

Sibling Sensitivity

By Polly Roberts

Parents of children with disabilities put much of their energy into maximizing their child's potential. Their primary focus is on making sure their child receives proper care, progresses and meets treatment goals, adjusts socially, succeeds at school...the list goes on and on.

But these parents face another, equally difficult, challenge: understanding and meeting the needs of the other children in their family. Like their parents, siblings of children with disabilities often wonder why this is happening to their family or why this has happened to their brother or sister instead of them. "They start to realize, 'My family isn't like every other family,'" said Crystal Tucker, an inpatient social worker at Children's Hospital of Richmond.

Communication is the Key

How a child copes with a sibling who has special needs and how much information a parent should share will vary based on the ages of both children and the age when the special need arose - whether it was at birth, caused by trauma or part of a disease process, said Gail Cervarich, a licensed clinical social worker at Children's Hospital of The King's Daughters (CHKD) in Norfolk. However, no matter when parents decide to talk with other siblings, Cervarich said one piece of advice stands out from all others: Let the children serve as the guide. "[Parents] should answer their questions as they arise, update family as changes occur, be open to discussing the challenges and joys of having special needs children," she said.

Kimberly Matias, an outpatient case manager at Children's Hospital of Richmond, agreed. "If a child has a question, ask them what they think the answer is," she said. "Then you know what you need to clarify. You don't know what they're thinking and they may never tell you [if you don't ask]." This rule is especially important, Matias added, if the other siblings are frightened by what's happening to their brother or sister. "It's important for siblings to know



Photos courtesy of "Hats Off to Sibs Day" at Kilmer Center, Fairfax County Public Schools

their brother or sister isn't in pain, and to know the things they still can do -- like feel love, laughter. They know what's funny," she said.

Answering a sibling's questions can become more complicated when the child with special needs has a potentially fatal diagnosis. Matias said parents should talk about what a fatal diagnosis could mean for the child and for the family. If parents aren't prepared to answer those questions when a sibling asks, Matias added, they should discuss their response and get back to the sibling.

Getting siblings talking and asking questions during the elementary and middle school years is important for their development later in life. "You don't want them to be 18 and waiting to talk about it since they were 7," Tucker said. "If they hold it all in until adolescence . . . they'll have questions and feel isolated and might take on destructive behavior."

Connecting through Sibshops

Siblings of children with special needs may find comfort through Sibshops. According to The Sibling Support Project, Sibshops are group workshops where brothers and sisters of children with special health and developmental needs obtain peer support and education in a recreational environment.

"They learn they aren't the only ones; they have a place to go that's just for them; they share their ideas, ways of coping, pride in their siblings, learn about other siblings, have fun, etc.," said Cervarich, who leads Sibshops at CHKD. Matias and Tucker, who lead Sibshops at Children's Hospital of Richmond, said while they sometimes jumpstart the workshops by asking questions, the siblings are the

ones who steer the conversation. "Sometimes, we can't get them to stop talking," Tucker laughed.

Designed for children in elementary and middle school, Sibshops aim to bring a sense of relief to siblings as they see they are not alone. "That's got to be a great feeling," Matias said. However, she added, Sibshops may not be right for all children, particularly ones who need to address more specific needs. If a parent has concerns about a child's safety or if either sibling is threatening to hurt the other, Matias said she recommends individual or family therapy.

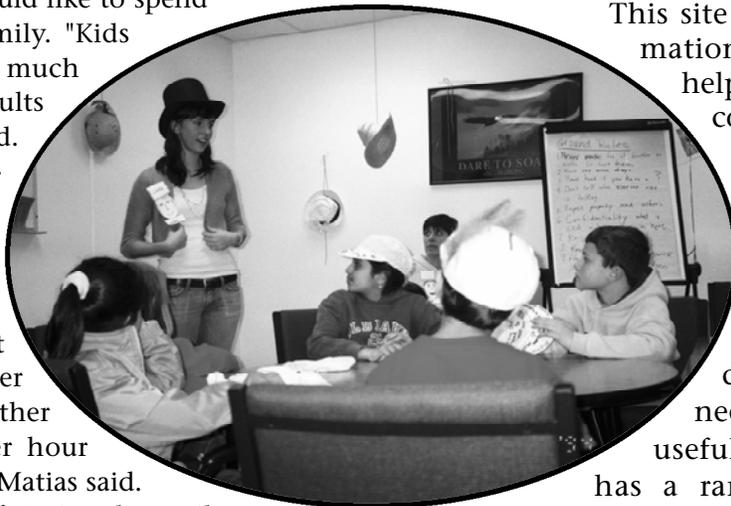
Cervarich said parents also should watch for changes in their child such as increase/decrease in appetite, moodiness, withdrawal, tearfulness, lack of concentration and/or falling grades to know if therapy is needed.

Walking the Tightrope

All parents with multiple children must find a way to balance their time with each child and address sibling rivalry issues, but the emotions become more complicated when a child with special needs is involved. "Just like any other family, parents want children to get along, but you can't make that happen . . . You still face the same struggles. It's normal, but it doesn't feel normal," Matias said. "A lot of what these siblings go through is totally OK and part of being a brother and sister."

Family emergency plans should include individual information for each member of the family so everyone is addressed and everyone feels valued, Matias said. In addition, parents can do their part by making special time for each sibling. Matias suggested sitting down with children individually and asking them how they would like to spend time together as a family. "Kids are so inventive, so much more than we as adults tend to be," Matias said. She recalled one mother who took her daughter to breakfast every day so the two of them would have quality time. "It didn't compare to the time her mom spent with her other sibling, but it was her hour and it was consistent," Matias said.

Deciding when, or if, to involve a sibling in his/her brother's or sister's care is tricky.



Tucker said if a sibling has reached an age where he/she can contribute and the parents feel comfortable, it can be considered, but parents must be careful not to pile too much on the other sibling. "You don't want it to be a burden," Tucker said. Following the sibling's lead will help prevent resentment from building. "The care issue depends on the needs of the sibling, the maturity of the sibling(s)," Cervarich said. "Again, talk, talk and listen . . . It's about stages of development, too." Above all, Cervarich said, parents must remember to take care of themselves, find help if they need it and consider joining a parent support group. ■

Polly Roberts is a writer and editor in Richmond. She has 5-year-old twin nieces, one of whom is diagnosed with cerebral palsy.

Related Resources

The Sibling Slam Book: What It's Really Like to Have a Brother or Sister with Special Needs
by Donald J. Meyer

Views from Our Shoes: Growing Up With a Brother or Sister With Special Needs
by Donald J. Meyer

It Isn't Fair! Siblings of Children with Disabilities
by Stanley D. Klein and Maxwell J. Schleifer.

www.siblingsupport.org

This site will offer more information about Sibshops and help you find one in your community.

In addition, search Yahoo to find a listserv so your child can connect with other siblings of children with special needs. This is especially useful if the other sibling has a rare special need. The Internet may be the only place for the child to find someone in a similar situation.