

Brothers and Sisters: Strategies for Supporting Siblings of Children who are Deaf-Blind

by Jackie Kenley and Myrna Media, CDBS Family Specialists

Brothers and sisters who have siblings with combined hearing and vision problems are *first of all people and important members of the family*. Siblings will probably want to know why this happened to their brother or sister and how it will affect them personally. This is especially important at the time the family is dealing with a new diagnosis; siblings need to be remembered at these times and have their questions answered and their concerns addressed. It will be helpful for siblings to understand exactly what and how much their sibling may see and hear, and about additional disabilities the sibling may have. Being open and actively listening to siblings may be tough for parents as they deal with a child who is deaf-blind, but these conversations are likely to be as healing for the parents as they are for the siblings.

Things to consider:

Emotional Stages. Learning to live with a child who is deaf-blind requires going through all kinds of emotional stages—anger, grief, sadness, hope and acceptance. To help deal with these emotions, it's a good idea to meet other parents of children with disabilities, share stories with them, and attend family support groups. Many times these various emotions come up at different times for individual family members. Birthdays and holidays are often tough on families, and this should be remembered and worked through as a family. For birthdays, sometimes it is very nice to celebrate each member of the family separately, if financially possible; if not, do not feel guilty about celebrating the siblings in a special way, or siblings might think there is a preference for the child who is deaf-blind.

Take a break! Giving the family a break from the responsibilities of caring for a child who is deaf-blind may be helpful, and provides family members the time to concentrate on other relationships in the family. Respite care or camps are a good idea for parents and siblings. Each child in the family has a need for individual care and attention, and giving this attention may require special effort and energy from parents. It is important for professionals working with the child who is deaf-blind to let the family know that it is *okay* for them to say we are tired, or we need help, and also emphasize that they are there to serve the entire family, not only the child who is deaf-blind.

There are positives as well as negatives. Having a sibling who is deaf-blind can have both positive and negative effects on the family. Different “behaviors”, surgeries, and illnesses are tough on all family members. For these moments of struggle, the family and friends as well as other people involved need to be united and provide all the support possible. Even time spent just holding hands or giving/receiving hugs can help soothe these moments. On the positive side, the ability to enjoy the accomplishments of a person who is deaf-blind, no matter how big

Fact sheets from California Deaf-Blind Services are to be used by both families and professionals serving individuals who are deaf-blind. The information applies to students 0–22 years of age. The purpose of the fact sheet is to give general information on a specific topic. More specific information for an individual student can be provided through individualized technical assistance available from CDBS. The fact sheet is a starting point for further information.

or small, can bring joy to all members of the family. The best way is to “celebrate”, meaning make a big deal out of these accomplishments.

Have a back-up plan. It is important for therapists and teachers to be open to the siblings’ presence and their questions. The most important thing for therapists and teachers to do is to be honest with families, and express if they are okay with the presence of siblings during therapy sessions, knowing that this might be a little disruptive. For parents, it is better if there is another older person in the house who can take the siblings someplace else while the therapy is given, because parents do not want the siblings to have hurt feelings if the professionals are not open to their presence.

Families need all the help they can get. It is necessary for medical professionals and counselors as well as regional center workers and related project personnel to offer each family all the help they can use, and provide all the resources in the community for the entire family and not just for the child who is deaf-blind.

Siblings may feel responsible for their brother or sister who is deaf-blind. These feelings of responsibility may be emotional, and later in life related to financial matters. Families often may not realize the specific concerns that siblings have. To avoid or prevent these future feelings, it is necessary to have conversations with the siblings that address all the important issues and concerns related to the child who is deaf-blind. It is important to give each individual sibling their own space and not overload them with extra responsibilities on top of the ones they already have. It is important to include siblings in planning for the future of the child who is deaf-blind. Using a person-centered planning approach is a good way to focus attention on the individual who is deaf-blind while at the same time including everyone who cares about the individuals’ future in the process.

Younger siblings need special consideration. It is important for parents as well as professionals working with children who are deaf-blind to remember that young siblings might have sensitive feelings that can be easily hurt. To avoid making the siblings feel left out or not wanted, we can make them feel they are important and include them in various activities throughout the day, e.g., bath, play.

We are all unique. Cultural and religious differences may strongly affect the way a family deals with a child with disabilities. Family and individual counseling may be helpful, but each family will likely have their own unique way of dealing with issues related to the child who is deaf-blind, and this needs to be understood and respected by the professionals involved with the family.