



"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



NATIONAL PEDIATRIC CARDIOLOGY
Quality Improvement Collaborative



{Name of Hospital Center}

[BABY'S NAME]'s Developmental Plan

Date: _____

My main goal for my baby's development in the next months is:

(this could include feeding, developmental milestones-tolerating tummy time x 5 min / rolling over, emotional/ behavioral goals)

Medical Tests and Health Screening:

- Hearing test: date completed: _____
 - Pass
 - Fail
- Genetic Testing:
 - Newborn Genetic Screen (State testing)
 - Karyotype / Chromosomes
 - Microarray (SNP)
 - FISH 22Q11
 - Other: _____



Things to be careful about when working with my baby (activity restrictions):

(e.g. is baby allowed to be placed on sternum / do tummy time, allowed to feed orally?)

For how long?

Things that I should be working on with my baby every day:

- 1) **Tummy time** for 5 minutes at a time, 3 times day (may need to work up gradually)
- 2) **Read** at least 1 book to your baby every day
- 3) **Talk to your baby** about what you see him/her doing and about what is around you
- 4) Sit on the floor and **play** with your baby, sing songs
- 5) Other:

Ways to help my baby feel calm:

(e.g. pacifier, rocking, listening to music)



{Name of Hospital Center}

Current Therapies:

- State Early Intervention program

Please ask for the name and specialty area of your baby's therapists:

Name: _____ Specialty: _____

Name: _____ Specialty: _____

Name: _____ Specialty: _____

- Outpatient** or **Inpatient**:

Type of Therapy:

What we are working on:

- Feeding therapy:
- Physical therapy (PT):
- Occupational therapy (OT):
- Speech therapy:
- Other:

Recommended therapies for your baby to start:

- State Early Intervention program

- Outpatient** or **Inpatient**:

Type of Therapy:

To work on:

- Feeding therapy:
- Physical therapy (PT):
- Occupational therapy (OT):
- Speech therapy:
- Other:

Recommended Medical Tests and follow up visits:

- Cardiac Neurodevelopmental Clinic: _____
- Hearing test: _____
- Genetic Testing: _____
- Other: _____



{Name of Hospital Center}

Who should I call to schedule therapies / services?

- Early Intervention program (all infants should be enrolled):** The Early Intervention Program in the state of {XXX, ex: Ohio} is called {XXX, ex: Help Me Grow}. The phone number for this program is: {1-800-XXX-XXXX} and their website is: {www.XXX}.
- Please call the following phone numbers to schedule evaluations or therapy if recommended above:**
 - **Physical therapy:**
 - **Occupational therapy:**
 - **Speech / language therapy:**
- Cardiac Neurodevelopmental Follow up clinic:** At {XXX, ex. Cincinnati Children's Hospital Medical Center} we have a specialized, multi-disciplinary cardiac neurodevelopmental clinic which includes: {a developmental pediatrician, a psychologist, OT/ PT, a social worker, a nutritionist, an education specialist, and a cardiologist}. Please call to schedule an appointment in our neurodevelopmental clinic for your baby to be evaluated by 9-12 months of age. The phone number is: {XXX-XXX-XXXX}.

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

- {Name of contact person}, {Role/ Title} at Phone: {XXX-XXX-XXXX}, e-mail: xxx@xxx.org.
- Also, please talk to your baby's primary care doctor about your baby's development.

"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**

