Introduction
There are 11.2 million CSHCN in the United States, representing 1 in 5 US households. The Maternal and Child Health Bureau (MCHB), part of the US Department of Health and Human Services, Health Resources and Services Administration, helps CSHCN and their families by administering programs and policies such as State Title V and MCH Programs, Community Health Centers, and Medicaid. Since 1989, MCHB has worked with State Title V and other partners to implement a common agenda for CSHCN:

Provide and promote family-centered, community-based, coordinated care for children with special health care needs and facilitate the development of community-based systems of services for such children and their families.¹

What is Family-Centered Care?²

Family-Centered Care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice which results in high quality services.

The foundation of family-centered care is the partnership between families and professionals:

- Families and professionals work together in the best interest of the child and the family. As the child grows, s/he assumes a partnership role.
- Everyone respects the skills and expertise brought to the relationship.
- Trust is acknowledged as fundamental. Communication and information sharing are open and objective.
- Participants make decisions together.
- There is a willingness to negotiate.

Who are Families of CSHCN?³

We all come from families. Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, or as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support.

As family members, we nurture, protect, and influence each other. Families have strengths that flow from individual members and from the family as a whole. Each family is a culture unto itself, with unique values and its own way of realizing dreams.

Together, our families are the source of our rich cultural heritage and spiritual diversity. Our families create neighborhoods, communities, states, and nations.
Families have long known that their relationship with their child’s doctor is fundamental in ensuring quality health care. This perspective has been substantiated by a growing body of evidence from scientific studies that demonstrates the benefit of family-centered care to the patient, the family, the provider and others. Highlights of this evidence are provided below.

How Does Family-Centered Care Benefit Families and Patients?

- Decreased anxiety
- Accelerated recovery time
- Better patient coping during procedures, hospitalizations, and recovery periods
- Increased parent confidence and problem-solving capacity

How Does Family-Centered Care Benefit Pediatricians and Other Providers?

- Improved clinical decision making on the basis of better information and collaborative processes
- Improved follow-through when the plan of care is developed collaboratively with families
- Greater understanding of the family’s strengths and caregiving capacities
- More efficient and effective use of professional time and health care resources
- Improved communication among members of the health care team
- An enhanced learning environment for future pediatricians and other professionals in training

What Can Families do to Initiate or Improve Family-Centered Care?

Because family-centered care starts with a strong family/provider partnership, the following tips may help you develop skills to be an equal, respected partner. More information is provided in the Family Voices publication Families Partnering with Providers, available on the Family Voices website.

1. **Be confident in the knowledge you have about your child.**
   You are your child’s primary care-giver. You know your child the best. You sense when something is wrong. You observe how your child feels, what makes him worse and what makes him better.

2. **Organize and keep information up-to-date about your child.**
   Keep a care notebook on your child, as it will help organize and store information to share with your child’s providers. Download a care notebook from: http://cshcn.org/planning-record-keeping/care-notebook.

3. **Educate yourself about your child’s diagnosis and medical treatment.**
   Be an educated consumer. Read as much as you can and talk with others who can help you.

4. **Communicate openly with your child’s provider.**
   Be honest with your child’s provider. Ask questions when you don’t understand. Ask your child’s provider for additional resources that would help your child and/or your family.

5. **Connect with other families.**
   Other families have been down the same road and connecting with them may provide information and support. Start by contacting your state’s Family-to-Family Health Information Center. Visit the Family Voices’ National Center for Family/Professional Partnerships website for contact information: http://www.fv-ncfpp.org.

6. **Be an advocate.**
   Some parents say that being a mom or dad also means being a chauffeur or a coach or any number of other roles. If you are a parent of a CSHCN, then you also need to be an advocate. Speak up for your child and help him to advocate for himself. Join with others to advocate for all CSHCN.

7. **Learn more about Family-Centered Care.**
   Family Voices has developed tools to help you and your child’s provider better understand and implement family-centered care. Download the FCC Tools from the Family Voices website: http://www.familyvoices.org.