It is difficult for others to fully comprehend what families of children with special health care needs struggle with on a daily basis. To address this lack of understanding, a mom of a child with special health care needs created the concept of a Care Map to help communicate the "bigger picture" of her family's specific situation to the individual pieces that make up the larger puzzle.

The Care Map is a tool to give the various parts of your "team" a glimpse into your life beyond just the part they may play.

- 1. Getting started The most important step is getting started. It will take you a few attempts to figure out how you want your Care Map to look. Even while it is a work in progress, your child's Care Map can be a valuable tool. Get started!
- 2. There is no "wrong way" to make a Care Map. Your Care Map will be as unique as you and your family. It will be different from others, but that doesn't make it "wrong"... it makes it YOURS!
- **3.** Keep it simple. Your Care Map will be a "snapshot" view at the various pieces of the puzzle that make up your family's life. It isn't about the little individual details ... it's about the big picture. Keep the details basic so the Care Map can help "tell your story."

4. Creating your child's Care Map:

- a. Starting with plain paper and a pencil, in the center draw a small circle. Next, write your child's name in this circle. (Note: For our example on the reverse side, we have used circles, but you can use any shape you choose when building your Care Map. You may find it helpful to trace objects, such as building blocks or other items around the house, when drawing your Care Map.)
- **b.** Draw a larger circle surrounding your child's circle. This is where you will write the names of the rest of your family/household. The "Family" circle should be the center of the page with room to "build off" in all directions.
- c. Now you will begin to add circles to represent the other pieces of your child's care team. Draw lines from the "Family" circle that will connect the additional categories that are part of your child's life. You may choose to use different shapes or colors to emphasize the various areas of your Care Map. (Suggestions would be broad categories for School/Education, Medical, Extracurricular Activities/Clubs, Agencies, Support Groups/Organizations, Financial, etc., as applicable to your child and family.)
- d. You will then connect smaller circles to represent subcategories that you will connect to these broader categories. (Example: From the "Family" circle, you have a line going to a category labeled "Medical." From "Medical," you may have lines connecting to smaller, surrounding subcategories/circles with labels such as "Pediatrician," "Oncologist," "Endocrinologist," "Dentist, "Ophthalmologist," etc.)

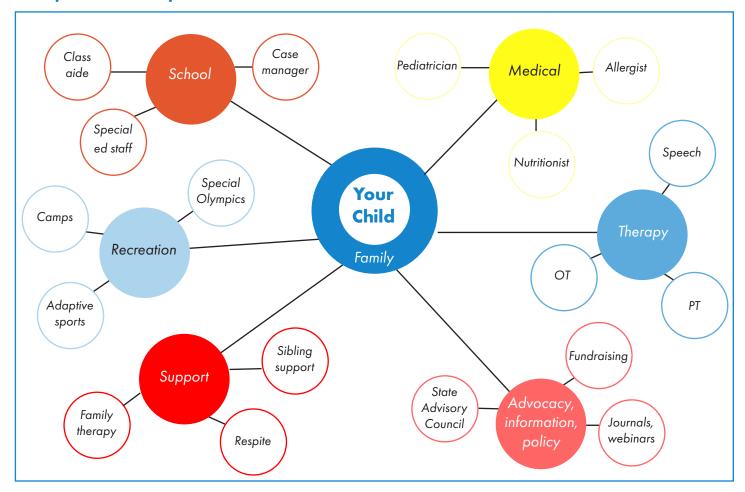
e. If you have any subcategories that need to be broken down further, you will follow the same step as before and build off that circle with smaller, supporting categories.

By now, you should have a good representation of the various pieces that play an important role in the caretaking of our child, but you can continue to make adjustments as needed. You will need to edit and update the Care Map periodically as your child's life changes over time.

Make copies of your completed Care Map so that you can easily share it without having to reproduce it each time. It is recommended that you share your Care Map with your child's doctors, IEP team, etc. The Care Map is a tool that may give these individuals – and even you! – a better understanding of the many, many pieces that create the beautiful picture that is your child's life.

For more information on Care Mapping, visit http://www.childrenshospital.org/ integrated-care-program/care-mapping.

Sample Care Map





This information is provided by Family Voices of Alabama and the Family-to-Family Health Information Center.

To learn more: <u>www.familyvoicesal.org</u> • 877-771-FVOA (3862)

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