SIBLINGS OF STUDENTS WITH DISABILITIES AND CHRONIC ILLNESS

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There is a profound effect on the family when a child is diagnosed with a disability or chronic illness. Adjustments must be made, often suddenly, to lifestyle and daily routine because increased time, attention, money, and support are directed at the disabled or ill child. The household may be affected by visits from professionals or extended family members. Parents are likely to be immersed in their own stages of grief and less able to be supportive of other children in the family, who may be frightened, hurt, or bewildered.

Impact on Siblings

Siblings of the child with a disability or serious illness must adapt to the new situation, because their reactions can affect the adjustment and self-esteem of each child in the family. Siblings play important roles in each other’s lives. Brothers and sisters may take on the roles of teacher, friend, companion, follower, protector, enemy, competitor, confidant, or role model, depending on ages, genders, and personalities. When one of the siblings is disabled or chronically ill, these roles can be affected.

Siblings with poor coping skills might be overwhelmed by stressful experiences. Children with unmet needs for nurturing may experience jealousy, while those who are in the midst of a developmental transition, such as starting school or puberty, may be particularly vulnerable to family stresses.

Additionally, siblings’ reactions to and relationships with the special-needs child are likely to change over time. A sibling who was taken for granted as a playmate may appear in a different light when a child’s friends ask questions or point out differences. A younger sibling may develop skills that surpass the older sibling with a developmental delay, changing the balance of power in the relationship. A crisis in a sibling’s illness may remind siblings of their own mortality.

As children become young adults, they may feel a responsibility for the special-needs sibling, or have worries about his or her care in the future. Older children may have concerns about planning their own families, whether or not genetics was a factor in the handicapping condition.

Unique Needs of Siblings

Parents and professionals are sometimes unaware of the unique needs and concerns of these non-disabled siblings. Many typical problems confront siblings of children with disabilities or chronic illness.

Embarrassment. Special-needs children sometimes have equipment, behaviors, seizures, or looks that may embarrass their siblings in public. In the same way that parents feel that their children’s behavior reflects on them, siblings identify with their special-needs sibling. Some children may feel personally challenged or hurt by stares or comments, and some may interpret curious looks as criticism. Some siblings decline to have friends over to visit for fear of embarrassment.

Guilt. Healthy siblings may feel some guilt over their well-being in contrast to a special-needs brother or sister. Some may even underachieve in an attempt to balance the scales. Siblings also may occasionally get angry with the brother or sister with a disability or illness and may suffer feelings of guilt when they realize that they are angry at behavior that could not be helped.

Isolation. Children may fear negative reactions from friends if they share information about a special-needs sibling. This can lead to feelings of isolation. They might notice the teasing that sometimes happens to special education students at school and seek to avoid being associated or targeted. Children are sometimes reluctant to discuss these feelings with parents, not wanting to add to a burden, or feeling it to be relatively unimportant.

Resentment. In virtually all families with more than one child, there is some competition for parents’ attention. This situation is complicated for the sibling of a special-needs child, because an ill or disabled...
child necessarily needs more parental attention in some areas. Younger children may use behaviors such as tantrums or even imitate the sibling’s disability. Older children may resent being asked to baby sit or otherwise care for a sibling, particularly if it comes at the cost of that child’s activities and interests.

**Ambivalence.** Children with ill or disabled siblings are likely to struggle with feelings of embarrassment, jealousy, and resentment in contrast to real feelings of love for the sibling. Experiencing such strongly conflicting feelings can be a source of confusion, especially for younger children.

**Financial consequences.** Medical and behavioral interventions and professional services can be expensive to a family, even with the help of public programs and comprehensive health insurance. Financial resources are just one more area, along with attention, time, and emotional investment that must be budgeted and prioritized by the family.

**Future concerns.** Siblings will accompany a child with a disability longer through life than professionals and even parents. Siblings may feel anxious about their role in future care and responsibility, and wonder how it will affect their own lives. They may also be concerned about their own chances of having a child with a disability.

**Pressure to achieve.** Often without realizing it parents can place excessive expectations on other children in the family to compensate for the child with special needs. When unrealistic, these expectations can create significant stress. Some children over perform to fit what they perceive as their role as the good or perfect child, or to work out their own sorrow for having a sibling with special needs.

**What I Can Do as a Parent**

Children in families with a special-needs child can learn early that *fair* does not mean *equal*. Conflicts can arise when parents overindulge any child at the expense of another.

**All children provide gifts to a family.** Families have a resilient capacity for normalizing all kinds of conditions and situations. For some families, a special-needs sibling creates no more waves than, for example, an unexpected new baby after siblings are older or a grandparent coming to live with the family. It is entirely possible for a brother or sister’s special needs to be a minor issue in a family.

**Open communication is essential in a family with a special-needs child.** When children perceive that some topics are forbidden or mysterious, it can create fear or withdrawal. Some children can even blame themselves for their sibling’s condition. Children have a right to clear discussion of feelings as well as factual information and answers to questions about the disability or illness. There are a number of books written for siblings of special needs children (see “Resources”) that can help stimulate a discussion. It can also be helpful to visit the special education classroom or school.

**Meet with your non-disabled child’s teachers.** Let teachers know how your child responds to his or her special-needs sibling. Sometimes school can be a safe haven for children to feel relaxed and normal. The teacher may be able to serve as a confidant or provide moral support or intervene with teasing or difficult questions from peers. Some children have used the opportunity to educate their peers, either formally (a class report) or informally about the illness or condition of the brother or sister. Under the guidance of the teacher this has sometimes been an opportunity for peers to show interest and support for their classmate. Sometimes parents are in a better position to do this sharing with the class. Teachers will appreciate knowing when there are particularly stressful times for a family, such as upcoming surgeries or treatments.

**Seek other support.** Consider a visit with your school counselor or psychologist, or perhaps a sibling support group in your area. You can best assess your child’s needs in this area. Some children vehemently protest this support. At their best, however, support groups and counseling can help normalize a siblings experiences and help him or her feel less isolated.

**Encourage children to express feelings.** Encourage and support your children’s expression of their true feelings about their special-needs sibling with you. Children need to express their emotions. As parents we can remember that no emotional response is unworthy and sharing feelings of anger or embarrassment can help defuse them. We can acknowledge their feelings without giving advice or sermons. Sometimes just listening sympathetically is all that is needed. Sharing parents’ feelings, both good and bad, can also help strengthen the bonds of communication with non-disabled siblings.

**The future of the special-needs child should be addressed as a family.** Siblings will need to know what the plan is for caring for and being responsible for their brother or sister. Make sure siblings know which support agencies and advocacy groups provide services. Some agencies even provide legal advice for setting up trusts or conservatorships.

**Spend time alone with each of your children.** This is good advice in any family of any size. Parents do not need to plan special outings. Running errands or doing the shopping together can provide unstructured time for sharing.
Provide as many opportunities for normal family life as possible. Families should feel free to invite friends to visit, participate in sports, take family vacations, and be part of their communities. Sometimes this may mean leaving the special-needs child with a caretaker. Many agencies provide for respite care for this purpose.

Avoid imposing roles on children. Special-needs children need not always be the dependent one in all ways. Non-disabled siblings need not take on parental roles too young. Stay attuned to each child's strengths and weaknesses and provide opportunities for each to be cared for and caretaker.

Watch for some surprising benefits. Siblings of those with special needs are in a unique position to learn empathy, tolerance, and a sense of humor. They often appreciate their own abilities more, and do not take for granted their health and their skills. Some families find that these siblings learn creative ways to teach and problem-solve based on their experiences helping their brother or sister. They are also sometimes privileged to witness amazing acts of kindness from others.

Resources
Written by parents, young adult siblings, younger siblings, and professionals.

The author's brother has cerebral palsy and mental retardation. Interviews with siblings ages 6–76 and ideas for coping.

Quotes from siblings of all ages.

A psychotherapist describes her own sibling experience, plus 60 interviews of other siblings of those with special needs.

For younger readers. Includes medical information about many disabilities.

Stories for Children
For ages 4–8, and concerns mental retardation.

A story about a girl named Anna and her disabled brother. Explores attitudes from others and impact on growing up.

For ages 4–8; concerns autism.

For ages 4–8; concerns severe special needs.

For ages 4–8; concerns Down syndrome.

For ages 10–14; is about "Queen Nerd" Alison and her autistic twin, Adam. A tormentor gets his comeuppance.

Websites
ERIC Clearinghouse on Disabilities and Gifted Education—http://ericed.org/faq/siblings.html
Resources on siblings of children with disabilities.
Sibling Support Project—www.thearc.org/siblingsupport

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