



"As a parent, I would want to understand sooner rather than later if my child was having developmental challenges. I would imagine with the results, they would also give tips on how to correct it. I personally think it's a great idea to intercept any development delays as soon as possible. This would not add any additional stress. I think this would be one of the easier things to do compared to all the meds/feedings/etc. Doing this in the comfort of the home definitely makes it doable."

-Father of a baby with HLHS, 7 weeks after Glenn surgery



DEVELOPMENTAL PLAN

Name of Hospital Medical Center

A Developmental Plan is a written document designed for each patient indicating his or her current developmental goals, activity restrictions that the family or therapists should be aware of when working with the infant, and a list of current and recommended therapies and services.

Supported by the National Pediatric Cardiology Quality Improvement Collaborative

"The NPC developmental screening initiative is a very important way for parents of high risk infants to learn about their child's development and to engage their children in intervention services as early as possible. This aligns well with the goals of the Cardiac Neurodevelopmental Outcome Consortium (CNOC) and the American Heart Association/ American Academy of Pediatrics Scientific Statement from 2012. It will encourage families of infants with CHD to recognize their child's developmental needs and facilitate families pursuing formal evaluations in neurodevelopmental clinics by 9-12 months of age."

-Bradley S. Marino, MD, MPP, MSCE, Heart Center
Co-Director, Ann and Robert H. Lurie Children's
Hospital of Chicago



NATIONAL PEDIATRIC CARDIOLOGY
Quality Improvement Collaborative



Neurodevelopmental Plan: Diagnosis to Stage I



{Name of Hospital Center}

[BABY'S NAME]'s Developmental Plan

Date: _____

One of the best ways to support your baby's development is to take care of yourself first. Here are some ideas:

- Get plenty of rest, sleep when you are able to
 - Eat a healthy, well balanced diet
 - Try to get some physical activity every day (go for a walk, exercise, yoga)
 - Spend some time with positive support people in your life
 - Other:
-



After your baby's heart surgery you will receive a plan with ideas of how to support your baby's development. Here are some things that you should know:

- Babies with congenital heart disease are at risk for having developmental delays.
- We will monitor your baby's development closely.
- We will give you suggestions that will help support your baby's development.
- Your baby will benefit from therapies such as feeding therapy or physical therapy.
- All babies with your child's heart condition should be referred for Early Intervention Services in your state. We will help with this.
- All babies with your child's heart condition should have an evaluation with an expert developmental specialist between the ages of 9-12 months old, *even if your baby seems to be doing well developmentally and meeting milestones*. We will help set this up.
- If babies get the right help early on – they will have the best developmental outcomes possible!

Here are some activities for you to do with your baby while in the hospital: (Note: can be customized depending on child's age / restrictions / developmental status; recommend including appropriate Learning Activities and Intervention Activities handouts)

- Read books to your baby every day
- Talk to your baby every day
- Hold and cuddle with your baby as much as possible when allowed by the medical team
- When your baby's doctor says it is okay, let your baby have lots of "tummy time" when awake
- Put your baby to sleep on his or her back

Who should I call if I have questions about my baby's development?

[Name], [role, title], phone number: xxx-xxx-xxxx, e-mail: xxx@xxx.org