Getting the Best for Your Special-Needs Baby

BY KRISTEN DE DEYN KIRK

Being a parent is overwhelming, no matter how well you've prepared with supplies, classes and advice.

And if you've also learned that your child will face a lifetime of extra challenges due to a disability, you can be even more frantic and nearly crushed with concern and confusion: What type of medical support will be needed? How will you know the care is the right care? Who will pay for it? Is your home equipped correctly for your child's safety? What happens when school starts? Will the teachers really know how to help? Will the school administrators make the extra support available?

Maureen Heald, a mother of 9-year-old twin boys with cerebral palsy, and JoAnna Bryant, a mother of a 13-year-old boy with autism, have been there. The two now work to help other parents through the maze of educators, doctors and administrators who are supposed to, but don't always know how to, care for children with disabilities. Heald does so as a parent support coordinator at Children's Hospital of the King's Daughters. Bryant also works at the hospital as a parent coordinator and serves as president of the Tidewater Autism Society of America. When talking with parents, they recommend the following so that special-needs children can have the best life possible:

• Grieve. Learning about your baby's disability is an emotional time and you should feel whatever it is you're feeling. Be honest with yourself and your mate.

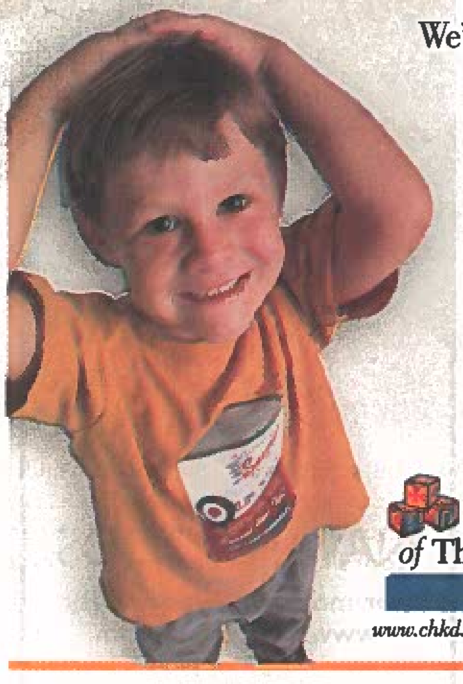
• After your child is born, he or she might be placed in the neo-natal intensive care unit. Get familiar with the room and how it is set up. Learn what all the acronyms you're hearing stand for and educate yourself on the other words doctors and nurses keep saying.

• Learn about the disability – to a degree. "Don't read beyond what you need to know," says Heald. Pay attention to what the doctor said specifically about your child's condition and look into information about that only. Otherwise, you could read about things that don't apply in your case and waste energy and time and cause yourself extra worry. As your child grows, attend conferences to learn more about his or her condition and connect with other parents.

• Join a support group. You'll start to hear about Federal laws and "Part C" and "Part B" and IDEA – the Individuals with Disabilities Education Act, and lots of confusing terms, and you will get confused. "Connecting with other parents helps you locate hidden services," says Bryant. "Veterans can help you find and navigate community and educational services. They guide you through and tell you what worked for them and what didn't. Knowing that, you can make your own decisions." Heald appreciates the emotional support a group provides as well. "It's very lonely," she says about being a parent to special-needs children. "You don't feel you have peers. Your neighbors with children aren't your peer group, and you're constantly reminded of that. At one time there weren't that many groups out there, but I found one through early intervention services."

• Be diplomatic. It's hard talking to educators, medical providers and insurers. You will probably cry, or at least want to cry, during meetings, but you can keep your calm if you're determined to do so. Remind people that you've known your child the longest and you know him or her best. Doctors are busy and can often only spend a maximum of 10 minutes with your child. Be sure you're making medical decisions as a team.

• Be honest, too. You'll feel better and probably educate the people



you're talking to. Heald remembers one insurer telling her that she understood her effort to get wheelchairs for her sons, because the woman's grandmother was in a wheelchair. "I let her know that the two situations were very different. She got my point," Heald recalls.

- Bring a professional advocator with you to meetings. Heald appreciated support that she got from a teacher at Children's Hospital. The teacher knew her sons and knew the laws so she was able to make points with both professional and personal points of view.

- Talk to your child's teacher. "You lead your child's education up until the point that you meet a [formal] educator," says Bryant. "You must tell the teacher what makes your child tick." After your initial meeting, you'll need to continue to develop a close relationship. This happens by giving the teacher your respect and spending regular time talking with each other.

- Remember to advocate in your own home. Heald says she spent eight years trying to make Christmas "okay" for one of her sons. She finally figured out the magic formula: Let him do what he wants. "It might mean letting him stay in his room if it all gets to be too much," she says. "That's what he wants and that's what's best for him. Learn to meet your child where he is (emotionally and mentally.)"

- Take advantage of Federal, state and private services. Bryant found help though the Center for Independent Living and the Community Services Board, and she investigated preschool services and waivers that are available through the state. She secured funding for what she calls respite care, someone who will come to her home twice a month to be with her son, so that she and her husband can spend time together. She also has someone come into her home and help her son with life skills, such as learning how to make a bed. Somehow, you have to find a way to be both patient and persistent. Bryant waited two years for one of the waivers, but never gave up the effort.

- Seek help for your relationship if you need it. Heald thinks the risk of divorce goes up 25 percent if your child is in the neonatal intensive care unit and even more if your child has a lifelong disability. The stress can tear you and your mate apart or bring you closer together – if you learn how to communicate and support each other. bg