

Meeting the Unique Concerns of Brothers and Sisters of Children with Special Needs

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In the United States, over five million children have disabilities or special health concerns. Most have brothers and sisters. Throughout their lives, these brothers and sisters will share many—if not most—of the same concerns that parents of children with special needs experience, as well as issues that are uniquely theirs. These concerns are well known to their parents and have been documented in the research and clinical literature. Among the concerns mentioned by authors, parents, and siblings themselves include:

- * a life-long and ever-changing need for information about the disability or illness (Lobato, 1990; Schorr-Ribera, 1992; Powell & Gallagher, 1993);
- * feelings of isolation when siblings are excluded from information available to other family members (Bendor, 1990), ignored by service providers (Doherty 1992), or denied access to peers who share their often ambivalent feelings about their siblings (Meyer & Vadasy, 1994);
- * feelings of guilt about having caused the illness or disability, or being spared having the condition (Koch-Hattem, 1986);
- * feelings of resentment when the child with special needs becomes the focus of the family's attention or when the child with special needs is indulged, overprotected, or permitted to engage in behaviors unacceptable by other family members (Poddeanu-Czehotsky, 1975; Bendor, 1990);
- * a perceived pressure to achieve in academics, sports, or behavior (Coleman, 1990);
- * increased caregiving demands, especially for older sisters (Seligman, 1979); and
- * concerns about their role in their sibling's future (Fish & Fitzgerald, 1980; Powell & Gallagher, 1993).

Increasingly, opportunities experienced by these brothers and sisters are also being acknowledged (Meyer & Vadasy, 1994; Powell & Gallagher, 1993; Turnbull & Turnbull, 1993). A short list of opportunities observed by parents and brothers and sisters could include:

- ☛ The insights a sibling will have on the human condition as a result of growing up with a brother or sister with special needs: *"She taught me how to love without reservation; without expectation of returned love. She taught me that everyone has strengths and weaknesses. Martha is no exception. She taught me that human value is not measured with IQ tests"* (Westra, 1992, p. 4).
- ☛ The maturity many brothers or sisters develop as a result of successfully coping with a sibling's special needs: *"I have a different outlook on life than many other people my age. I understand that you can't take anything for granted. And you have to be able to look at the*

positives...With Jennifer, there are negatives, but there's so much more that is good" (Andrea, age 19, in Binkard et al., 1987, p. 19).

- ✎ The pride brothers and sisters report in their sibling's abilities: "Jennifer has probably achieved more than I have. She's been through so much. She couldn't even talk when she started school; now she can, and she can understand others. She's really fulfilling her potential. I'm not sure the rest of us are" (Cassie, age 18, in Binkard et al., 1987, p. 17).
- ✎ The loyalty brothers and sisters display toward their siblings and families: "I'm used to being kind to my brother and sister, so I'm kind to everybody else. But, if someone starts a fight, I will fight. I won't put up with anyone teasing Wade or Jolene" (Morrow, 1992, p.4).
- ✎ The appreciation many brothers and sisters have for their good health and own families: "Living with Melissa's handicaps makes me so much more cognizant of my own blessings. She provides a constant reminder of what life could have been like for me if I had been my parents' oldest daughter. This encourages me to take advantage of my mental capacities and to take care of my healthy body" (Watson, 1991 p. 108).

Within the family, siblings will likely spend more time with the child with special needs than any other person, with the exception of the child's mother. And, because the sibling relationship is generally the longest-lasting relationship in the family, brothers and sisters are likely to experience these concerns for a long period of time. Sibling issues are, consequently, lifespan issues: preschool-age siblings will grapple with issues not faced by their peers in the community; so will siblings who are senior citizens. Yet, many brothers and sisters grow up without resources—such as access to support programs and sources of information—that would help them in their roles, and that many parents may take for granted.

Below are suggestions for parents and service providers to minimize siblings' concerns and maximize their opportunities:

1. Provide brothers and sisters with age appropriate information.

Most brothers and sisters have a life-long, and ever-changing need for information. Parents and service providers have an obligation to proactively provide siblings with helpful information.

2. Provide siblings with opportunities to meet other siblings of children with special needs.

For most parents, the thought of "going it alone," without the benefit of knowing another parent in a similar situation is unthinkable. Yet, this happens routinely to brothers and sisters.

3. Encourage good communication with typically developing children.

While good communication between parent and child is important, it is especially important in families where there is a child with special needs. Books, such as *How to Talk So Kids Will Listen and Listen So Kids Will Talk* and *Siblings Without Rivalry* (both by Faber and Mazlich), provide helpful tips on communicating with children.

4. Encourage parents to set aside special time to spend with the typically developing children.

Children need to know from their parents' deeds and words that their parents care about them as individuals. When parents carve time out of a busy schedule to grab a bite at a local burger joint or window shop at the mall with the typically developing child, it conveys a message that parents "are there" for them as well.

5. Encourage parents and service providers to learn more about siblings' experiences.

Sibling panels, books, newsletters and videos are all excellent means of learning more about sibling issues.

6. Encourage parents to reassure their typically developing children by planning for the future of the child with special needs.

Early in life, brothers and sisters worry about what obligations they will have toward their sibling in the days to come. Parents should be encouraged to plan for the future and share these plans with their children. When brothers and sisters are "brought into the loop" and given the message that they have their parents' blessing to pursue their dreams, their future involvement with their sibling will be a choice instead of an obligation.

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