

Having a Sibling with Special Needs

By Dr. Serena Patterson and Monika Grünberg, RCC

Serena's nephew John, who lives in the United States, is 8 years old. His sister, Sophia, is 9. But it is John who is the real "eldest" in this family, feeling the pressure to set a good example and to look after Sophia, whose autism sets her apart as different from other playmates and makes her vulnerable in ways that John is not. The two of them have been inseparable since their adoption 7 years ago; they are the best of playmates. But as John become more aware of peer judgments, and more able to question what is "fair", difficulties sometimes arise. Embarrassment, loyalty, duty, love and exasperation all cross his face over the space of just a few seconds as he says, "look what Sophie just did!" and surveys the damage of a ruined project. Neither John, nor anyone else, is ever sure exactly how much to hold her accountable; it is sometimes a confusing and delicate balance living with one who sometimes appears to understand perfectly, and other times misses the most obvious social clues and information.

Having a sibling with special needs is a life-shaping experience, and, for better or for worse, it is something that happens to us without our consent. Adults who grew up with such siblings often look back on it as having helped to build compassion, responsibility, and an attitude of easy acceptance toward difference and disability. But they may also remember feeling unimportant, and jealous of the attention given to the other child. When the special needs develop suddenly because of an accident or illness, the sibling's feeling may be particularly confusing.

Here is another family story. When Serena's mother Joan was seven years old, her older sister developed a life-threatening disease that required their mother to stay in the city, at the hospital, for many weeks. When little Joan missed her mother the most, she would hope that the sister would die so that her mother would come home and love her all the more for being the only surviving daughter. Then, feeling guilty over the wish, Joan would try to be extra good and no trouble to the "hired girl" who was left to mind the farmhouse. For over thirty years Joan vividly remembered the day that she took a pair of scissors to a portrait photograph of her sister, ruining it forever. Imagine her surprise to find the photograph, unharmed, among her mother's things; her "memory" was the dream or fantasy of a little child, buried in so much guilt that it became real. It became important to Joan to forgive that child she once was, for harboring "murderous thoughts" and being jealous of a gravely ill sister. It also became important to forgive the sister, and to see both of them as innocent players in a drama that they had no real power to create or to solve at the time.

Adults can help a great deal with the rivalries between a sibling with unusual special needs and one who is, at least for the time, the "normal" one. There is no language available for the situation that is completely value neutral, but it may help to think of children at this time as being different in both the intensity and the kinds of needs that they have, while remembering that all children have needs that are special to them. When one child's needs are stretching the family's resources to the limit (as happens when one child is very ill, very disabled, or going through a particularly difficult crisis), the others have their own special needs list. If we could read that list, it may look like this:



Special Needs of the Special Child's Extra Special Sibling:

- ❖ **I need to have something that I can do to help.** It needs to be real, appropriate to my own age and abilities, and appreciated.
- ❖ **I need time alone with an adult (or two) who loves me,** and who will focus just on me for a while. This could be a special auntie or uncle, a cherished family friend, or a grandparent.
- ❖ **I need information.** Answer my questions with honesty, patience, and language that I can understand.
- ❖ **I need my parents to have other adults to talk to,** who can help them through so that I can concentrate on the kid stuff.
- ❖ **I need to play.** If I am a young child, let me play pretend, alone or with friends, because this is how I work out many things in my mind. If I am too old for pretend, let me use my emotional energy toward something creative or physical, so that I can transform it in my own terms.
- ❖ **I need breaks.** If I am an older child or teenager, let me go with my peers and put the family's concerns away for a while. Give me a break from being my brother's, or sister's keeper, and let me know that it is ok to leave them behind sometimes with other safe keepers.
- ❖ **I need the freedom to feel.** Let it be all right for me to have both positive and negative feelings toward my sibling.
- ❖ **I need direction.** Make clear rules about how I can, and cannot, express my negative feelings. Don't sit by and allow me to become a bully or to do things that will haunt me later; help me to stay within safe boundaries of behavior when I am feeling angry. (For example, remind me that hitting pillows is fine, but hitting people is not).
- ❖ **I need to feel good about myself.**

There have been many sisters and brothers of children with disabilities who have grown up enriched by the experience in unexpected ways. For example, the delightful "Little House" books, so cherished by generations of children for their vivid descriptions of American pioneer life, were written by Laura Ingalls Wilder. Fans of Wilder will recall Laura's rivalry with her older sister, Mary, who became blind from Scarlet Fever. What is not said is that Laura became Mary's eyes, describing for her all the visual details of their life. In describing the world to Mary, Laura became a wonderful wordsmith. Here she gained the skill that would be first passed on to her own daughter, a renowned journalist of her time, and later be set down for generations as these women collaborated on the acclaimed children's book series.

In a way, all of our childhoods and early family lives become material for that larger creation we call "my life story". It can be hard, as a parent, watching children cope with challenges that they did not choose and that may seem to be unfair burdens at the time. We can't often take those challenges away, and our silence about them won't help, either. But we can give children the tools and the secure foundation that they need to turn these challenges into personal gifts of creativity, acceptance, compassion, responsible caring, and a greater respect for themselves.

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