

NPC-QIC Toolkit

Optimizing Neurodevelopment & Supporting Infant Gross Motor Outcomes

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National Pediatric Cardiology
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“Parents and caregivers are concerned about, and eager to support their single ventricle child’s development. They want to be actively involved in their developmental care from birth, and too often might feel that their concerns are not immediately prioritized by the care team. Development can seem to take a back seat when infants are born with serious heart conditions and spend time in inpatient settings, but it is important to teach parents the skills, strategies and therapies necessary to support their families as early as possible. The work to continue supporting developmental care for single ventricle patients is critical for all families.”

– Jennie Briend, Parent

I. Executive Summary

What is the purpose of this toolkit?

Neurodevelopmental disability is a significant concern for individuals with complex congenital heart disease (CHD) across the lifespan. Gross motor delays, in particular, are common in infants with single ventricle CHD, with >60% of NPC QIC-enrolled infants **not** scoring “on target” at 12 months on the Ages & Stages Questionnaire (ASQ) developmental screener. The early identification and treatment of developmental concerns, starting in infancy, can positively impact developmental trajectory for these infants. This toolkit was created to share intervention strategies to promote optimal gross motor outcomes and describes supportive developmental care practices for both hospital and home settings.

Strategies included in the toolkit are based on current evidence from the CHD population. When evidence is not available from the CHD population, we have relied on research from other high-risk populations, clinical consensus, and learnings from the NPC-QIC Gross Motor Improvement Project. As the evidence in the field of cardiac neurodevelopment expands, care recommendations will continue to be refined. It is important for clinicians to stay current with the latest best practice guidelines supporting development in the CHD population.

Who is this toolkit for?

The target audience for this toolkit is interdisciplinary professionals and parents caring for infants with single ventricle CHD. The information in this toolkit can also be shared with infants’ medical home providers, early intervention professionals, and key stakeholders, such as hospital administrators.

What are ways that this toolkit can be useful to a cardiac program?

- Enhance care practices to sites already providing developmentally supportive inpatient care and outpatient neurodevelopmental clinics.
- Provide guidance to programs who are newly starting on their inpatient neurodevelopmental care journey and/or who may not have an outpatient neurodevelopmental clinic.
- Provide guidance to care providers, including physicians, nurses, advanced practice providers, therapists, and psychologists, working with infants with single ventricle CHD to enhance opportunities for interventions such as infant holding, tummy time and supportive positioning, and timely referrals to outpatient early intervention services.
- Support parents to be active participants in developmental care in the hospital setting and provide a “how to” guide for at home infant exercises.
- Encourage hospital administrators to support initiatives that promote developmentally supportive care such as inpatient therapeutic interventions and outpatient cardiac neurodevelopmental clinics.

What is included in the toolkit?

The toolkit provides comprehensive information about the developmental needs of infants with single ventricle CHD and strategies to support developmental progression. This resource is geared to a wide audience including interdisciplinary professionals and family members. Therefore, not all sections may be applicable to your work or interests. Some sections have hyperlinks that you can select for more detailed information about specific topics or examples of tools or resources, such as developmental plans.

The toolkit includes the following content:

- **Key concepts**, or guiding principles, to best support the developmental needs of infants with CHD. This is most helpful for the *medical team* to provide developmentally supportive care. The *supporting parents* section is written by a parent and is a helpful resource for parents.
- **Intervention strategies** by developmental phase as well as special considerations, such as sternal and prone precautions. This is helpful for *both professionals and parents*.
- **“Deeper dive into valuable interventions”** which includes diagrams and descriptions of how to do tummy time, infant holding, and range of motion exercises. This section is particularly helpful for *parents*.
- **QI: Gross motor improvement project** which describes the multisite NPC–QIC initiative to improve ASQ gross motor scores, ASQ screening completion, and use of developmental plans. This section includes lessons learned and QI resources and is helpful for *medical and QI teams* wanting to improve developmental care.

Take Home Messages: Strategies to Optimize Neurodevelopment

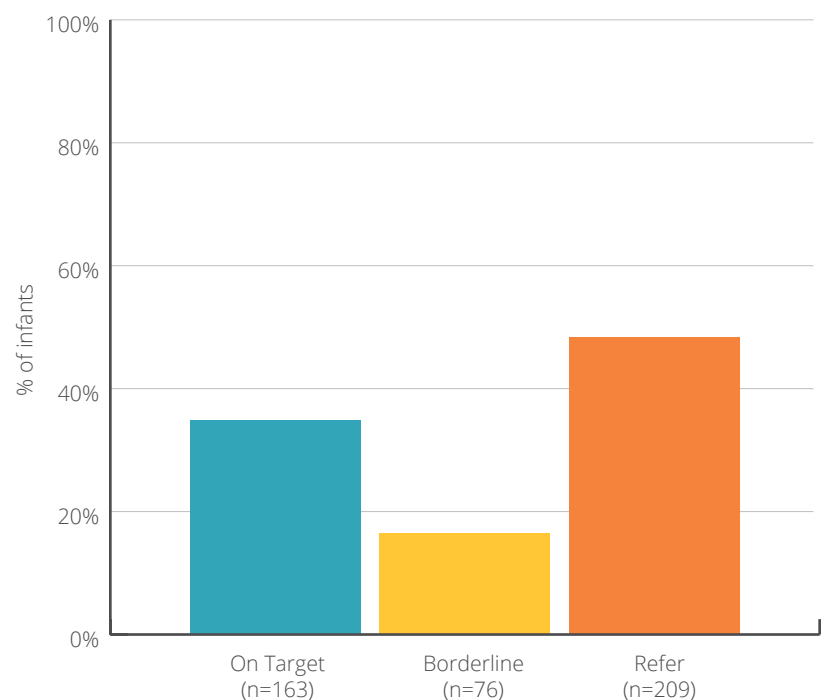
- Neurodevelopmental care should be a continuum starting at the time of CHD diagnosis and carrying through inpatient settings, including the cardiac intensive care unit (CICU), cardiac step-down unit, home, and outpatient settings.
- There are **4 key concepts** that care centers should incorporate when designing or evaluating the effectiveness of their neurodevelopmental care programs:
 - 1) Administer **developmental screening** using a standardized screening tool
 - 2) Provide individualized, family-centered **developmental care**
 - 3) **Support parents** in participating in activities that promote their infant’s developmental progression
 - 4) **Engage in therapy services** in inpatient and outpatient settings and **establish care in a neurodevelopmental clinic**
- Maximize opportunities for infants to participate in specific care practices that support parent–infant bonding and gross motor skill development starting as early as possible:
 - Parents holding infants starting in the ICU
 - Prone positioning and tummy time
 - Optimizing sensory experiences to impact developmental outcomes
 - Learning activities to promote gross motor skill progression
- Consider your medical center’s recommended duration of postoperative sternal precautions and how this may impact infants’ ability to participate in tummy time.
- Provide families with written, up-to-date developmental plans at critical time points including time of diagnosis, stage 1 and stage 2 discharge, and by 4 weeks post-op if still in the inpatient setting. More frequent developmental plans are also helpful.
- Ensure timely referrals to inpatient and outpatient therapy services, such as physical therapy (PT) and occupational therapy (OT).
- Refer all infants with single ventricle CHD to your state’s early intervention program for evaluation and treatment.
- Refer all infants with single ventricle CHD to a neurodevelopmental clinic for formal assessment by 9–12 months of age aligned with recommendations by the American Heart Association (AHA) & American Academy of Pediatricsⁱ (AAP) and the Cardiac Neurodevelopmental Outcome Collaborative (CNOC)ⁱⁱ.
- Gross motor developmental interventions are connected to overall neurodevelopmental interventions. Gross motor skills in infancy lay the foundation for future development across domains.
- Encourage your site’s QI team to test interventions to improve rates of developmental screening and receipt of developmental plans.

II. Background & Scope

The incidence of congenital heart disease (CHD) is 4 to 8 per 1000 live births. Approximately 2% of children with CHD have a single ventricle physiology or HLHS^{iii iv}. Developmental delay (DD), especially delayed motor skill development, is common among infants with CHD^v. Infants with single-ventricle physiology are at increased risk compared to infants with other CHD conditions for fine and gross motor delay^{vi}. Experiences in the first 12 months for an infant with single ventricle CHD are quite different from the typical infant experience due to multiple surgeries, medical procedures, and often lengthy hospitalizations. In addition, inpatient and outpatient factors may contribute to infants' developmental course including sternal precautions, restrictions in holding and typical mobilization, limitations in tummy time, types and frequency of therapies provided throughout infancy, and the degree of parental engagement in developmental activities. There is practice variation across sites related to the type and duration of post-op restrictions and infant developmental care approaches. At age 12 months, infants with single ventricle CHD commonly exhibit delays in most of their gross motor milestones, including those skills occurring in supine, prone, sitting, and standing^{vii}.

Infants with single ventricle CHD who are enrolled in NPC-QIC complete developmental screening using the ASQ at targeted timepoints from birth to 12 months. The ASQ developmental screening results for NPC QIC-enrolled infants consistently demonstrate a high prevalence of gross motor delay relative to other developmental domains. Figure 1 shows that at 12 months of age only 36% of infants scored in the "on target" range. This provides an opportunity for use of quality improvement (QI) methodology to achieve better gross motor outcomes.

**Developmental Screening (ASQ-3)
Gross Motor Domain, 12-month (n=448)**



III. Key Concepts: Supporting Neurodevelopment

Since children with CHD are at increased risk of developmental impairments, early intervention during infancy, a period in which brain neuroplasticity is high, is critically important. Centers can ensure that they are providing developmentally supportive care to infants by incorporating 4 key concepts, or guiding principles, into their routine practices. Neurodevelopmental care is a continuum that should start at birth and remain present throughout inpatient settings, including the intensive care unit (ICU), outpatient, and home settings.

Here are 4 Key Concepts to optimize neurodevelopment:

1. Conduct routine **developmental screening** to identify potential developmental delay.
2. Provide individualized, family-centered **developmental care** practices in the inpatient setting to minimize the stress of the hospital experience for the infant and family.
3. **Support parents** in understanding typical developmental progression and ways to promote their infant's development.
4. **Engaging in therapy** services such as physical, occupational, and speech-language therapy, throughout infancy is central in facilitating appropriate developmental progression. **Establishing care in a neurodevelopmental clinic** by 9–12 months of age supports ongoing evaluation and treatment of developmental needs.

1. Developmental Screening

Use of a standardized, developmental screening tool such as the ASQ at 6, 9, and 12 months of age (or as early as 4 months of age, if the infant is at least 2 weeks post-op from stage 2 surgery by this age) is suggested for close monitoring of developmental progression and to support the need for formal developmental evaluation or referral to early intervention and outpatient therapy services.

Among children with CHD, children with single ventricle CHD are at the highest risk for having developmental delays or disabilities (DD)^{viii}, close monitoring of development starting in infancy is critical. Although the American Academy of Pediatrics (AAP) recommends developmental surveillance at all pediatric visits and screening using a standardized screening tests at 9-, 18-, and 30-month well child visits for all children^{ix}, those at high risk for DD warrant closer monitoring. Parents of children with complex CHD commonly report that discussions about development “take the back seat” during pediatric visits, compared to the child's more acute medical needs, especially in the first year of life. Furthermore, primary care physicians may reassure families that developmental delays are expected given the child's medical history (open heart surgery, hospitalizations). While developmental delays are common in infancy, there are helpful interventions, that when started early have the potential to improve developmental outcomes. NPC-QIC has implemented developmental screening for infants in the collaborative starting post-op from Stage 2 palliation surgery until 12 months of age (all infants are screened at 6, 9, & 12 months of age; some infants are screened at 4 months if they are 2 weeks or more post op from stage 2 surgery), using a standardized screening tool, the ASQ. Developmental screening starting early in infancy, prior to the first formal neurodevelopmental evaluation at 9–12 months of age recommended by the AHA/ AAP's joint scientific statement^x, empowers parents and medical teams to better support infant's development by promoting access to early invention services and therapies as soon as they are indicated.

It is important to note that the ASQ is a screening tool only and is not diagnostic of developmental delays. After completing an ASQ, scores indicate whether a baby appears to be on target or is below a cut-off score for each developmental domain (communication, problem solving, fine motor, gross motor, social-emotional) indicating the need for further evaluation by a medical professional or therapist. ASQ screening is a first step to identifying areas of possible concern, evaluating concerns further, and starting interventions to support the infant, such as at-home exercises, or referrals for early intervention therapies.

2. Developmental Care

Developmental care should be integrated into inpatient cardiac units as it has been shown to improve neurodevelopmental outcomes for the high-risk infant. Examples of developmental care include integrating family into all aspects of care, understanding and responding to the infant's cues, providing a soothing environment, protecting sleep, offering skin-to-skin and holding opportunities, and controlling pain with non-pharmacologic soothing.

While survival rates for children with CHD have significantly improved, neurologic abnormality and neurodevelopmental impairment have increased. While some developmental differences and challenges seen in children with CHD are explained by the cumulative effect of medical complications associated with CHD, many sequelae are not easily explained by medical complications alone. Hospital and environmental challenges such as noxious stimuli, painful procedures, sleep deprivation, decreased parent contact, challenges to comfortable positions and decreased movement, along with invasive lines and tubes produce infant and parent stress, both effecting parent infant interactions and less than optimal infant interactions, movement, and brain development.^{.xi}

It has been proven repeatedly that individualized developmental care in the newborn ICU improves neurodevelopment and psychosocial outcomes for fragile infants and their families and is widely agreed to be best practice for vulnerable high-risk infants.^{.xii xiii xiv xv xvi xvii} Over the past decade, literature has emerged calling for developmental care to be integrated into the care of infants with CHD.^{.xxiv xxv xxvi xxvii} Developmental care is an approach to individualize the care for fragile infants and their families to maximize neurodevelopmental outcomes. The intervention of developmental care is designed to minimize the mismatch between the fragile brain's expectations and the experiences of stress and pain inherent in ICU environment. An ICU that provides individualized, developmentally-supportive, and family-centered care includes a soothing environment which encourages sleep and healing, supports parents as their child's primary caregiver, includes reading an infant's behavior and cues to provide continual adjustment of caregiving in support of the child's wellbeing, strengths, and healing.^{.xxvii xxxix xxxx} Parent involvement and education are important aspects of individualized developmental care. Helping parents understand their infant's or child's behavior while in the hospital can lead to positive interactions. In individualized developmental care, parents are recognized as the stable, familiar, predictable providers who are involved in all aspects of caregiving. As Winnicott^{.xxxix} reported, there are no infants without parents.

While individualized developmental care is of utmost importance, the extreme nature of medical needs of patients in the CICU provides an extra layer of challenge. Patients in the CICU are subjected to complex life-saving procedures, painful invasive medication and monitoring lines, intubation tubes, drains, and prolonged hospital stays, particularly in the case of post-surgical complications. Although developmental care practices are implemented to varying degrees in many North American CICUs, recent research indicates that developmental care practices fluctuate within and across CICUs and there are no guidelines for developmental care for the cardiac patient. The ability to regulate sound and television use, reduce the use of sedation and restraints, engage in infant holding, and fully integrate families into the care of the infant have been noted as challenging in the CICU. Furthermore, most units identified they were unable to engage in developmental care without additional education and allocation of resources, a formal developmental task force/committee and regularly scheduled developmental rounds.^{.xxxii xxxiii xxxiv xxxv}



3. Supporting parents *(from the perspective of a parent of a child with HLHS)*

Parents are vital members of their infant’s care team at every stage, including surgical recovery, hospitalization, and setting the foundation for future developmental support and success. Whenever possible, infants with single ventricle CHD should be treated the same as heart-healthy and typically developing children. It is common for infants to experience developmental delays over the course of their treatments, and it is important for parents to know and be educated on the developmental goals that their child is working towards. Parents are encouraged to review *“A Deeper Dive into Valuable Interventions”* section of the toolkit for suggestions of ways to work with their baby. Families who are looking to connect with other parents should be referred to **Sisters by Heart** for support.

During periods of hospitalization, parents should be encouraged to be at the bedside and involved in as many daily care routines as possible. Clinical staff teaching parents how to take ownership of daily care activities in a safe manner helps to solidify the parent’s bond with their infant, establish a normal parental role, and will build families’ confidence in caring for their infant after hospital discharge. Opportunities for families to engage in developmentally supportive activities with their child such as reading, talking to and playing with their child, should be intentionally set in place. Families should be provided with a key contact to approach with any concerns or questions about their child’s neurodevelopmental needs, but it is every team member’s responsibility to know where to direct specific questions. Over time caregivers will learn how to encourage and achieve goals with their child and meet milestones at their pace.

Many infants benefit from participation in therapies to work on building strength, coordination, and motor skills, which should actively train parents so they can practice the exercises with their child at home and in the inpatient setting when indicated. Caregivers should be given anticipatory guidance about risks for delays, developmental screening, and ongoing care starting at the time of diagnosis of a single ventricle heart defect. This conversation should be revisited routinely as the patient progresses.

Once home, parents who have questions or concerns about their child’s development can start by reaching out to their child’s primary care provider (PCP) and sharing developmental plans. The AAP^{xxvii} recommends that pediatricians conduct developmental surveillance and screening at well child visits. PCPs are familiar with typical development and should be able to refer infants for further evaluation and treatment through the state Early Intervention (EI) program or local outpatient therapies. It is important for the PCP to complete all scheduled developmental surveillance and screeners despite potential hospitalizations, as it is expected for the patient to improve over time. Additionally, many cardiac programs have specialized neurodevelopmental clinics that may

include a developmental pediatrician, neurologist, psychologist, and/or other allied health professionals who could connect with families and answer questions. It is helpful for single ventricle care teams to clearly identify for families who to contact and when with questions about development (e.g., PCP or a neurodevelopmental professional within the cardiac program, or both).

4. Engaging with Therapy throughout Infancy & Establishing Care in a Neurodevelopmental Clinic

A multidisciplinary neurodevelopmental team allows for optimal developmentally supportive care from birth, through the inpatient stay, and into the outpatient setting. This team frequently includes physical therapy (PT), occupational therapy (OT), speech–language pathology (SLP), psychology, neuropsychology, child life, social work, nursing, physicians, music therapy, integrative medicine, volunteers, and the family. PTs and OTs have expertise in evaluating motor development and recommending strategies to build strength and coordination to achieve motor milestones. SLPs and OTs have expertise in feeding and SLPs have expertise in the development of communication skills. Involvement of therapists is recommended across infancy. A variety of therapy options are available from hospitalization to ongoing developmental support at home.

All infants with single ventricle CHD should be referred to a neurodevelopmental clinic by 9–12 months of age for formal developmental assessments and to establish longitudinal care, aligned with recommendations by the American Heart Association (AHA) & American Academy of Pediatrics (AAP)^{xxxvii} and the Cardiac Neurodevelopmental Outcome Collaborative (CNOC)^{xxxviii}. The Cardiac Neurodevelopmental Outcome Collaborative (**CNOC**) advised NPC QIC in the design of the network’s neurodevelopmental QI initiative and has provided ongoing collaboration. CNOC’s mission is to determine and implement best practices of neurodevelopmental services for individuals with CHD and their families through clinical, QI, and research initiatives. The knowledge generated by CNOC’s work will continue to improve care and neurodevelopmental outcomes for individuals with CHD. Sites interested in starting cardiac neurodevelopmental clinic programs are encouraged to connect with CNOC.

Developmental Support while Inpatient:

Automatic therapy orders for rehabilitative services (PT, OT, and SLP) upon hospital admission allows early initiation of developmentally supportive interventions. These services support opportunities for holding, skin to skin, state regulation, and feeding in early infancy, as well as supporting and progressing global development. Depending on each infant’s needs, therapy services can be provided daily to weekly while inpatient, and weekly to consultative in the outpatient and home–based settings.

Providing consistent and routine developmental care practices offers the infant continuous neuroprotection in the cardiac ICU and step–down unit environments. Unit–wide practice guidelines on developmental care minimize variability in care and allow the medical team to determine when patients are medically appropriate for clustering medications and cares, increasing time increments between hands on cares, and holding out of bed and/or kangaroo care.

Developmental care rounds consist of the inpatient neurodevelopmental team meeting to discuss ways to support individual infants and their families during the hospital stay. Developmental care rounds offer an opportunity for the neurodevelopmental care team to meet with families, to understand and support families’ goals, as well as ensure that families are comfortable with all aspects of care. This is particularly important as they progress through their inpatient stay, and care transitions from nursing–provided care to caregiver–provided care. Common areas of discussion include developmentally supportive positioning and handling, feeding strategies, participating in cares, establishing typical infant routines like sleeping and bathing, minimizing interruptions during sleep, modifying the environment, and general mobility.

Developmental plans provide a written document displayed at the bedside with individualized recommendations to support the infant and family. Developmental plans should be created by the multidisciplinary team and further supported by education provided during therapy sessions. Families, volunteers, nurses, and other providers can utilize these resources when interacting with the patient. Our network goal is to achieve level 1 (80%) reliability of infants receiving an up-to-date developmental plan at critical time points: diagnosis and at the time of discharge after Stage 1 and Stage 2 surgeries.

See examples of developmental plans from sites participating in the Gross Motor Improvement Project:

- [Developmental plan template—time of CHD diagnosis](#)
- [Developmental plan after Stage 1 and Stage 2 surgery](#)

Utilizing standardized assessments can allow inpatient care providers to establish baseline neurobehavioral and neuromotor skills and support therapy referral recommendations. These assessments may be done by therapists (PT, OT, SLP), psychologists, or other developmental professionals and findings can be helpful in guiding the inpatient therapy plan of care and recommendations for ongoing therapy following discharge. Common assessment tools include, but are not limited to, the NICU Network Neurobehavior Scale (NNS), Test of Infant Motor Performance (TIMP), Bayley Scales of Infant and Toddler Development, Pretechl and Hadder-Agra's General Movement Method Assessments (GMA), Newborn Individualized Developmental Care and Assessment Program (NIDCAP), Newborn Behavioral Observation (NBO), and Newborn Behavioral Assessment Scale (NBAS).

Developmental Support at Home:

As infants approach hospital discharge, the goal is for a seamless transition home and into ongoing therapy services. Depending on each family's situation and the individual needs of the infant, referrals can include State Early Intervention (EI) Programs (Part C, Individuals with Disabilities Education Act- IDEA), home health care, or outpatient therapy services. In addition, therapy involvement integrated into interstage or cardiology clinic visits can allow for consistent support for development and feeding. We recommend referring all infants with single ventricle CHD to their state's EI program for eligibility evaluation at the time of hospital discharge after stage 2 palliation surgery, given their high-risk status and providing families with information about their state's EI program to contact in the future if new concerns arise prior to 3 years of age.

Acting on results of developmental screening. When ASQ data is returned, families should be contacted by a neurodevelopmental team member to discuss results and determine therapy referral needs. Several institutes have found it helpful to set up a telehealth visit with a neurodevelopmental team member, often including a therapist, for patients with red flag ASQ results to offer immediate home programming. When a concerning gross motor ASQ score is received, every effort should be made to ensure the infant is receiving physical and/or occupational therapy services.

Cardiac neurodevelopmental follow up clinics provide the opportunity for multidisciplinary teams to complete formal developmental assessments, answer family questions, and offer further recommendations and appropriate referrals. It is recommended that infants with single ventricle CHD be evaluated in a neurodevelopmental clinic by 9–12 months of age. Neurodevelopmental clinics can continue to provide longitudinal developmental care through the preschool and school-aged years. If developmental assessments yield concerning gross or fine motor findings, the infant should be referred for PT or OT services, respectively. If the assessments yield concerns with communication skills, then the child should be referred to a SLP. Sites interested in starting cardiac neurodevelopmental clinic programs are encouraged to connect with [CNOC](#).

IV. Intervention Strategies by Developmental Phase:

Table: Intervention Strategies by Developmental Stage to Support Infants with Single Ventricle CHD

This table, organized by infant stages, includes information about typical developmental milestones for all children (as a reference) as well as information specific to infants with CHD: 1) activities for parents and infants and 2) interventions to promote development. It is common for infants with single ventricle CHD to be delayed in meeting developmental milestones. However, information about typical milestone development has been included to support parents' understanding of their infants' developmental progression.

References about typical development (all children):

- AAP web page: [healthychildren.org](https://www.healthychildren.org/English/ages-stages/baby/Pages/Movement-Birth-to-Three-Months.aspx); topics- newborn behavior: <https://www.healthychildren.org/English/ages-stages/baby/Pages/Movement-Birth-to-Three-Months.aspx>
- CDC developmental milestones: <https://www.cdc.gov/ncbddd/actearly/milestones/index.html>
- Pathways.org (has videos of infants demonstrating developmental milestones): <https://pathways.org/all-ages/milestones/>

Please see this [Family Education Sheet on including developmentally supportive activities for 0-6 months](#).

Abbreviations:

DD: Developmental Delay

OT: Occupational therapy

EI: Early Intervention

SLP: Speech Language Pathology

PT: Physical therapy

Age Range or Care Stage	Typical Developmental Milestones	Activities for parents and infants	Interventions / Therapies
Prenatal	General fetal movements with variable sequences that wax and wane in intensity, force, and speed.	Prioritizing maternal health and well-being <ul style="list-style-type: none"> • Rest and sleep • Eating healthy well-balanced diet • Physical activity (walking, yoga) • Spending time with positive support people • Planning for delivery and setting up support plan for hospitalization / Stage 1 surgery 	<ul style="list-style-type: none"> • Mental health care / counseling for family members, if needed • Provide Developmental Plan including ways to bond with infant • Counsel parents about need for close developmental monitoring due to high risk of DD <ul style="list-style-type: none"> • Developmental screening • Cardiac Neurodevelopmental clinic care
Newborn period (Birth-to-Stage 1) <i>(cont'd)</i>	<ul style="list-style-type: none"> • Active movements in the first few weeks are a mix of general movements and reflexes rather than controlled movements • Movements can be jerky or jittery, but should have some variability • Medications, such as prostaglandins, can also cause tremulous movements • Newborns' vision is best about 1 foot in front of them • Infants may look towards familiar sounds and voices • Infants will make attempts to right their head but cannot yet support their heads 	<ul style="list-style-type: none"> • Participate in cares • Learn infant's cues <ul style="list-style-type: none"> • Stress and approach behaviors • Hold and cuddle with infant • Skin-to-skin contact as much as possible (even in the ICU) <ul style="list-style-type: none"> • Participate in calming strategies, such as positive touch, finger holds, containment, or encircled holding if skin-to-skin is not possible • Provide positive/intentional touch and massage • Tummy time when awake and with skin-to-skin holding • Talk to infant <ul style="list-style-type: none"> • Reading books • Narration of daily care routines 	<ul style="list-style-type: none"> • Clustered cares/touch times and four hand cares • Protected sleep • Procedural support <ul style="list-style-type: none"> • Non-pharmacologic (positioning to promote physiologic flexion with hands to face and legs tucked, non-nutritive sucking, containment, skin to skin, sucrose, sensorial saturation) • Pharmacologic • Individualized positioning <ul style="list-style-type: none"> • Utilize the Infant Positioning Assessment Tool (IPAT) • Use of positioning aids to promote developmentally supportive positioning • Oral care with colostrum/breast milk <i>(cont'd)</i>

Age Range or Care Stage	Typical Developmental Milestones	Activities for parents and infants	Interventions / Therapies
Newborn period (Birth-to-Stage 1)			<ul style="list-style-type: none"> · Environmental interventions <ul style="list-style-type: none"> · Cycled lighting with indirect, natural lighting when possible · Low noise exposure · Room temperature · Parental Involvement/empowerment <ul style="list-style-type: none"> · Teaching parents when/how to participate in daily care routines <p>PT and OT can provide:</p> <ul style="list-style-type: none"> · Individualized positioning recommendations · Mobilization and opportunities for active guided movement · Range of motion/stretch/elongation · Positive/intentional touch and massage · Monitoring head shape and postural symmetry · State regulation · Family education on developmentally supportive intervention · Support for oral motor skills and non-nutritive sucking
Interstage (Stage 1-to-Stage 2) [approximately 2 weeks–4 months]	<p>1 month: fixing and following with eyes, building strength in neck to support head control</p> <p>2 months: lifting head up when lying on tummy; examining hands moving in front of face, starting to move hands to mouth; smiling; looking at faces; makes sounds other than crying; reacts to sounds</p> <p>3 months: straightening out fingers (no longer fist); kicking legs; may swipe at objects hanging out of reach; may be able to hold / shake rattle</p>	<ul style="list-style-type: none"> · While hospitalized, continue with above activities, increase activities to infant's tolerance and as allowed by medical equipment · Developmental progression · Encouraging infant's midline orientation and tactile exploration including hands to face, hands to body, hands to clothes, hands to knees, and visual exploration · Gently rolling infant into side lying to promote midline play and to increase tolerance for movement transitions · Tummy time can be continued while held at chest, in lap, or over bolster. · Supported upright sitting with support in front of chin and back of head. As infant gets stronger, move your support to upper back and chest · Follow back to sleep guidelines · Alter head rotation with each sleep if infant has a turning preference · Download the CDC's free milestone tracker app to track infant's progress: https://www.cdc.gov/ncbddd/actearly/milestones-app.html · Engage with EI services and/or additional therapy services once home · Click here for a family education sheet on developmentally supportive activities for parents to do with their 0–6 month old 	<ul style="list-style-type: none"> · Developmental plan at Stage 1 discharge or weekly while inpatient · While inpatient, receive regular PT/OT interventions for developmentally supportive positioning, range of motion, stretching, graduated strengthening activities, monitoring head shape and postural symmetry (i.e., prevent torticollis) · Practice tummy time with families · Send toolkit home with parents with progressive exercises · Referral to state EI program · Consider completing a standardized neurobehavioral or neuromotor assessment, see "Utilizing standardized assessments" section above · Consider referral to outpatient or home health therapies if warranted (i.e. concerning neurologic assessment): PT (gross motor), OT (fine motor, dysphagia/feeding, sensory), and/or SLP (dysphagia/feeding)
Stage 2 post-op period and recovery [approximately 4–6 months] <i>(cont'd)</i>	<p>4 months: makes cooing sounds; turns head to sound of voice; looks at hands with interest; holds head steady without support; pushes onto forearms / elbows when on tummy</p> <p>6 months: likes to look at self in mirror; laughs; blows <i>(cont'd)</i></p>	<ul style="list-style-type: none"> · Participate in cares · Talk to infant <ul style="list-style-type: none"> · Reading books · Narration of daily care routines · Hold and cuddle with infant · Skin-to-skin contact as much as possible (even in the ICU) · Help infant with movement transitions: rolling back to/from tummy, side lying to/from sitting, <i>(cont'd)</i> 	<ul style="list-style-type: none"> · Developmental plan at Stage 2 discharge or weekly while inpatient · While inpatient, receive regular PT and OT treatments for assisting with sensory and motor developmental progression; OT and SLP consults as needed for dysphagia concerns <ul style="list-style-type: none"> · Provide play mat and age appropriate toys while hospitalized · Send toolkit home with parents with progressive exercises <i>(cont'd)</i>

Age Range or Care Stage	Typical Developmental Milestones	Activities for parents and infants	Interventions / Therapies
<p>Stage 2 post-op period and recovery [approximately 4–6 months]</p>	<p>raspberries; takes turns making sounds; reaches to grab a toy; rolls from tummy to back; pushes up with straight arms when on tummy, holds head and upper body steadier when sitting with support, will sit with upper body prop</p>	<ul style="list-style-type: none"> · reaching across midline in sitting, etc. · Tummy time when awake as allowed by medical team · Help infant bring hands to knees and then to feet · Encourage pre-reaching and reaching skills · Supported sitting with less support and short sit positions with transition to supported standing following sternal precautions · Limit screen time (screens not recommended < 2 years of age) · Follow back to sleep guidelines · Complete developmental screening with ASQ at target intervals (6 months for all infants); may start at 4 months if medically stable s/p Stage 2 surgery · Click here for a family education sheet on developmentally supportive activities for parents to do with their 0–6 month old 	<ul style="list-style-type: none"> · Refer to state EI program · Consider outpatient or home health therapies if warranted (i.e. concerning neurologic assessment): PT (gross motor), OT (fine motor, dysphagia/feeding, sensory) or SLP (dysphagia/feeding) · Use completed ASQ to refer for domain-specific further evaluation if infant is not “on target” (e.g., refer to PT for further evaluation if not on target for gross motor)
<p>7–9 months</p>	<p>Gross motor (using large muscles to move)</p> <ul style="list-style-type: none"> · Sits without support · Sits and reaches for toys without falling · Moves from tummy/back into sitting · Starts creeping/crawling (alternating arms/legs) <p>Fine motor (using small muscles in hands)</p> <ul style="list-style-type: none"> · Picks up objects with thumbs/fingers · Explores objects with hands and mouth · Turns several pages in a board book at once · Moves things from one hand to the other · Bangs two things together <p>Social/Interactive</p> <ul style="list-style-type: none"> · Can be shy, clingy, or fearful around strangers · Lifts arms to be picked up · Smiles with peek-a-boo <p>Speech</p> <ul style="list-style-type: none"> · Uses variety of sounds-syllable combinations in babbling · Imitates sounds · Starts to recognize sound of name · Looks at familiar objects/people when named 	<ul style="list-style-type: none"> · Playing in a variety of positions including tummy, sitting, rolling, weight bearing on legs · Place toys out of reach and encourage infant to move to get them · Place toys on surfaces of different heights to encourage changing position from sit-to-stand and cruising · Use toys where an action causes something to happen to the toy or containers and boxes with toys that can be taken in and out. · Respond to infant’s reaching, looking, and sounds by looking back at them, speaking to them, and imitating them · Read books and point out pictures and colors · Talk while doing daily activities (i.e., when dressing say “put on the shirt”, when bathing say “turn on the water” when feeding say “eating crackers”) · Take infant on stroller rides and point out objects by name · Play social games (peek-a-boo, pat-a-cake) and sing songs · Hold and cuddle with infant · Limit screen time (screens not recommended < 2 years of age) · Follow back to sleep guideline 	<ul style="list-style-type: none"> · Refer to state EI program (if not previously referred) · Consider outpatient or home health therapies if warranted (concerning neurologic assessment, delay in motor skills): PT (gross motor), OT (fine motor, dysphagia/feeding, sensory), and/or SLP (dysphagia/feeding) · Complete developmental screening with ASQ at target interval (9 months) & refer for domain-specific further evaluation if infant is not “on target” (e.g. refer to PT for further evaluation if not on target for gross motor) · Refer for evaluation in specialized neurodevelopmental clinic by 9–12 months of age

Age Range or Care Stage	Typical Developmental Milestones	Activities for parents and infants	Interventions / Therapies
10–12 months	<p>Gross motor (using large muscles to move)</p> <ul style="list-style-type: none"> · Pulls to stand and cruises along furniture · Stands alone · Climbs over and around objects <p>Fine motor (using small muscles in hands)</p> <ul style="list-style-type: none"> · Claps hands · Releases toy into a container · Uses thumb and index finger to pick up tiny objects <p>Social/Interactive</p> <ul style="list-style-type: none"> · Enjoys listening to songs · Responds to name <p>Speech</p> <ul style="list-style-type: none"> · Calls parent “mama” or “dada” or another special name · Imitates speech sounds · Understands what “no” means · Uses hand movements to communicate wants and needs · Waves “bye” 	<ul style="list-style-type: none"> · Play in a variety of positions, as above, and on a variety of surfaces that can be found at home or at the park (floor, grass, sand). · Talk to infant about what you are doing (narrate). Use simple commands to increase listening and paying attention <ul style="list-style-type: none"> · “get ball” · “give me” · “put in” · Read books and point out objects and colors · Point to interesting things you see to help infant pay attention to things others are “showing” · Play social games (peek-a-boo, pat-a-cake) and sing songs · Try to redirect infant to new activities when getting into something (save using “no” for unsafe behaviors) · Give infant time to warm up to and get to know new caregivers (bring a favorite toy/ blanket for comfort) · Encourage opportunities for peer social interactions (play group, childcare, story time at library) · Hold and cuddle infant · Limit screen time (screens not recommended < 2 years of age) · Follow back to sleep guidelines · Follow up with Cardiac Neurodevelopmental clinic by 12 months of age · Complete developmental screening with ASQ at 12 months 	<ul style="list-style-type: none"> · Refer to state EI program (if not previously referred) · Consider outpatient or home health therapies if warranted (concerning neurologic assessment, delay in motor skills): PT (gross motor), OT (fine motor, dysphagia/feeding, sensory), and/or SLP (dysphagia/feeding) · Use completed 12-month ASQ to refer for domain-specific further evaluation if infant is not “on target” (e.g. refer to PT for further evaluation if not on target for gross motor) · Refer for evaluation in specialized neurodevelopmental clinic by 9–12 months of age

Special Considerations for Interventions

Sternal & Prone Precautions:

Sternal and/or prone precautions typically exist following cardiac surgery to allow time for sternotomy healing and prevent wound dehiscence and infection.^{xxxix xl} In general, restrictions for lifting under the arms, pulling from the arms, and prone or modified prone positioning are the most common precautions.^{xli} To date, there is not universally acknowledged sternal or prone precautions in practice following sternotomy. Because of this, there is a wide range of practices across cardiac institutions. For example, among the 15 sites participating in the NPC–QIC Gross Motor Improvement Project, 90% of sites limit lifting the infant under the arms and 72% limit pulling the infant by the arms. The timeframe that these precautions are implemented ranges from 1–7 or more weeks with 75% at 5–6 weeks. 27% of participating sites have no formal prone restrictions after surgery and 63% allow prone positioning within 2 weeks of chest closure. Over the course of the project (2019–2022), there were no major shifts in practice in lifting or handling restrictions following surgery, however, prone activity trended towards starting earlier following surgery.

It is important to understand institution–specific guidelines and communicate them clearly and consistently to families. More research is recommended in this area to establish standardized evidence–based recommendations to decrease variation in practice across sites and assist in supporting motor skill progression.

[Click here](#) to see example sternal precautions handouts provided to families.

Vital Signs:

An infant’s diagnosis, surgical interventions, and other variables (medications, comorbidities) influence their vital sign expectations. Heart rate, respiratory rate, and blood pressure should trend with age-matched norms. For the infant with single ventricle CHD, oxygen saturations are typically 75–85%. Continual monitoring of vital sign response compared to each infant’s baseline during activity is important during intervention. Adverse responses to activity include increased work of breathing, retractions, nasal flaring, diaphoresis, color changes, irritability, and post-exertional fatigue. Any adverse responses should be reported to the primary provider team (cardiothoracic surgery, cardiology, heart failure). Tracking an individual infant’s vital signs over time can be helpful in providing a baseline comparison, as well as trends.

Lines & Tubes:

In general, lines and tubes should not limit participation in therapy or developmentally supportive activities. Providing infants with time unswaddled and without mittens allows for extremity movement and self-calming strategies. It is important to double check the security of lines and tubes prior to mobilizing out of bed. It can be helpful to clip lines and tubes to the patient’s gown or clothing to prevent pulling. It is important to remember that line and tube security is every provider’s responsibility. To ensure safety with cares, handling techniques, and transitions, it can be helpful, when appropriate, to educate families and caregivers on how to navigate their child’s lines and tubes.

State Regulation/Physiologic Stability:

Behavioral assessments should be incorporated into all cares. Infants typically exhibit stress as progressive dysregulation of the state, motor, and autonomic subsystems. Recognizing and responding to the infant’s cues can help prevent dysregulation and adverse changes in hemodynamic stability.

State Stress Signs	Motor Stress Signs	Autonomic Stress Signs	Signs of Self-Regulation
<ul style="list-style-type: none">• Gaze aversion• Glassy eyes• Grimace• Hyperalert/staring• Irritability• Rapid transitions between sleep<->wake<->crying• Shutdown	<ul style="list-style-type: none">• Frantic flailing movements• Finger splaying• Generalized hypotonia• Hyperextension of extremities/salute	<ul style="list-style-type: none">• Color changes (pallor, flushing, cyanosis)• Sneezing• Visceral responses (vomiting, gagging, hiccups, passing gas/stool)• Vital sign changes• Yawning	<ul style="list-style-type: none">• Hand-to-mouth• Hand or foot clasp• Grasping• Sucking• Visual fixing on faces

Adverse Neurologic Events:

Children with congenital heart defects are at a higher risk for neurological injuries. It is important to practice observation of patients to monitor for signs of asymmetry, seizures, and atypical movement patterns. Consider providing education to families about signs and symptoms of neurological events, as well as a developmental care plan that is personalized to the patient in the event or presence of a neurological event.

V. A Deeper Dive into Valuable Interventions



Tummy Time

Tummy time is an essential activity to promote an infant's motor skills, including head and trunk control, upper/lower extremity strength and weight bearing. The World Health Organization recommends infants under 1 year of age do at least 30 minutes of tummy time throughout the day^{xlii}. Infants with CHD who did less than 15 minutes of tummy time a day following cardiac surgery demonstrated more motor impairment^{xliii}. Starting tummy time work in the hospital is vital to model its importance to families and may help contribute to greater family comfort with the activity, ultimately improving improved participation with continuing tummy time at home. [Click here](#) to see how Children's Wisconsin increased tummy time practice in the ICU.

There are several ways to facilitate tummy time following cardiac surgery which are listed below in progressive order starting with the activity that is easiest for the infant.

- **Modified tummy time in chest-to-chest position:** The parent or caregiver should sit upright and place infant on their chest. To work on head and trunk control, encourage infant to lift head and turn side to side. The parent or caregiver can use their voice as stimulation to facilitate this. When cleared from any precautions, encourage infant to bear weight and push off their forearms and hands. To progress the infant's head and trunk control, parent or caregiver can recline their body position back.
- **Tummy time elevated on a pillow:** Place infant on a breastfeeding pillow, like a Boppy, with upper extremities tucked into a flexed position for weightbearing. As the infant's skills progress, this position can also work on lower extremity weightbearing and strengthening. Parent or caregiver tucks the baby's knees under their hips. This position can also be used safely with babies with G tubes and/or tracheostomy tubes once good tract formation is achieved.
- **Tummy time over a blanket or towel roll:** Place rolled blanket or towel under chest. Position the infant's arms forward with arms flexed to bear weight on forearms. Provide support at upper arms and shoulders as needed. In the beginning, an infant may also need support and facilitation to lift their head. This is another safe tummy time option for an infant with a G tube and/or tracheostomy tube with good tract formation.



- **Tummy time on a flat surface:** Place infant on a flat surface and encourage them to lift and extend their head to clear airway. Use toys, faces and/or voices to facilitate head rotation to both sides.



Holding and Skin to Skin

Holding a hospitalized infant has the ability to decrease pain and stress and is an aspect of family-integrated developmental care now recommended for infants with CHD^{xliv xlv xlvii}. Skin to skin, also referred to as kangaroo care, is a form of infant holding and refers to when an infant dressed in a diaper is held to a parent's bare chest. Infant holding and skin to skin provides increased physical contact and closeness between the infant and parent and is a safe and feasible intervention for the infant with CHD both pre- and postoperatively^{xlvi}. When true skin to skin is not an option, mobilizing out of bed to be held by a caregiver is a viable option to facilitate many of the same benefits.^{xlvi} Every institution should implement guidelines or protocols to support routine holding practices while the infant is hospitalized.^{xlvi} These guidelines support bedside care providers to identify patients appropriate for holding and safely engage in holding practices. Skin to skin is also an activity that should be continued after the infant transitions home and demonstrates benefit until the infant is 3–6 months of age. [Click here](#) to see transfer methods and safety strategies to support holding in the ICU.



“There is no feeling like the feeling of holding your world in your arms.”

– Michelle Gross

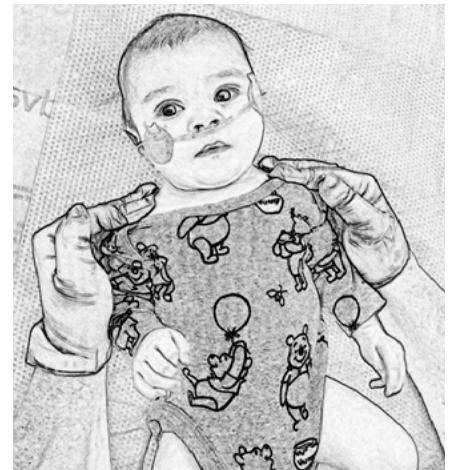
Range of Motion Exercises

Range of motion exercises involve the movement of joints, either passively or actively, through their available range in order to promote joint mobility, prevent contractures, and improve comfort. Passive range of motion exercises are a form of early mobility for an infant with CHD, especially in the early postoperative time period when their mobility may be otherwise limited. Passive range of motion has been proven a safe and feasible exercise to be performed on infants with single ventricle CHD in the immediate postoperative period and could be a promising intervention for improved growth in this population¹. When completing range of motion exercises when infant is actively resisting the movement and complete full range as able. For more information on how passive range of motion is being studied in the single ventricle CHD population, [click here](#). Complete full range as able: Repeat 10–15 repetitions at each joint as tolerated, and perform on each side. This is a great opportunity to incorporate positive touch and massage, especially to infants who are sensitive to touch, resist movement of their limbs, or who have increased stiffness. Range of motion should be a gentle and enjoyable experience for the infant.

- **Neck:** Begin with infant's head in neutral position making sure head is not flexed forward or extending backwards. Place one hand on top of infant's shoulder and use opposite hand to facilitate head rotation in preferred direction.



- **Shoulders:** Begin with infant in a supine position and place hands on top of infant's shoulders providing downward input to facilitate shoulder depression. This encourages shoulders to move away from the neck and ears. When a child is no longer on sternal precautions, hold infant's hand/wrist and guide arm at the elbow to bring up above head in a "so big" position.



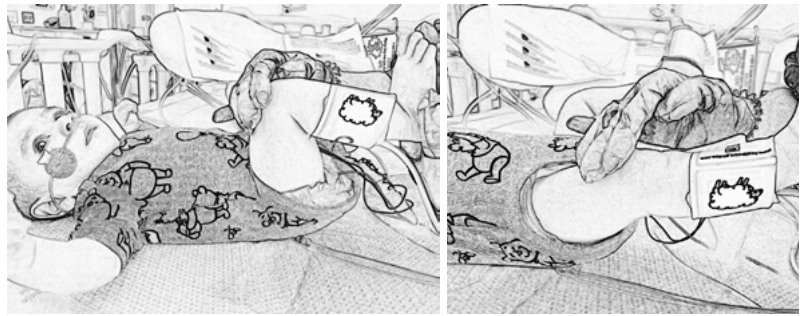
- **Wrist/hand:** Hold infant's hand in palm and move wrist up and down. If an infant rests in a fist position, gently open hand by straightening fingers and guiding thumb outside of palm.



- **Pelvis/hips:** Place cupped hands under infant's bottom at hips and guide the hips to the right and left creating a side bend position in the direction of the stretch. Then use cupped hands to bring lower body into a knees to chest position with back remaining on surface.



- **Knee/Ankle:** Place hands below infant’s knees to move legs in an up and down “bicycle” movement. Encourage full range of knee into a straight and bent position. For ankle range, hold infant’s foot at back of lower calf and at mid foot. Encourage an up and down motion to point toes and pull them up towards the calf.



Equipment Considerations

There are a variety of equipment options available for infants during hospitalization and after discharge home. These recommended equipment options are designed to promote optimal infant positioning, state regulation, provide proprioceptive input and environmental interaction. Available equipment will vary by institution and are not considered vital for parents to purchase for home use, as each infant’s preference will vary. When using devices, always ensure spinal and pelvic alignment are maintained and that the infant is provided opportunities to bring hands to midline for play. Many of these devices provide important upright developmental experiences for the infant during a time when the infant might lack the strength and skill to maintain upright positions on their own. However, these devices can also inhibit infant movement, and their overuse can contribute to developmental delay. When home, it is important to limit time in these devices to not longer than 20 minutes at a time, no more than twice daily.

Recommended Equipment	Equipment to be Avoided
<ul style="list-style-type: none"> • Blanket • Swaddle/sleep sack • Mobile • Sound machine on low volume • Mirror • Activity gym with age-appropriate toys • Swing • Infant seat (stationary vs rocking) • Highchair • Exersaucer • Infant carriers with appropriate hip positioning • Wedges • Baby activity seats in moderation and with close supervision 	<ul style="list-style-type: none"> • Screen time • Door frame jumper • Sound machine in isolette • Baby Walker



VI. Quality improvement: Gross Motor Improvement Project

Project History and Detail

The NPC-QIC Gross Motor Improvement Project, a multicenter quality improvement project, was designed to improve gross motor outcomes for infants by 12 months of age. The project was presented to the network in March 2019 with an invitation for interested sites to enroll. Fifteen NPC-QIC sites applied to participate in the project, completed a site characteristics survey regarding baseline neurodevelopmental practices, and began forming their local teams. The project was formally launched in January 2020. Sites participating in the project committed to increasing rates of developmental screening (ASQ completion) for infants enrolled in NPC QIC and testing interventions to support inpatient and outpatient interventions to address gross motor development for infants. It was hypothesized that by better supporting infants' development, there would be an improvement in overall gross motor development scores at age 12-months, measured by the ASQ. To maintain site engagement, bimonthly webinars were held over the course of the project where data was reviewed, sites shared their own gross motor PDSA cycle findings, quality improvement fundamentals were taught, and parents shared their personal perspective on gross motor topics. The project concluded in September 2022.

This section includes a summary of the project, including the aims, key driver diagram, run charts of outcome measures, and a summary of our challenges, successes, and lessons learned.

Global Aim:

- Decrease mortality and improve quality of life for infants with single ventricle congenital heart disease and their families.

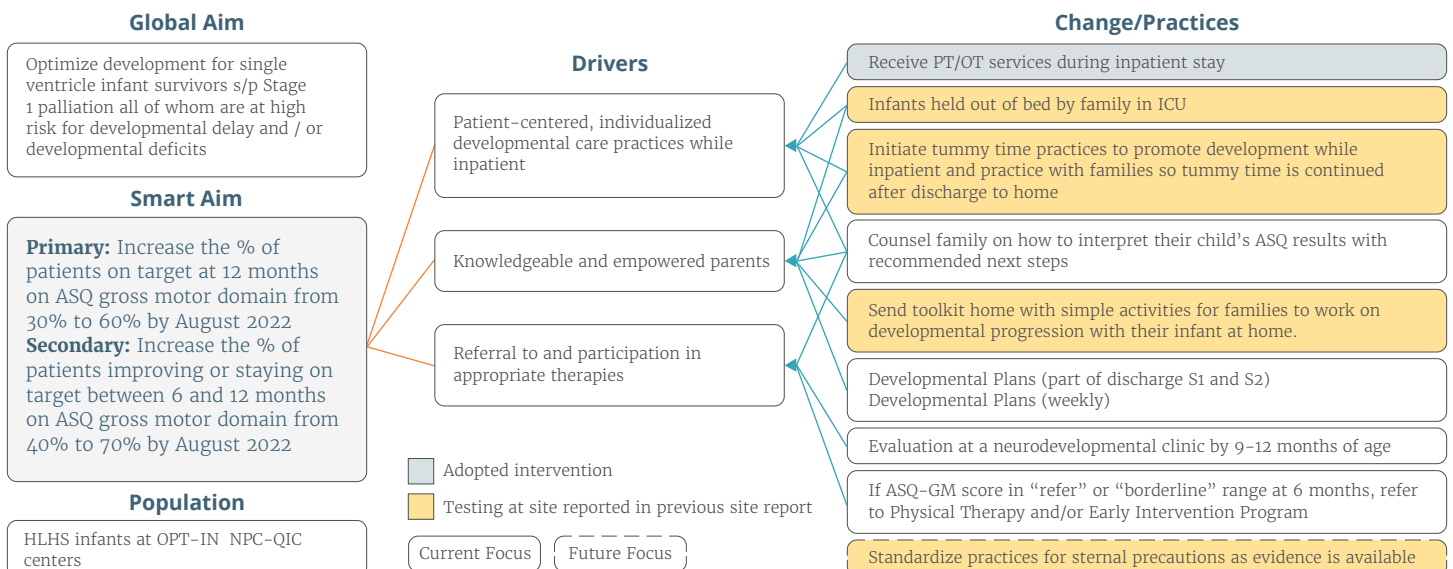
Smart Aims:

Improve gross motor development skills by 1 year of age as measured by:

- Increase the percent of infants scoring in the “on target” range on the ASQ Gross Motor Domain at 12 months of age
- Increase the percent of infants shifting to an improved category from 6 to 12 months on the ASQ Gross Motor Domain

Key Driver Diagram

Gross Motor Improvement Project



Foundational Requirement: Adhere to ASQ Screening

Revised 10/16/2021

Project Data

Project Timeline

Q3 2017 – Q1 2019	Q2 2019 – Q4 2019	Q1 2020 – Q3 2022
Pre-Project Baseline Data Period	Project Design	Active Project Work

Improvement Approach:

Step 1: Reliably complete ASQ screening at 6 and 12 months

Step 2: Reliably complete a developmental plan at critical timepoints (Stage 1 and 2 discharge)

Outcome Data

ASQ Screening Completion: Process Measure & Foundational Requirement

As a foundational requirement for participation in the Gross Motor Improvement project, sites were given a target of achieving level 1 (80%) reliability for the completion of ASQ surveys at 6 and 12 months. Without consistent ASQ screening data collection, detecting a change in the primary aim is challenging due to small sample size. Collection of the ASQ, which is the first parent-report measure incorporated into NPC QIC, was challenging for many sites due to the system for sending and collecting ASQ screeners, the need for parents to administer the screening tests, and the amount of work required at the site level to send out the screeners at the right time and track responses from parents. Across the NPC QIC network <20% of infants complete the 12-month ASQ. Among the 15 participating sites, a 33% ASQ completion rate was achieved, better than the network as a whole but below the target of level 1 reliability. See Figure 2 comparing ASQ completion in sites not participating vs. participating in the Gross Motor Improvement Project.

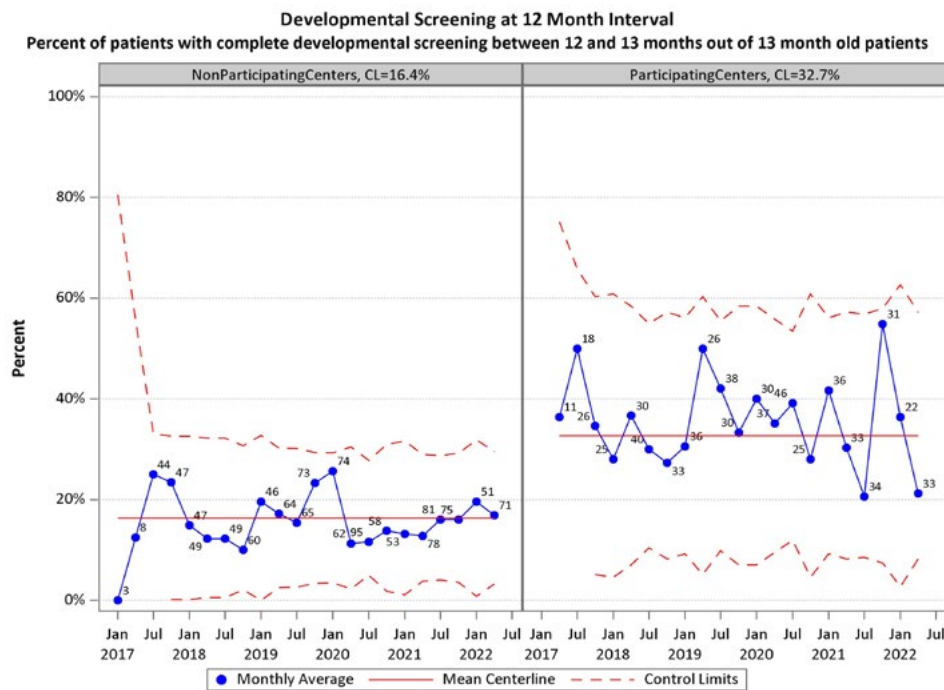


Figure 2: % of infants with completed ASQ at 12 months (Project Process Measure)

ASQ Gross Motor Scores: Primary Outcome Measure

The primary outcomes for this project were improvement in 1) the percent of infants scoring in the “on target” range on the 12-month ASQ Gross Motor domain (see Figure 3) and 2) the percent of infants improving to a better result category on the 12-month ASQ Gross Motor domain at 12 months relative to 6 months (see Figure 4). No changes in these outcomes have been achieved.

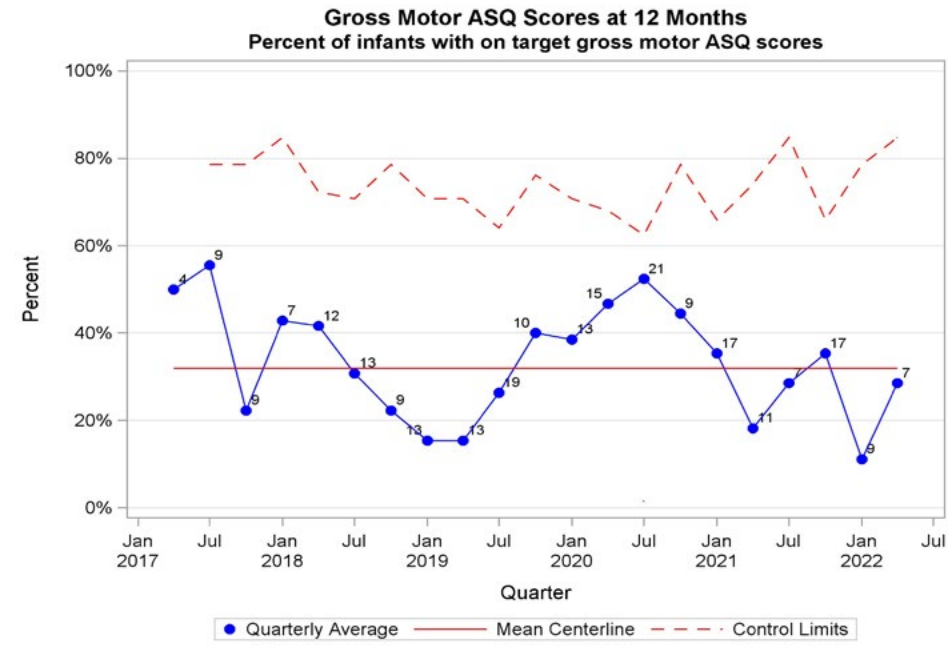


Figure 3: % of infants on target at 12 months (Project SMART Aim)

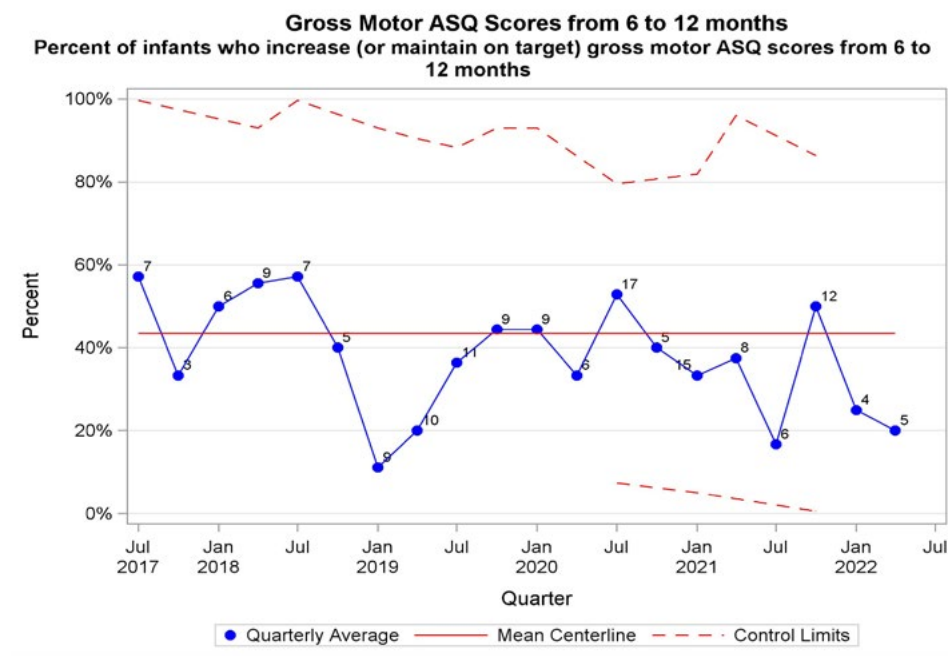


Figure 4: % of infants improving ASQ scores from 6 to 12 months (Project SMART Aim)

Developmental Plans: Process Measure

Reliable completion of Developmental Plans at the time of discharge from Stage 1 and Stage 2 surgeries was a process measure that sites worked to achieve. Developmental Plans are written, up-to-date documents shared with parents documenting the infant's developmental goals and treatment approach, such as therapies, tummy time goals, or progressive exercises for families to work on. Participating sites have nearly achieved level 1 reliability for the Stage 1 discharge time point and currently are at 69.5% for Stage 2 discharge developmental plans.

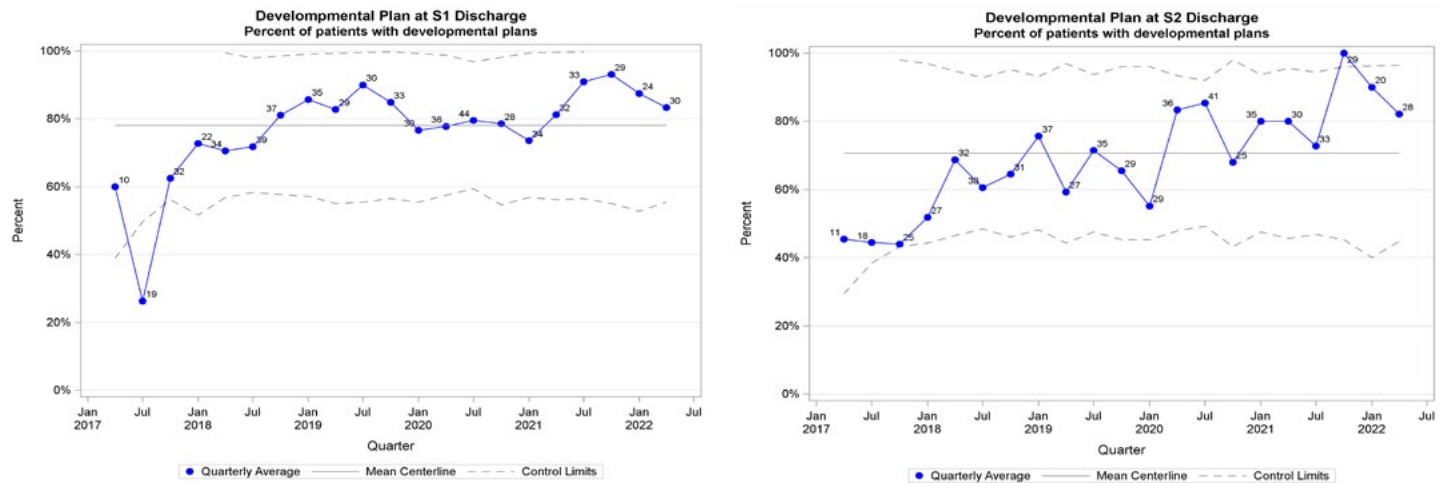


Figure 5: % of infants provided with developmental plans at Stage 1 and 2 discharge

Conclusions: Project Learnings

Although the Gross Motor Improvement Project teams did not achieve improved gross motor scores on the ASQ for infants at 12 months of age during the project, this work has contributed to improved understanding of gross motor development and strategies to optimize developmental care for infants with single ventricle CHD.

Successes:

- Developmental Plans: participating sites have nearly achieved level 1 reliability for the Stage 1 discharge time point and currently are at 69.5% for Stage 2 discharge developmental plans. This means that parents now receive individualized written plans with strategies to support their infant's development when they are discharged home from the hospital.
- Although reliably completing parent reported ASQ screening is a challenge, by using QI methodology to test intervention strategies, sites can improve their ASQ completion rates.
- Parental involvement in this project was a key component and strongly encouraged throughout. There was a dedicated webinar for parents to share their perspective on gross motor topic which was so impactful that a parent share was included in each subsequent webinar.
- The sharing of PDSA cycles, innovative practice ideas, and program development promotes an environment of collaboration and learning of benefit to all participants.
- Having the accountability of a formal QI project increased ongoing site participation in PDSA cycles and may assist with the maintenance of this work even after project conclusion.
- While this project focused on interventions for the single ventricle CHD population, interventions implemented can be applied to assist all infants with CHD.

Reflections: Challenges & Opportunities

- A multicenter QI project aiming to improve gross motor outcomes is feasible. The collaborative nature of this project facilitated teaching and learning opportunities between participating sites resulting in shifts in developmental care practice and reducing variation in care. These shifts in practice were noted in several areas, including more sites implementing a formal infant holding protocol in the ICU, fewer tummy time restrictions following surgery with more sites starting tummy time earlier, increased family involvement in practicing tummy time while inpatient, earlier follow up in cardiac neurodevelopmental clinic by 12 months of age. These processes certainly contribute to improved care of these infants and their families. You can view highlights from the pre and post site characteristic survey results [here](#).
- Reliably collecting the ASQ is challenging. Even the highly committed sites of this project had difficulty increasing data collection rates. Site resources dedicated to this are often limited and many parents report finding the ASQ burdensome to complete while caring for a medically complex infant. Without a robust sample of ASQ scores, it is challenging to truly understand how our project interventions influence developmental outcomes. [See examples](#) of different PDSA cycles centers shared in the project to increase collecting ASQ scores.
- With small N's, improvements in ASQ scores from 6 to 12 months may be slow to be detected.
- Our outcome measure of improving gross motor scores at 12 months of age may be too early to observe improvement in gross motor outcomes. We hypothesize that many infants might continue to experience gross motor delay that will improve by 15–18 months. Unfortunately, the data to support this with ASQ scores is not available from the NPC–QIC registry.
- The project started at the onset of the COVID–19 pandemic, where resources to support project interventions were even more scarce. The impact of COVID–19 on this project is difficult to measure as it effected healthcare delivery, staffing, parent's ability to be present at the bedside, and mental health. Despite the challenges presented by COVID–19, participating project sites maintained engaged in the project to the best of their ability.
- [Click here](#) to see examples of project PDSA cycles
 - Wisconsin, June 2020 webinar—tummy time competition
 - Advocate, August 2020—increasing tummy time/ handout
 - Iowa, June 2020 webinar—bedside tool
 - Primary Children's, May 2021 webinar—bedside tool
 - Boston, December 2020 webinar—developmental care

“Our ND team has been able to put processes in place to improve ASQ collection, developmental plans, parent education of developmental activities that are sustainable for our team. By collaborating with and learning from other institutions participating in the project, we have gotten so many additional ideas to enhance our program.”

– Gross Motor Improvement Project Participant

VII. Acknowledgments

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Pilot Sites

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- Boston Children’s Hospital
- Children’s Hospitals and Clinics of Minnesota
- Children’s Medical Center Dallas
- Children’s Hospital Colorado
- Children’s Hospital Los Angeles **Center participating with no data collection*
- Children’s Hospital of Philadelphia
- Children’s Hospital of Pittsburgh of UPMC
- Children’s Hospital of Wisconsin
- Nationwide Children’s Hospital
- Nemours Cardiac Center, A.I DuPont Hospital for Children
- Nicklaus Children’s Hospital
- Phoenix Children’s Hospital
- Primary Children’s Hospital
- St. Louis Children’s Hospital
- University of Iowa Stead Family Children’s Hospital

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