EDUCATE YOURSELF
Knowledge is power. The more you can learn about your baby’s CHD and any developmental issues that might come with it, the better prepared you will be and the more confident you will feel working with your child to reduce developmental and learning issues and making decisions as your child grows.

SEEK SUPPORT
Dealing with developmental, learning and behavioral issues can be very difficult and emotional for parents. It can help to put a support system in place. Your child’s healthcare team can be helpful in providing support and recommending support resources. You may have resources in your local area or state. Also, there are support groups for parents who have been through similar experiences and can provide support from someone who has been there.

GET SCREENING AND TREATMENT
If you have a child who is at risk for neurodevelopmental issues, you will want to make sure your child is screened at recommended times. (See the Development and Education form in this Guide.) If you are near a children’s hospital that treats children with severe congenital heart disease, check to see if they have a neurodevelopmental program. If not, you may be able to find a developmental pediatrician or other specialist who can screen your child and suggest treatment. Be sure to, follow up on recommended treatment as soon as possible.

FOLLOW YOUR INSTINCT
If you feel like your child isn’t developing correctly, having problems learning, or having behavioral issues that seem different than other children your child’s age, talk to your child’s doctor or healthcare provider. Many parents believe these issues may be just part of their heart condition or what happens after surgery, and this may or may not be true. Don’t feel like you are a problem if you ask questions and check out your concerns. Most healthcare providers want you to ask questions and share concerns.

BE HAPPY WITH PROGRESS!
Don’t measure success by comparing your child with other babies or children your child’s age. It’s easy to get caught up in a tangle of what your child “should be able to do.” Every child is different, so don’t use other children, even your own other children, to figure out what is right for your child. Instead, focus on even small accomplishments and the things your child is able to do. This is what is most important.

Finally, if you feel frustrated, overwhelmed or are unable to manage, call your child’s doctor so he or she can help you find support. Don’t be afraid to get help if you need it. Also, sometimes, children will need additional help or care, and getting that help as early as possible is important.