Sibshops

Workshops for Siblings of Children With Support Needs

# What Siblings Would Like Parents and Service Providers to Know

In the United States, there are over 32 million people who have cognitive disabilities and/or mental health concerns, in addition to those who have health concerns. Most of these people have typically developing siblings. Brothers and sisters are too important to ignore, if for only these reasons:

- These siblings will be in the lives of family members with support needs longer than anyone. Siblings will be there after parents are gone and special education services are a distant memory. If they are provided with support and information, they can help their sibs live dignified lives from childhood to their senior years.

- Throughout their lives, siblings share many of the concerns that parents of children with support needs experience, including isolation, a need for information, guilt, concerns about the future, and caregiving demands. Siblings also face issues that are uniquely theirs including resentment, peer issues, embarrassment, and pressure to achieve.

Despite the important and life-long roles they will play in the lives of their siblings who have support needs, even the most family-friendly agencies often overlook siblings. Siblings, often left in the literal and figurative waiting rooms of service delivery systems, deserve better. True "family-centered" care and services will arrive when siblings are actively included in agencies' functional definition of "family."

The Sibling Support Project facilitated a discussion on SibNet, its online community for adult siblings of people with disabilities, regarding the considerations siblings want from parents, other family members, and service providers. Below is a discussion of themes discussed by SibNet members and recommendations from the Sibling Support Project:

1. The Right to One's Own Life. Throughout their lives, siblings may play many different roles in the lives of their siblings who have support needs. Regardless of the contributions they may make, the basic right of siblings to their own lives must always be remembered. Parents and service providers should not make assumptions about responsibilities typically developing siblings may assume without a frank and open discussion. "Nothing about us without us"—a phrase popular with disability advocates —applies to siblings as well. Self-determination, after all, is for everyone —including siblings.

2. Acknowledging Siblings' Concerns. Like parents, siblings will experience a wide array of often-ambivalent emotions regarding the impact of their siblings' support needs. These feelings should be both expected and acknowledged by parents and other family members and service providers. Because most siblings will have the longest-lasting relationship with the family member who has a disability, these concerns will change over time. Parents and providers would be wise to learn more about siblings' life-long and ever-changing concerns.

3. Expectations for Typically Developing Siblings. Families need to set high expectations for all their children. However, some typically developing siblings react to their siblings' disability by setting unrealistically high expectations for themselves —and some feel they must somehow compensate for their siblings' support needs. Parents can help their typically developing children by conveying clear expectations and unconditional support – even and especially when they aren't "perfect."

4. Expect Typical Behavior from Typically Developing Siblings. Although difficult for parents to watch, teasing, name-calling, arguing, and other forms of conflict are common among most siblings -– even when one has support needs. While parents may be appalled at siblings' harshness toward one another, much of this conflict can be a beneficial part of normal social development. A child with Down syndrome who grows up with siblings with whom he sometimes fights will likely be better prepared to face life in the community as an adult than a child with Down syndrome who grows up as an only child. Regardless of how adaptive or developmentally appropriate it might be, typical sibling conflict is more likely to result in feelings of guilt when one sibling has special health or developmental needs. When conflict arises, the message sent to many siblings is, "Leave your sibling alone. You are bigger, you are stronger, you should know better. It is your job to compromise." Typically developing siblings deserve a life where they, like other children, sometimes misbehave, get angry, and fight with their siblings.

5. Expectations for the Family Member with Support needs. When families have high expectations for their children who have support needs, everyone will benefit. As adults, typically developing siblings will likely play important roles in the lives of their siblings who have disabilities. Parents can help siblings now by helping their children who have support needs acquire skills that will allow them to be as independent as possible as adults. To the extent possible, parents should have the same expectations for the child with support needs regarding chores and personal responsibility as they do for their typically developing children. Not only will similar expectations foster independence, they will also minimize the resentment expressed by siblings when there are two sets of rules — one for them, and another for their sibs who have support needs.

6. The Right to a Safe Environment. Some siblings live with brothers and sisters who have challenging behaviors. Other siblings assume responsibilities for themselves and their siblings that go beyond their age level and place all parties in vulnerable situations. Siblings deserve to have their own personal safety given as much importance as the family member who has support needs.

7. Opportunities to Meet Peers. For most parents, the thought of "going it alone," and raising a child with support needs without the benefit of knowing another parent in a similar situation, would be unthinkable. Yet, this routinely happens to siblings. Sibshops, online communities such as SibNet, Sib20 and SibTeen, and similar efforts offer siblings the common-sense support and validation that parents get from Parent-to-Parent programs and similar programs. Siblings —like parents —like to know that they are not alone with their unique joys and concerns.

8. Opportunities to Obtain Information. Throughout their lives, siblings have an ever-changing need for information about their sibling's disability, and its treatment and implications. Parents and service providers have an obligation to proactively provide siblings with helpful information. Any agency that represents a specific disability or illness and prepares materials for parents and other adults should prepare materials for siblings and young readers as well.

9. Sibs' Concerns about the Future. Early in life, many siblings worry about what obligations they will have toward their sibling in the days to come. Ways parents can reassure their typically developing children are to make plans for the future of their children with support needs, involve and listen to their typically-developing children as they make these plans, consider backup plans, and know that siblings' attitudes about the extent of their involvement as adults may change over time. When siblings are "brought into the loop" and understand early that they have their parents' blessing to pursue their dreams, their future involvement with their sibling will be a choice instead of an obligation. For their own good and for the good of their siblings who have disabilities, brothers and sisters should be afforded the right to their own lives. This includes having a say in whether and how they will be involved in the lives of their siblings who have disabilities as adults, and the level, type, and duration of involvement.

10. Including Both Sons and Daughters. Just as daughters are usually the family members who care for aging parents, adult sisters are usually the family members who look after the family member with support needs when parents no longer can. Serious exploration of sharing responsibilities among siblings —including brothers —should be considered.

11. Communication. Good communication between parents and children is always important, and especially so in families with a child who has support needs. An evening course in active listening can help improve communication among all family members. Books such as How to Talk So Kids Will Listen and Listen So Kids Will Talk and Siblings Without Rivalry (both by Adele Faber and Elaine Mazlich) provide helpful tips on communicating with children.

12. One-on-One time with Parents. 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 take a hike, grab a bite at a local burger joint, or window shop with their typically developing children, it conveys a message that parents "are there" for them as well, and provides an excellent opportunity to talk about a wide range of topics.

13. Celebrate Every Child's Achievements and Milestones. Over the years, we've met siblings whose parents did not attend their high school graduation —even when their children were valedictorians —because the parents were unable to leave their child with support needs. We've also met siblings whose wedding plans were dictated by the needs of their sibling who had a disability. One child's support needs should not overshadow another's achievements and milestones. Families who seek respite resources, strive for flexibility, and seek creative solutions can help assure that the accomplishments of all family members are celebrated.

14. Parents' Perspective is More Important than the Actual Disability. Parents would be wise to remember that the parents' interpretation of their child's disability will be a greater influence on the adaptation of their typically developing sibling than the actual disability itself. When parents seek support, information, and respite for themselves, they model resilience and healthy attitudes and behaviors for their typically developing children.

15. Include Siblings in the Definition of "Family." Many educational, health care, and social service agencies profess a desire to offer family-centered services but continue to overlook the family members who will have the longest-lasting relationship with the person who has the support needs —the sisters and brothers. When siblings receive the considerations and services they deserve, agencies can claim to offer "family-centered"—instead of "parent-centered"—services.

16. Actively Reach Out to Siblings. Parents and agency personnel should consider inviting (but not requiring) siblings to attend informational, IEP, IFSP, and transition planning meetings, and clinic visits. Siblings frequently have legitimate questions that can be answered by service providers. Siblings also have informed opinions and perspectives which can make positive contributions to the child's team.

17. Learn More About Life as a Sibling. Anyone interested in families ought to be interested in siblings and their concerns. Parents and providers can learn more about “life as a sib” by facilitating a Sibshop, hosting a sibling panel, or reading books and seeing films by and about siblings. Guidelines for conducting a sibling panel are available from the Sibling Support Project and in the Sibshop curriculum. Visit www.siblingsupport.org for sibling-related books.

18. Create Local Programs Specifically for Siblings. If your community has a Parent-to-Parent Program or similar parent support effort, a fair question to ask is: why isn’t there a similar effort for the siblings? Like their parents, siblings benefit from talking with others who "get it." Sibshops and other programs for preschool, school-age, teen, and adult siblings are growing in number. The Sibling Support Project, which maintains a database of hundreds of Sibshops and other sibling programs, provides training and technical assistance on how to create local programs for siblings.

19. Include Siblings on Advisory Boards and in Policies Regarding Families. Reserving board seats for siblings will give the board a unique, important perspective and reflect the agency's concern for the well-being of brothers and sisters. Developing policies based on the important roles played by siblings will help assure that their concerns and contributions are a part of the agency's commitment to families.

20. Fund Services for Siblings. No classmate in an inclusive classroom will have a greater impact on the social development of a child with a disability than their brothers and sisters will. They will be their siblings' life-long "typically developing role models." As noted earlier, brothers and sisters will likely be in the lives of their siblings longer than anyone —longer than their parents and certainly longer than any service provider. For most brothers and sisters, their future and the future of their siblings with support needs are inexorably entwined. Despite this, there is little funding to support projects that will help siblings get the information, skills, and support they will need throughout their lives. Agencies would be wise to invest in the family members who will take a personal interest in the well-being of people with disabilities and advocate for them when their parents no longer can. As one sister wrote: “We will become caregivers for our siblings when our parents no longer can. Anyone interested in the welfare of people with disabilities ought to be interested in us.”

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