

Sibshops have been described as peer support groups for the brothers and sisters of children with developmental disabilities and “special health care needs.” Literature from web sites on the topic reveals a variety of philosophies about the reasons for and perceived benefits of sibshops:

- They can provide help to children who may feel guilt, anger, fear, jealousy, isolation, and/or other negative emotions brought on by having a brother/sister with a disability.
- Opportunities for peer support and education are provided within fun activities.
- “Therapeutic” benefits for children may include sharing the “ups and downs” and “embarrassment” when one’s brother/sister has a disability.
- School psychologists, social workers, and other professionals should be involved in the lives of children to help them deal with the “problems” of having a brother/sister with a disability.

Well, all of this bothers me. Before going further, please understand that my criticism of sibshops is not a criticism of people who run sibshops, but of the concept, itself. Those involved in sibshops are, no doubt, very caring people. Like many other practices in Disability World, however, this is a concept brimming with the best of intentions, but which may have less than desirable outcomes. I believe it’s important to carefully examine the conventional wisdom of disability issues instead of simply assuming everything is hunky-dory.

What message is sent to our children if we believe they have “problems” and need “therapeutic” or peer support because a brother or sister has a disability, and then encourage (or require) our children to attend sibshops? Where did our children get these feelings and ideas in the first place? From us—their own parents!

Sibshops may appear to be a viable solution to real issues. And children who attend sibshops may, indeed, enjoy themselves. But it seems we’re counting on sibshops to solve a problem that’s of *our own making*.

Sibshops: A Sensible Solution?

Revolutionary Common Sense
by Kathie Snow, www.disabilityisnatural.com

In the process, we may unintentionally perpetuate unhealthy perceptions in our children about themselves, their families, and their brothers/sisters with disabilities.

The leadership of sibshops (as described in promotional materials and on web sites)—psychologists,

social workers, special ed teachers, medical professionals, and adults who have brothers or sisters with disabilities—is also disturbing to me. Why aren’t the “true experts”—adults and/or children with disabilities—participating in leadership positions? It seems conspiratorial, as if it’s “those people” who are causing the problems in the first place, so we sure don’t want them at the meetings, *much less as leaders!*

The idea that I would send my daughter to an unknown group of professionals and “peers” to deal with “problems” that were most likely generated from within our home is frightful. What if the information she learns is in conflict with our family’s values? Isn’t there a possibility that this could make the “problem” worse? And who should my daughter believe? Her parents or the “experts” and “peers?” More importantly, unless *I* take actions to improve the home situation so my daughter is not experiencing “problems,” isn’t her participation in a sibshop the equivalent of putting a temporary bandage on a festering wound?

As you can probably tell, our family has never used the services of a sibshop. I can’t imagine trying to get my daughter (who has a younger brother with cerebral palsy) to attend a meeting. What would I say? “Honey, I know your life is hard because of your brother. I don’t want you to feel alone in this awful situation, so there’s a fun place where you can go and be with others like you.” *Gag!* (Would I be sending her to a pity party?) What harm would I be doing my daughter? What harm would I be doing my son? Where should I tell Benjamin his sister is going? “Benj, your having a disability has created some stress in Emily’s life, so she’s going to a support group to deal with it.” Or do I lie about her activities to keep it a secret from Benjamin? More conspiracy!

I believe the concept of sibshops can be hurtful to children with disabilities and their brothers and

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sisters. The notion that a medical condition which a child has—something he has no control over—could be the cause of other people’s “problems” is equivalent to the outrageous and dangerous “blaming the victim” paradigm.

Parents I’ve talked to seem to fall on one side or the other. Many think sibshops are the greatest thing since sliced bread; just as many share feelings similar to what I’ve stated here. Few are in the ambivalent middle.

Let’s go back to the origin of this dilemma: what children learn about their brothers and sisters with disabilities and how they feel about the situation is a direct reflection on *our* (the parents’) feelings, language, and actions. If *we* have focused all our attention on the child with disability, and if *we* have presented the disability or the situation as aberrant, difficult, or stressful, our children will embrace our attitudes and actions as The Truth. How could they not? The attitudes, beliefs, and actions of children are, to a great extent, mirror images of their parents’. So perhaps it’s the *demeanor of parents*, rather than a child having a brother/sister with a disability that is the genesis of a child’s “problems.”

In my own family (and others have shared similar stories), Emily learned—from our words and actions—that whatever differences our family experienced were normal and natural for us, and more importantly, that *all families* experience differences! When Benjamin required “more” of our time and attention, we ensured Emily received the time and attention she needed. Simultaneously, we didn’t exempt Benjamin from responsibility or full participation in family life. For example, Emily was assigned chores appropriate to her abilities, and so was Benjamin. And never was Benjamin excluded from any family activity (movies, vacations, etc.) just because we may have had to do things differently than other families. We also made thoughtful decisions to eliminate anything—services, language, attitudes, actions—that had a negative effect on any member of the family.

Emily (now 18) has never experienced the “embarrassment or shame” which is supposedly common

to brothers/sisters of children with disabilities (an issue sibshops are said to address). *My husband and I* have never chosen to be embarrassed by Benjamin (and it is a choice), so Emily never learned that. She realized, in fact, that the way her friends perceived and treated her brother was influenced by how *she* treated her brother (including how she talked about him). Her friends followed *her* lead, just as she followed ours.

I agree that the presence of a disability, as noted by some sibshop literature, *does* touch the entire family. But far from having a negative effect, it can strengthen each member of the family, and the family as a whole. It’s all a matter of perspective: is the glass half full or half empty?

It’s never too late to change. Parents can adopt new ways of thinking today, and teach their children that disability is natural. This paradigm can lead us down a different path—a path which our children will travel with us, which does not lead to “problems” and the need for sibshops to remedy these “problems.”

A child can never be better than what his parents think of him.

Marcelene Cox

Finally, a word about “sibling.” I’ve used “brother/sister” in this article, instead of “sibling.” It’s a conscious choice, because to me “sibling” represents medical model

language. This word is seldom used in conversations in the Real World. I’ve never asked a new acquaintance, “Do you have siblings?” I ask, “Do you have any brothers or sisters?” Many of us recognize the dangers of labeling and then grouping children by their diagnoses. Isn’t labeling a child as “the sibling of [whomever]” and *grouping them* by that label a potentially harmful practice, too?

If our hope is to create a world where people with disabilities are valued and included, the changes must start in our own homes. My faith that this hope will become a reality is reinvigorated on a routine basis, and never more so than the day long ago when nine-year-old Emily said, “You know, Mom, if I ever have a baby with a disability, it won’t be a big deal.”

I think the world will be a better place if we all adopted my daughter’s attitude—let’s not make a “big deal” out of a disability. Let’s do it for our own wonderful children, for the millions of others alive today, and for the precious babies who are not yet born.