4</i>	Income is sufficient, well managed; has discretionary income and is able to save. <i>Does client have discretionary income and can save? (Yes) = 5</i>	
Food	No food or means to prepare it. Relies to a significant degree on other sources of free or low-cost food. <i>Does the client have food or means to prepare it? (No) = 1</i>	Household is on food stamps. <i>Can the client meet basic food needs without food stamps? (No) = 2</i>	Can meet basic food needs, but requires occasional assistance. <i>Can the client meet basic food needs without any assistance? (No) = 3</i>	Can meet basic food needs without assistance. <i>Can client satisfy any food need? (No) = 4</i>	Can choose to purchase any food household desires. <i>Can client satisfy any food need? (Yes) = 5</i>	
Transportation	No access to transportation, public or private; may have car that is inoperable. <i>Does client have access to transportation? (No) = 1</i>	Transportation is available, but unreliable, unpredictable, unaffordable; may have car but no insurance, license, etc. <i>Is the transportation reliable? (No) = 2</i>	Transportation is available and reliable, but limited and/or inconvenient; drivers are licensed and minimally insured. <i>Is the transportation generally accessible and/or convenient? (No) = 3</i>	Transportation is generally accessible to meet basic travel needs. <i>Is the transportation affordable? (No) = 4</i>	Transportation is readily available and affordable; car is adequately insured. <i>Is the transportation affordable? (Yes) = 5</i>	
Legal	Current outstanding tickets, warrants. <i>Does client have outstanding tickets or warrants? (Yes) = 1</i>	Current charges/trial pending, noncompliance with probation/parole, or JFS involvement <i>Does client have outstanding tickets or warrants, or open JFS case? (No) AND Is client noncompliant with parole/probation? (Yes) OR Does client have charges/trial pending? (Yes) = 2</i>	Fully compliant with probation/parole terms. <i>Has client been on parole/probation in the past 12 months? (Yes) AND Is client compliant with parole/probation? (Yes) = 3</i>	Has successfully completed probation/parole within past 12 months, no new charges filed. <i>Has client been on parole/probation in the past 12 months? (No) AND Does client have charges/trial pending? (No) = 4</i>	No active criminal justice involvement in more than 12 months and/or no felony criminal history. <i>Does the client have a criminal history in the past 12 months? (No) = 5</i>	

Evaluation of Non-Medical Needs for Children with Medical Complexity – A Modified Self-Sufficiency Matrix ^{13, 14, 15} (continued)

Domain	1 = In Crisis	2 = Vulnerable	3 = Safe	4 = Building Capacity	5 = Empowered	Score
Substance Abuse	<p>Meets criteria for severe abuse/dependence; resulting problems so severe that institutional living or hospitalization may be necessary.</p> <p>Does client require hospitalization or institutional living? (Yes) = 1</p>	<p>Meets criteria for dependence; preoccupation with use and/or obtaining drugs/alcohol; withdrawal or withdrawal avoidance behaviors evident; use results in avoidance or neglect of essential life activities.</p> <p>Does client require hospitalization or institutional living? (No) AND Is the client not seriously dependent on drugs or alcohol? (No) = 2</p>	<p>Use within last 6 months; evidence of persistent or recurrent social, occupational, emotional or physical problems related to use (such as disruptive behavior or housing problems); problems have persisted for at least one month.</p> <p>Is the client not seriously dependent on drugs or alcohol? (Yes) AND Does client not show evidence of recurrent social, emotional, or physical problems associated with drug or alcohol use? (No) = 3</p>	<p>Client has used during last 6 months, but no evidence of persistent or recurrent social, occupational, emotional, or physical problems related to use; no evidence of recurrent dangerous use.</p> <p>Does client not show evidence of recurrent social, emotional, or physical problems associated with drug or alcohol use? (Yes) AND Is client free from substance abuse problems during past 6 months? (No) = 4</p>	<p>No drug use/alcohol abuse in last 6 months.</p> <p>Is client free from substance abuse problems during past 6 months? (Yes) = 5</p>	
Safety (of home, neighborhood, risk of abuse)	<p>Home or residence is not safe; immediate level of lethality is extremely high; possible CPS involvement.</p> <p>Is family safe; is the physical environment of the children secure? (No) = 1</p>	<p>Safety is threatened/ temporary protection is available; level of risk of harm is high.</p> <p>Is the safety of the household threatened, but temporary protection is available? (Yes) = 2</p>	<p>Current level of safety is minimally adequate; ongoing safety planning is essential.</p> <p>Is the current safety environment minimally adequate? (Yes) = 3</p>	<p>Environment is safe, however, future of such is uncertain; safety planning is important.</p> <p>Is the current environment safe yet the future is uncertain? (Yes) = 4</p>	<p>Environment is apparently safe and stable.</p>	
Adult Education	<p>Literacy problems and/or no high school diploma/GED are serious barriers to employment.</p> <p>Does the client have a high school diploma or GED? (No) AND Is literacy a serious barrier to employment? (Yes) = 1</p>	<p>Enrolled in literacy and/or GED program and/or has sufficient command of English to where language is not a barrier to employment.</p> <p>Does the client have a high school diploma or GED? (No) AND Is literacy a serious barrier to employment? (No) = 2</p>	<p>Has high school diploma/GED.</p> <p>Does the client have a high school diploma or GED? (Yes) AND Does the client have the education/literacy skills to function effectively in society? (No) = 3</p>	<p>Needs additional education/ training to improve employment situation and/or to resolve literacy problems to where they are able to function effectively in society.</p> <p>Has the client completed education/training needed to become employable? (No) = 4</p>	<p>Has completed education/ training needed to become employable. No literacy problems.</p> <p>Has the client completed education/training needed to become employable? (Yes) = 5</p>	

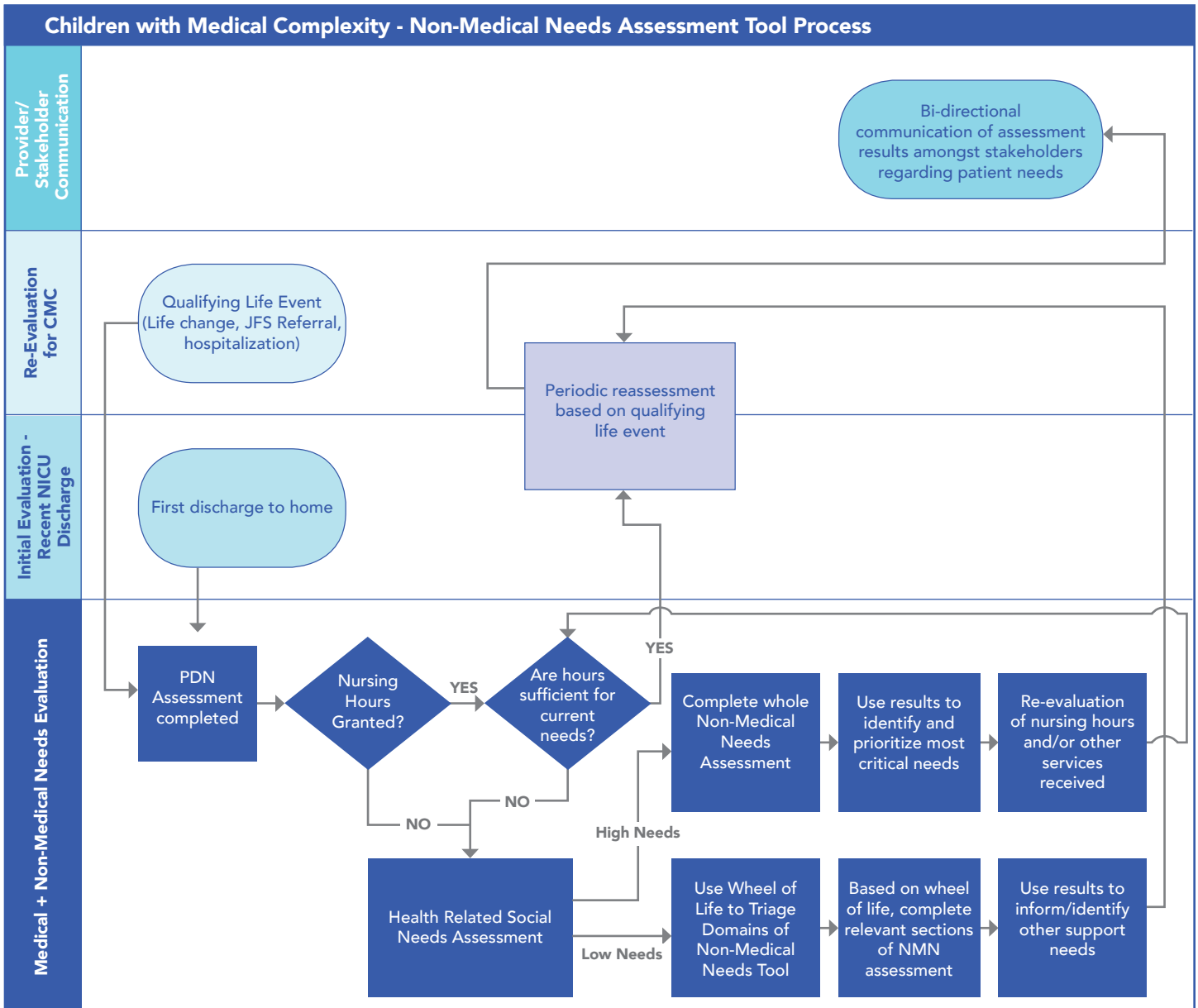
Thinking About Care in the First Few Years after Discharge

Addressing Changes over Time

For the pediatric population with technological dependence, current assessment of ongoing nursing and home care needs would benefit from unified and standardized tools and policies, with particular focus on the unique needs of children whose families are

delivering care similar to hospital level in their own homes. Processes for reassessment frequency, remediation of identified care gaps and re-evaluation of social determinant risk factors should be applied in a reliable fashion to support appropriate care.

Matching Needs with Resources after Discharge



Acknowledgements

Ohio Department of Medicaid
Kim DeDino, MS, RD, CSP

OHIO PERINATAL QUALITY COLLABORATIVE

Faculty Leadership Team

Improvement Lead

Dan Benscoter, DO

Content Lead

Kristin Voos, MD

Senior Advisors

Heather Kaplan, MD, MSCE

Jennifer Lail, MD

Carole Lannon, MD, MPH

Maurizio Macaluso, MD, DrPH, FACE

Garey Noritz, MD

Michele Walsh, MD

Project Management Team

Senior Specialist Project Management

Lindsey Hoberg, MHA, CPM

Suzanne Culbertson, MPH

Kate Haralson, MPH, CPM

Lakshmi Prasad, MPH

Bianca Williams, MPA

Quality Improvement Consultant

Andrea Hoberman, MPH

Family Engagement Specialist

Laura Miller, CPXP

Program Advisors

Sandra Fuller, MEd

Karen Hughes, MPH

Data Management and Biomedical Informatics Team

Benjamin Burns, BS

Jennifer Collins, MPH

Rushi Goswami, MBBS, MPH, CPH

Krassimir Kotzev, BS

Pierce Kuhnell, MS

Jessi Lipscomb, BS

Jeremy Nix, BS

Kristen Tillman, BA

PARTICIPATING NICU TEAMS

Akron Children's Hospital

Clinical Leads

Kelly Powell, BA, BSN, RN

Alison Protain, DO

Anand Kantak, MD

Stephanie Allen, MSN, RN

Michael Bigham, MD

Denise Fabian, LISW

Alexis Host, Parent Partner

Suzanne Felter, RN-BC

Kim Firestone, MSc, RRT

Sarah Friebert, MD

Marybeth Fry, MEd

Marlene Hardy-Gomez, NP

Lisa Heenan, BSN, RN

Andrea Legg, Parent Partner

Karen Ianiro, LISW-S

Kimberly McKinley, RN

Scott Schachinger, DO

Monica Smith, RN

Connie Teal, CNS

Cincinnati Children's Hospital

Clinical Leads

Lisa Mack, MSN, BSN, RN

Stephanie Merhar, MD

Abbie Ball, BSN, RN

Megan Brammer, BS, RRT

Megan Cargioli, MSW, LISW

Michelle Coleman, MSN, RN, CPN, QOM

Jaclyn Elmore, RN

Melissa House, MD

Beth Ann Johnson, MD, MA

Carrie Martin, MSN, CNP

Michelle Shinkle, MSN, RN

Catherine Sipniewski, BSN, RN, RNC-NIC, CLC

Theresia Tuttle, RRT-NPS, MRC

Acknowledgements

Dayton Children's Hospital

Clinical Leads

Mari Jo Rosenbauer, MS, RNC, CPNP, IBCLC
M. David Yohannan, MD

Michelle Begley, MSW, LSW

Gena Buehrer, BSN

James Duffee, MD, MPH

Alicia Link

Denise Martin, BSN, RN, CPN

Carol Murray, MS, CPNP-AC, PCNS-BC

Nicole Schneider, BSN

Amy Weng RRT, CPFT RCP

Nationwide Children's Hospital

Clinical Leads

Roopali Bapat, MD

Margaret Holston, RN, BSN

Thomas Bartman, MD, PhD

Robin Catlett, APN

Karen Clark, RN

Mary Coles, MSN, RN

Kimberly Conkol, RN

Adeline Cursio, CNS

Renee Gardikes Gingery, BSN, RN

Katherine Garrison, LISW-S

Rhonda Geduldig, MS, RN

Mary (Walton) Gossard, MSN, RN, CNS

Jonathan Grischkan, MD

Judith Hanlon, MS, RN

Sarah Hastie, BSN, RNC-NIC

Erin Keels, MS, APRN, NNP-BC

Krysten Kendall, RN

Katelyn Krivchenia, MD

Marissa Larouere, MBA, BSN, RN

Meredith Lind, MD

J. Wells Logan, MD

Susan Lynch, MD

Vicky Merritt, MSN, RN

Mohannad Moallem, MD

L. Ryan Nicoll, MSW, LISW-S

Angela Oswald-Morelli, LISW-S

Lyndsey Paxton, BSN, RN

Teresa Puthoff, PharmD

Gregory Ryshen, MS, MBA, CQE

Amy Schlegel, MD

Ruth Seabrook, MD

Jonathan Slaughter, MD, MPH

Jodi Smathers, MSN, RN

Melanie Sobleskie, RN

Leslie Thomas, MSN, APRN, NNP-BC

Rainbow Babies and Children's Hospital

Clinical Lead

Monika Bhola, MD

Kimberly Barnett, RN

Leslie A. Clarke, MS, MBA, RN

Kathleen Deakins, RRT

Veronica Deleon, RN

Tara Glenn, MD

Renee Grabski, RN

Leta Houston-Hickey, NNP

Ann Kessler, LISW-S

Katie Luzier, RN

Candice Mack, RN

Allison Payne, MD, MSCR

Kristine Thompson, Parent Liaison

PARENT PARTNERS

Akron: Alexis Host, Andrea Legg

Dayton: Tiffany Baldasare

Rainbow: Kristine Thompson

Cincinnati: Jennifer Carroll

Nationwide: Krysten Kendall, Anne Slifer

PARTICIPATING MANAGED CARE PLANS

Buckeye Community Health Plan

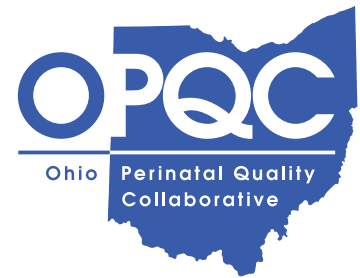
CareSource

Molina Healthcare of Ohio

Paramount Advantage

UnitedHealthcare Community Plan

The OPQC NICU Graduates Project is funded by the Ohio Department of Medicaid and administered by the Ohio Colleges of Medicine Government Resource Center. The views expressed in this presentation, are solely those of the authors and do not represent the views of the state of Ohio or federal Medicaid programs.



www.opqc.net

Email us at: info@opqc.net

