Living With A Sibling Who Has A Disability

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When a child is born with or diagnosed with a disability, the whole family is impacted. Although the parents are the primary caretakers for whom the responsibility of these children usually falls, the siblings are also greatly impacted. Although the presence of a brother or sister with a disability is considered stressful, there are many positive effects both the disabled and non-disabled siblings have on each other. However, these are common pitfalls that occur as members of the family grieve, develop an understanding of the disability and its effects, and handle other daily life stressors. This is compounded by the developmental issues that occur as siblings grow up and has to cope with these issues from a new developmental perspective (Rubin, 2002).

Children who have siblings with a disability are often well behaved, responsible, and have a strong ability to be compassionate (NICHCY, 1994). They often have to grow up quickly, learning that "life is not fair" before other children their age. They are also faced with the realities of financial hardship, fear, and recognition that parents can't always "make things better" far earlier than would be expected. Although these characteristics are desirable, understanding that siblings may be behaving this way due to fear and anxiety is very important.

In general, young children are very concrete in their thinking ability (Rubin, 2002). They understand objects and relationships based on their senses (i.e. the feel of the texture of objects on the skin and in the mouth, sounds objects make when banged together, etc.). Because the infant's world generally consists of them and first expands to include parents and immediate family members, there is little or no understanding of how things affect others. This is called egocentrism and it decreases as the child's world expands when he/she goes to school and continues to expand his/her world and when their neurological functioning develops to include the ability to better understand how others see and experience things and events. As children go to school, they begin to see how others are similar and different and their sibling's differences become more apparent (Schubert, 2003). At this time, they may begin to wonder whether they will become disabled themselves or worry that the disability is contagious. As they become adolescents, siblings may be embarrassed by their brother or sister, and then feel guilty about this embarrassment. They may feel burdened by responsibilities not only to complete increased chores but by the feeling that they must protect their siblings from the teasing and criticism of others (NICHCY, 1994; Schubert, 2003; ARCH, 1993).

The development of abstract reasoning and the understanding that things affect everyone either directly or indirectly is usually completed by the end of childhood, but many individuals never attain this level of functioning (Rubin, 2002). Throughout this process the child is likely to have to grieve issues at each developmental level. It is therefore important to realize that even if a child has lived with a disabled sibling for many years and seems to have a strong understanding of the disability, there will still be grieving to be done. For example, a young child who does not have the verbal skills to ask questions or understand the feelings he/she is experiencing may act out their confusion through

behavior problems. Some of these problems may include difficulty focusing their attention, listening, following directions, becoming aggressive, and withdrawing. As they get older they may feel guilty about "causing" the sibling's disability. It is quite normal for children to have ambivalent feelings about brothers and sisters, even before they are born. They may have wished that the child would never be born or they may have accidentally hit or kicked their mother in the abdomen when she was pregnant. Magical thinking, or the belief that one can cause things to happen because it was imagined is prevalent among school-age children. At this age there is a tendency for behavior to fall on opposite sides of the continuum. Trying to be overly helpful with their siblings out of guilt or as a way to decrease the stresses on the parents, or to become non-compliant as a way to gain the parents' attention. As older children and adults, siblings may learn to hide their feelings to keep from "burdening" others (Rainbow Babies, 2001).

The sibling relationship is unique and powerful. Unlike the parents, siblings of disabled children don't usually have a concept of life without living with someone who has a disability (Meyer & Vadasy, 1994). The sibling relationship is often the longest lasting because it continues past the death of the parents. Also, siblings share a history between them that is more similar than they will experience with anyone else. The acceptance of the disabled sibling by the non-disabled sibling is imperative in the overall development and self-esteem of both children (NICHCY, 1994).

While disabled siblings may feel anger about their differences and frustrated because they can't do everything that their non-disabled sibling does, they also need to develop a sense of independence and confidence that they can have control of parts of their lives (NICHCY, 1994). Many parents feel guilty about the disability and may blame themselves. As a result, they may let the disabled child get away with behavior that they would otherwise find unacceptable. There is often conflict as the non-disabled siblings feel that they are being treated unfairly. This can lead to beliefs that the disabled child is the parents' favorite because of the time spent helping the disabled child and excusing the negative behaviors. This should be addressed early; setting reasonable expectations of the disabled child and having them complete appropriate chores. Although they may not be able to do the chores expected of the non-disabled child, they should be held accountable for their responsibilities and disciplined in a developmentally appropriate manner. In this way non-disabled children see that they are not solely responsible for chores about the home and don't experience feelings of rejection as the "less favored" child. It also helps the disabled child learn what is expected of them so that they are prepared to accept responsibilities as they begin school or participate in social groups. It is also important to regularly (and often) praise the non-handicapped child for the efforts that they make and the help that they provide.

Siblings are also the first people that we learn to fight with, compromise and make up with. It is very important that all members of the family be open and honest in expressing their feelings (NICHCY, 1994; ARCH, 1993; Rubin, 2002; Rainbow Babies, 2001; Baylor, 1999). Often non-disabled siblings are fearful of adding to the family stress level and hold their feelings inside to avoid conflict. They may feel guilty for their

feelings of anger and embarrassment and be reluctant to express these for fear of being scolded or thought to be "bad". Openly discussing the feelings helps these children keep from holding in these feelings until they spill out in explosive anger, depression, or show up in physical complaints such as headaches and stomach aches. Children are wonderful barometers of family tension. If they are not told what is causing this tension, they often believe that they have caused it (NICHCY, 1994). By having parents that model their own feelings openly and honestly, the children learn to manage their feelings more effectively and avoid many of the costly mental and physical symptoms that affect both themselves and the whole family (Janes-Hodder & Keene, 1999). In this way these feelings are likely to be addressed gently on a day-to-day basis rather than through more painful confrontations.

Siblings will often ask questions that will become more detailed as they grow older (SIOP, 1999). They may have a strong need to have as much information as they can about the disability that endures their whole lifetime and frequently become advocates for individuals with special needs (ARCH, 1993). Again, it is important for families and professionals to answer these questions as openly and honestly as possible, while taking into consideration the child's developmental level. Just because a child can explain his brother or sister's condition to others does not mean that he/she understands how the disability will impact his/her own life (NICHCY, 1994). He/she may not realize that his/her sibling is handicapped until school begins. Just because a child lives with a brother or sister with a disability does not mean that they understand it. They have to be told specifically about the limitations (and strengths) that having a disability can cause. Having information puts fears into perspective. In most cases, the fear of the "unknown" is worse than the reality of the truth. Without this knowledge, non-disabled children may feel that their parents are not protecting their disabled sibling or that others are hurting him/her (Rainbow Babies, 2001). This may lead to fearfulness of medical professionals and difficulty trusting others. Although fear, embarrassment, and anger still occur, knowledge helps the individual to cope. Even though the provision of information and communication is very important, it is also important to let each child determine how much information he or she wants to hear (SIOP, 1999). Resistance is a good indicator or an individual's coping style and readiness to cope with more information. Some children prefer to know as much as possible, while others don't want to know any more information than they have to. Both methods are normal and healthy as long as they do not cause increased stress for the child or disruptions in the family.

As the non-disabled siblings get older, they may have fears about the future (NICHCY, 1994). Parents also experience these fears, but may be reluctant to express them to their children. Teenagers begin to wonder what will happen to the disabled child when their parents die or are too old to care for them. They may assume that it will be their responsibility to take care of the adult disabled sibling and fear how potential mates and friends will react. Although, many siblings chose to help in the care of their disabled brothers and sisters, this should not be an assumption. Research suggests that older sisters most often bear the brunt of the responsibility and often feel resentful of this expectation (ARCH, 1993). Having a financial plan and will that specifically states how this child is to be cared for will help to reduce the stress a sibling experiences,

particularly in the case of a sudden death of one or both parents (NICHCY, 1994). Setting up this plan when the disabled child is still a young child is also important as there are often waiting lists for services and housing, particularly as the individual becomes an adult. Speaking openly about these plans as the non-disabled child becomes old enough is strongly suggested. Having both the non-disabled and the disabled siblings participate in this decision-making is imperative in setting up an effective plan with a transition that is as smooth as it can be. Handicapped siblings may want to experience independence at the level that they are capable and should be encouraged to make plans for their life beyond the family home. In this way they feel encouraged and trusted by others to do as much for themselves as possible, while feeling secure in the understanding that someone will be there to help them if they make a mistake.

How the family is likely to react to the stress of having a child with a disability depends on many factors, including family and community resources, current stressors, financial resources, the number of children in the family, the severity of the disability, acceptance of the disabled child, communication between family members, family coping skills, and child-rearing practices (NICHCY, 1994). Siblings of these children have a unique relationship with their brother/sister and can play a major role in helping to maintain family cohesiveness. However, without help, they are likely to have problems that make family unity even harder. Information provided by the Baylor College of Medicine, the Esophageal Atresia/Tracheosophageal Fistula Child and Family Support Connection, Pediatric Physical Therapy, Inc., Rainbow Babies and Children's Hospital, the University of Connecticut, and NICHCY (National Information Center for Children and Youth with Disabilities websites suggest the following in helping siblings of disabled children.

- Discuss feelings and emotions openly and honestly and let them know that all feelings are ok;
- Be truthful in each situation
- Allow siblings to become actively involved in the care of the ill child;
- Work to recognize the sibling's concerns (they may not be obvious);
- Provide jobs or tasks for the sibling and the disabled child to feel a part of the family;
- Make time for each child as well as the family as a whole;
- Allow all children time to be on their own;
- Inform others including teachers, relatives, parents of the children's friends about the situation;
- Continue usual family activities and encourage participation in activities outside the home;
- Understand the grief process (denial, bargaining, anger, sadness, and acceptance);
- Keep schedules as routine as possible;
- Encourage children to visit their siblings in the hospital, however, if they are hesitant, allow them to chose whether they will go or not;
- Keep communication open even during hospital visits or separations through telephone calls, email, and letters;
- Allow the sibling to determine whether or not to participate in discussions regarding the disability and how much information that he/she wants to know;
- Seek family and sibling support groups;

- Plan in advance, some events for each child to bring a sense of normalcy, hope and excitement for the future;
- Make financial plans and will early to ensure the care of the disabled sibling and choices for the non-disabled sibling;
- Include both the non-disabled and disabled child in family decisions and plans for the future;
- As much as possible, minimize expectations of older siblings to care for the handicapped child; and
- Attempt to emphasize the positive abilities of the handicapped child rather than the disabilities;

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