

Tool Kit

For Siblings of Children with Special Needs

May 2011



MACOMB INTERMEDIATE SCHOOL DISTRICT
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We are the Macomb Intermediate School District.

We exist to provide our clients quality service, high caliber support, and cutting edge leadership.

Our primary clients are the 21 school districts of Macomb County. They are our most important customers – indeed, our reason for being.

Within these districts we focus our efforts on school staff. We work to increase their skills and capabilities so their students can experience more effective educational programs.

We also serve the handicapped. In fact, we are committed to working directly with youngsters with disabilities who reside in Macomb County's school districts.

And we are involved with the educational community across the country. Many of our staff members are leaders in state and national programs. Many are working with colleges and universities. Still others are exchanging information with their professional colleagues. All these activities have a single purpose: to identify and develop techniques and programs that improve learning opportunities in Macomb County.

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Table of Contents

	Page
Preamble	4
Overview	5
Effects on Siblings	5
Effects on Children with Special Needs	7
Effects on Family	7
Service Coordinator Considerations	9
Intervention Strategies	10
Considerations for Families	11
Recommended Books	18
References	20
Acknowledgements	21

Preamble

This tool kit was created to help families and children with special needs. We hope that the information provided in this tool kit will help ease familial worries and help families have a better understanding of what to expect from all of their children when coping with special needs.

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

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

Children with special-needs are children first. They are members of our families and our community. Acknowledging that each of us has our own particular strengths and needs will help all of us build a stronger society.

Overview

The ERIC Clearinghouse on Disabilities and Gifted Education states that 5.8 million children are diagnosed with a disability. Although dealing with a mentally, physically or emotionally challenged child can be difficult for parents, it can also affect the child's siblings when they are growing up. While some of the emotional effects can be negative, such as depression, they can also result in positive emotional effects, with the siblings being more compassionate and understanding of other people's differences.

The birth of a child with a disability or chronic illness, or the discovery that a child has a disability, has a profound effect on a family. Children suddenly must adjust to a brother or sister who, because of their condition, may require a large portion of family time, attention, money and psychological support. Yet it is an important concern that the child adjust to the sibling with a disability. It is important because the child's reactions to a sibling with a disability can affect the overall adjustment and development of self-esteem in both children.

In any family, each sibling and each relationship that siblings have, is unique, important and special. Brothers and sisters influence each other and play important roles in each other's lives. Indeed, sibling relationships make up a child's first social network and are the basis for his or her interactions with people outside the family (Powell & Ogle, 1985). Brothers and sisters are playmates first; as they mature, they take on new roles with each other. They may, over the years, be many things to each other -- teacher, friend, companion, follower, protector, enemy, competitor, confidant, role model. When this relationship is affected by a sibling's disability or chronic illness, the long-term benefits of the relationship may be altered (Crnic & Leconte, 1986). For example, the child with a disability may have limited opportunities to interact with other children outside the family; thus, social interaction between siblings often takes on increasing importance.

Brothers and sisters of children with special needs are too important to ignore. Authors of Sibshops: Workshops for Siblings of Children with Special Needs, Donald J. Mejer and Patricia F Vadasy, say that despite the important and lifelong roles siblings will play in the lives of their siblings with special needs, even the most family-friendly agencies often overlook brothers and sisters. Brothers and sisters, often left in the literal and figurative waiting rooms of service delivery systems, deserve better. True family-centered care and services will be achieved when siblings are actively included in agencies' functional definition of "family."

(<http://specialchildren.about.com/od/supportforsiblings/a/siblingsknow.htm>)

Effects on Siblings:

Each child's personality and temperament plays an important role in his response toward a sibling, including one with a disability. Each child's reaction to having a sibling with a disability will vary depending on his or her age and developmental level. The responses and feelings of the child toward the sibling with a disability are not likely to be static, but rather tend to change over time as the child adapts to having a brother or sister with a disability and copes with day-

Macomb Intermediate School District

to-day realities. Siblings of children with special needs have special needs themselves. Their sister or brother with special needs *will* get a bigger share of attention. While having a sibling with special needs presents challenges, it also comes with opportunities. Kids who grow up with a sibling with special health or developmental needs may have more of a chance to develop many good qualities, including:

- Patience
- Kindness and supportiveness
- Acceptance of differences
- Compassion and helpfulness
- Empathy for others and insight into coping with challenges
- Dependability and loyalty that may come from standing up for their brother or sister
- Ability to advocate

“He is soooo funny! And he helps me be friends with kids like TJ (a child with autism in her class). Even my teacher says I am a good friend to TJ. It’s one of my talents!”

Summer, 5, sister

Siblings also can grow up feeling the negative effects of having a sibling with special needs. Siblings of children with special abilities or needs may act out to get parents' attention. The impact on family dynamics can go much deeper particularly with siblings of children with special-needs, who may:

“Kids sometime make fun of my brother and it makes me sad and I have to say, ‘Don’t make fun of my brother! He has seizures and other stuff he can’t help it!’ cause I am mad. Sometimes I get embarrassed when kids make fun of him if I’m playing with him cause then they might think that I’m like that, too.”
Summer, 5, sister

- Feel alone or jealous about extra attention for their sibling and interpret it as rejection
- Wish they had medical problems to get more attention
- Worry they might "catch" what their sibling has
- Be overly helpful or non-compliant for attention
- Try to ease parents' burdens by not making demands or feeling guilty if they do
- Feel guilty for their own good health or have negative thoughts about their sibling with special-needs
- Feel embarrassed or resent having to involve their sibling with neighborhood friends
- Resent having to care for a sibling or worry about their sibling's future

Depression

Depression, a serious mood disorder in which the patient feels sad or worthless, can affect siblings of a mentally challenged child. The Vanderbilt Kennedy Center reports that research done at the University of Wisconsin-Madison found that 63 percent of siblings experience depression. Depressive symptoms may be linked to other emotional difficulties, such as the child being resentful or embarrassed by her challenged sibling. The depressed child may also be scared about her sibling, feel

Macomb Intermediate School District

guilty about being "normal," or be angry about a lack of attention from her parents. Red flags for depression include withdrawal, frequent crying, hopelessness, appetite changes, loss of interest, sudden or gradual marked behavior changes, and talking about self-mutilation.

Pressure to Perform

The sibling of a challenged child may feel extra pressure on him, either to take care of his sibling or do the activities that his sibling cannot. Even if the parents are not putting the pressure on the child, he may feel as though they are. The child may also feel lost or ignored, thinking that all of the attention is being directed at the challenged sibling. Parents should be aware of signs that the child needs help or more one-on-one time. If the child strives for perfection and has poor concentration or self-esteem, parents may consider those signals and act accordingly. Siblings may feel obligated to compensate for the child with the disability, to make up for that child's limitations. They may be acting as a surrogate parent, assuming more responsibility than would be usual in the care of a sibling.

Effects on Children with Special Needs:

Children with special needs also experience stress as family members. These common stresses include frustration at not being able to make themselves understood; unhappiness at being left to play alone; irritation over constant reminders about everything; withdrawal because of lack of social skills; low self-esteem and anger resulting from an inability to do things as easily and quickly as their brothers and sisters. Through it all, with understanding and support, there are usually many positive interactions and normal sibling give-and-take situations from which each learns and matures.

Effects on Family:

All too often child with special needs can quickly become the center of family attention, for better or worse. While an intensive focus on therapy and treatment can be good for the child receiving the services, siblings can often feel neglected -- and if one parent is taking on most of the burden or disagrees with the course being followed, strain can show in a marriage as well.

Dr. Scott L. Barkin, Executive Director of the Block Institute in Brooklyn, N.Y., says concerns of parents of a child with special needs with typically developing siblings can include any or all of the following:

- As a parent am I giving each of my children all the attention they need and desire, or am I neglecting my "typically" developing child(ren)?
- Will my typically developing child have to make too many sacrifices?
- Will my children develop a relationship? Will they play together?
- Will my typically developing child become resentful?

Macomb Intermediate School District

"My advice to parents isn't simply to make sure you spend X amount of time with each child," Barkin says. "This needs to be done in conjunction with investing in processing who your child is. Every child needs to believe they are understood, appreciated, regarded and acknowledged. What each child requires to feel that is different."

"Relationships between siblings, with or without the presence of a disability, develop in encouraging, nurturing environments," Dr. Barkin says. "These relationships require love, commitment, respect, patience, communication and universally are not always easy."

One thing all these moms strive to remember is that their typical children have feelings that must be allowed to be expressed. Programs such as Sibshops, which has workshops in the United States and internationally, acknowledge that being the brother or sister of a child with special-needs can be difficult. Sometimes siblings feel good; sometimes they feel bad. A lot of the time they feel somewhere in between.

Sibshops authors, Meyer and Vadasy, stress the inclusion of siblings in all areas surrounding the child with the special needs for several reasons:

- These brothers and sisters will be in the lives of family members with special needs longer than anyone else. Brothers and sisters will be there after parents are gone and special education services are a distant memory. If these brothers and sisters are provided with support and information, they can help their siblings live dignified lives from childhood to their senior years.
- Throughout their lives, brothers and sisters share many of the concerns that parents of children with special needs experience, including isolation, a need for information, guilt, concerns about the future and caregiving demands. Brothers and sisters also face issues that are uniquely theirs, including resentment, peer issues, embarrassment and pressure to achieve.

Finally, the positive or negative nature of the relationships between siblings and among family members may be influenced by factors such as these:

- the family's resources
- the family's lifestyle
- the family's child-rearing practices
- the kind and severity of the disability
- the number of children in the family
- the age differences between children in the family
- the other stress-producing conditions that exist in the family
- the kinds of coping mechanisms and interaction patterns that exist within the family
- the kind and quality of the support services available in the community

Service Coordinator Considerations:

Preschool-aged siblings, for example, may feel confused, afraid, anxious, and angry about a brother or sister's disability or illness. All children are different; the intensity of a child's concerns, needs, and experiences will vary from sibling to sibling, as will a child's reaction to and interpretation of events. The younger the child the more difficult it may be for him or her to understand the situation and to interpret events realistically. Siblings may resent the time their parents give to the sibling with a handicap and perceive it as rejection. They may wonder what is wrong with them that their parents love their sister or brother with a disability more. During the early years the sibling may mimic the physical or behavioral actions of the child with a disability, or the sibling may regress in behavioral development. Later on, he or she may be prone to extremes of behavior such as "acting out" or becoming the "perfect" child.

"During one of my son's long seizures, when he first began getting them, my 5 year old daughter began rolling on the floor and shaking."
A mom

Elementary school-aged children may feel embarrassed or ashamed as they recognize differences between their sibling and someone else's brother or sister. They may worry about "catching" or developing the problem, and they may feel guilt because they themselves do not have a disability. They may also feel protective and supportive of their sibling, and this may trigger conflicts with peers.

"Sometimes I worry about the possibility of having a child with Autism Spectrum Disorder since several members of my family have this condition. Having a sister with Asperger's Disorder has taught me a lot, but it is still scary to think that I may have to face this kind of challenge with my own kids."
Amanda, 27, sister

Young adults may have future-oriented concerns. They may wonder what will become of their brother or sister with a disability. They may also be concerned about how the people they socialize with, date, and later marry will accept the brother or sister with a disability. Additional issues faced by young adults may include

genetic counseling when planning their own families, and coping with anxiety about future responsibilities for the brother or sister with a disability or illness.

"I sometimes get so frustrated with my brother, but I know it is not his fault. Don't get me wrong—I love him like he is. You know, I have always wanted to spend just one day like him just to know how he feels and thinks."
Dean, 18, brother

Parents and professionals need to be aware that there may be a gap between the sibling's knowledge and actions. A sibling may be able to rationally explain a brother's or sister's disability to inquiring friends or neighbors, but may still exhibit temper tantrums over the same sibling's actions in the home.

Most importantly, the need for information and understanding does not have to be addressed solely by the parents. A child's disability is a concern that should be shared by parents, helping professionals, the community and society.

Macomb Intermediate School District

Intervention Strategies:

Parents set the tone for sibling interactions and attitudes by example and by direct communications. In any family, children should be treated fairly and valued as individuals, praised as well as disciplined and each child should have special times with parents. Thus, parents should periodically assess the home situation. Although important goals for a child with special needs are to develop feelings of self-worth and self-trust, to become as independent as possible, to develop trust in others, and to develop to the fullest of his or her abilities, these goals are also important to siblings.

To every extent possible, parents should require their children with disabilities to do as much as possible for themselves. Families should provide every opportunity for a normal family life by doing things together, such as cleaning the house or yard; or going on family outings to the movies, the playground, museums or restaurants. Always, the child with the disability should be allowed to participate as much as possible in family chores, and should have specific chores assigned as do the other children.

All family members should share caregiving responsibilities for the child with a disability or chronic illness. It is especially important that the burden for caregiving does not fall onto the shoulders of an older sibling. If there is an older sister, there is a tendency in some families to give her the primary responsibility, or an excessive amount of it. Today, however, more communities are providing resources to ease the family's caregiving burdens. Examples include recreation activities, respite care and parent support groups.

Powell and Ogle (1985) present several strategies suggested by siblings themselves for parents to consider in their interactions with their children. These siblings suggest that parents should:

- Be open and honest
- Limit the caregiving responsibilities of siblings
- Use respite care and other supportive services
- Accept the disability
- Schedule special time with the sibling
- Let siblings settle their own differences
- Welcome other children and friends into the home
- Praise all siblings
- Recognize that they are the most important, most powerful teachers of their children
- Listen to siblings
- Involve all siblings in family events and decisions
- Require the child with special-needs to do as much for himself or herself as possible
- Recognize each child's unique qualities and family contribution
- Recognize special stress times for siblings and plan to minimize negative effects
- Use professionals when indicated to help siblings
- Teach siblings to interact
- Provide opportunities for a normal family life and normal family activities
- Join sibling-related organizations

Macomb Intermediate School District

Children with special-needs, disabilities or chronic illness may often need more help and require more attention and planning from their parents and others in order to achieve their maximum independence. The special and unique bond among siblings can foster and encourage the positive growth of the entire family.

Considerations for Families:

Sibling Rivalry

It is impossible to treat all children equally; however, parents should be as fair as possible and take steps to minimize sibling rivalry. Pediatrician Scott Steinberg, MD. says that dealing with misperceptions and emotional responses can help prevent rivalry and starts with fostering communication. "Try to be a good listener. Encourage siblings to express themselves, including negative feelings. Ask them what they like best and least about each other. Let your children know it's okay to get mad at their special-needs sibling and not to feel guilty if they sometimes resent the extra attention." One good way to combat misperceptions, he says, is to describe to children their sibling's special needs or abilities, starting with simple explanations around ages 5 or 6. "Share with them how a health condition is evaluated and treated and what to expect. Talk about their sibling's strengths and weaknesses and the best ways to interact with that child."

*"It isn't fair when Lukey gets to miss school for a test at the hospital. He gets prizes and treats from everyone **and** no school!"*
Summer, 5, sister

Another suggestion from Steinberg is to be sure to have children with special-needs do as much for themselves as they can and assign them tasks so everybody has responsibilities. Do chores together as a family. He suggests setting siblings up to cooperate rather than compete, for instance by having them race against the clock as a team rather than individually to complete chores. He also recommends devoting time to family activities that everyone enjoys.

"Let each child know he or she is special," Steinberg says. "Make sure they're able to develop their own interests and identity. Try to get a few minutes a day alone between each parent and child." Exclusive time with parents will be especially valuable to the sibling of the child with special-needs. He also cautions against overburdening older children with care duties for their siblings. All siblings of the child with special-needs can be enlisted as "partners" with parents in understanding and addressing their sibling's requirements.

In addition, sibling support groups can connect children with others who have similar experiences. The [Sibling Support Project](#) facilitated a discussion on [SibNet](#), its listserv

Macomb Intermediate School District

for adult siblings of people with disabilities, regarding the considerations that siblings want from parents, other family members and service providers. The following are sixteen different themes discussed by SibNet members and recommendations from the Sibling Support Project:

1. The Right to One's Own Life

Throughout their lives, brothers and sisters may play many different roles in the lives of their siblings with special 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 that typically developing siblings may assume without a frank and open discussion. *"Nothing about us without us"* -- a phrase popular with self-advocates who have disabilities -- applies to siblings as well. Self-determination, after all, is for everyone -- including brothers and sisters.

"During my formative years I would say there was some jealousy due to the significant amount of time and attention my parents spent on my younger sister. However, it wasn't a huge factor in that I was quite a bit older than her. In addition, I think as a youth it is pretty common to have some feelings of embarrassment being associated with a special needs sibling, but my experience is you grow out of that attitude pretty early on. As I grew older, I became more protective of her and understanding of the sacrifices my parents made, and appreciated her more as an individual."

Bob, 62, brother

2. Acknowledging Siblings' Concerns

Like parents, brothers and sisters will experience a wide array of often ambivalent emotions regarding the effect their siblings' special needs has on them and the family as a whole. 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' lifelong and ever-changing concerns.

3. Expectations for Typically Developing Siblings

Families need to set high expectations for *all* of their children. Some typically developing brothers and sisters, however, react to their siblings' disability by setting unrealistically high expectations for themselves, and some feel that they must somehow compensate for their siblings' special needs. Parents can help their typically developing children by conveying clear expectations and unconditional support.

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 brothers and sisters -- even when one has special needs. Although 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

Macomb Intermediate School District

result in feelings of guilt when one sibling has special health or developmental needs. When conflict arises, the message sent to many brothers and sisters 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 Special Needs

When families have high expectations for their children with special needs, everyone will benefit. As adults, typically developing brothers and sisters will likely play important roles in the lives of their siblings with disabilities. Parents can help siblings now by assisting their children with special 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 special 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 siblings who have special needs.

"My brother and sister and I all have chores to do around the house, but not my other brother with Down syndrome. My parents think he can't even unload the dishwasher. But, I know he can because I make him do it when they go out!"

Rachael, 15, sister

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 with special needs.

"My sister and I were talking about visiting the Toledo Zoo with Early On® one summer. We both still remember though it has been over 10 years. We expected to be the older kids, "helpers". At a time when we felt somewhat in the way, we were able to fit in with the group, be with all the kids (siblings of kids in the program with their siblings) and have lots of snacks. We didn't have any added responsibilities; we were just kids. We still are impressed with this trip and we all have a good time remembering this adventure."

Kay, 27, sister

7. Opportunities to Meet Peers

For most parents, the thought of "going it alone" -- raising a child with special needs without the benefit of knowing another parent in a similar situation -- would be unthinkable. Yet, this routinely happens to brothers and sisters. Sibshops, listservs such as SibNet and [SibKids](#), and similar efforts offer siblings the common-sense support and validation that parents get from Parent-to-Parent programs and similar programs. Brothers and sisters -- like parents -- like to know that they are not alone with their unique joys and concerns.

8. Opportunities to Obtain Information

Throughout their lives, brothers and sisters 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. Siblings' Concerns About the Future

Early in life, many brothers and sisters worry about what obligations they will have toward their sibling in the days to come. Parents can reassure their typically developing children by making plans for the future of their children with special needs, listening to their typically developing children's suggestions as they make these plans, considering backup plans, and realizing that their typically developing children's availability may change over time. When brothers and sisters are brought "into the loop" and given the message early that they have their parents' blessing to pursue their own dreams, their future involvement with their sibling who has a disability will be a choice instead of an obligation. For their own good and for the good of their siblings with 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 with disabilities as adults and the level, type and duration of that involvement.

"Oh. I honestly never gave much thought to having an aunt with special needs. I was never embarrassed about it as a kid or anything. As I got older I more just thought about how the care for her would impact my parents."

Rob, 34, nephew

"Well the most difficult thing about having a special needs sibling (as an adult) is when your parents have not adequately planned for that siblings' adult life and have basically left it to the other children to figure it out and to assume that responsibility for the rest of their adult lives."

It causes friction between spouses and other siblings and stress and worry about what will become of that sibling after we are no longer able to care for her. It is hurtful to watch her be treated as "wallpaper" by other family members who often ignore her even when she is in the same room. And even though our parents were reluctant to make hard decisions when she was younger, it is unfair that she should carry the blame for what she cannot now do at 50+ years that maybe she might have been able to do if other choices were made for her when she was younger."

My advice to special need parents would be to make sure you have a plan in place to provide for that child as an adult. If not everyone in your family will be hurt including the special needs child."

Judy, 66, sister

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 special needs when parents no longer can. Serious exploration of sharing responsibilities among siblings—including brothers—should be considered.

11. Communication

Although good communication between parents and children is always important, it is especially important in families where there is a child who has special needs. An evening course in active listening can help improve communication among all family members, and books such as *How to Talk*

So Kids Will Listen and Listen So Kids Will Talk (2004) and *Siblings without Rivalry* (1999) (both by Adele Faber and Elaine Mazlish) 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 grab a bite at a local burger joint or window shop at the mall 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 special needs. We've also met siblings whose wedding plans were dictated by the needs of their sibling with a disability. One child's special needs should not overshadow another's achievements and milestones. Families who seek respite resources and creative solutions and strive for flexibility can help ensure 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.

*"However I present
my child is usually
how others
perceive him!"
A mom*

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 special needs -- the sisters and brothers. When brothers and sisters receive the considerations and services they deserve, agencies can claim to offer "family-centered" -- instead of "parent-centered" -- services.

16. Actively Reach Out to Brothers and Sisters

Parents and agency personnel should consider inviting (but not requiring) brothers and sisters to attend informational, individualized education plan (IEP), individualized family service plan (IFSP), transition planning meetings and clinic visits. Siblings frequently have legitimate questions that can be answered by service providers. Brothers and sisters also have informed opinions and perspectives and can make positive contributions to the child's team.

When to Seek Help

Sometimes sibling's have feelings that can so intense or disruptive that a child may need some professional counseling to help him cope. Signs to watch for include sleep or appetite disturbance, hopelessness, poor concentration, low self-esteem, talk of hurting oneself, loss of interest in activities, frequent crying or worrying, difficulty separating from parents, perfectionism, or what can be physical symptoms of emotional distress, such as headaches or stomachaches. Meeting and talking with other kids going through the same thing can also be very helpful, however, a pediatrician should be contacted if a child displays any of the warning signs.

Message from a sister

I have four siblings: an older brother, an older sister, and two younger sisters. My youngest sister Sarah has Down syndrome. I was eleven years old when she was born and my other younger sister Leah and I had just transferred to a private school; our older siblings were already in high school. It seemed Leah and I were miles away in another world. There was so much to try and understand during the first year of Sarah's life for everyone in my family. I remember going to appointments with my parents and meeting the Cardiologists and Ophthalmologist who introduced themselves to me as if we would be seeing each other again. A lot of this went over my head but I wanted to understand and I wanted my baby sister to be healthy. It seems like everything was so unknown then and I didn't really know what I was supposed to be worried about because Sarah seemed fine despite her diagnosis.

As the months passed, every milestone Sarah was heading toward became a very important goal. It was a silent understanding which Leah and I arrived at to become Sarah's playmates, but as our mother had emphasized, we must be good examples, too. It was in probably March or April when Sarah began to watch me when my family would be sitting together for dinner. Sarah would stare at me from across the table, completely serious, undistracted, an unchanging expression on her

"We have decided we are going to get our daughter some counseling. She isn't sleeping, cries all of the time, doesn't enjoy the things that she used to, and has had some of those other warning signs. It's been like that since my son first had problems. I just kept thinking they would go away on their own if she had some time, only they haven't. My kids share a bedroom because we have a two bedroom home. Since we have my son's night seizures fairly controlled, we recently moved him out of our room and back in with his sister. Every night since, our daughter has run into our room screaming that he is having a seizure. We always run to check, but it has not once been a seizure. Then, last night, our daughter came downstairs after being in bed for about an hour and broke down in tears. "Every time he moves I'm afraid he is having a seizure again. Then, mom will cry, the police and ambulance men will come again and they'll have to take him to the hospital again. And I hate those men!" She also said, "I wish I was the little sister with the seizures or that I didn't have anybody because I can't take this anymore." It made me sad for her because the last time the ambulance was at our house was six months ago. For her to still be terrified told me that she still must be harboring a great deal of stress, anxiety, and responsibility." A mom

Macomb Intermediate School District

face, as I ate, talked. I was a little awkward already as I was almost 12 years old but this was really uncomfortable and it seemed nothing I did could break her gaze. She did this every evening. I finally realized she was not looking for something specific from me, she was simply observing and soon enough, she began to copy me. So, I have tried to be a good example for Sarah to follow, hopefully not disappointing her too much as well as for my other little sister, Leah.

I think Leah and I adopted self-awareness behaviors, becoming conscientious of our actions, words and emotions as much as we could at our ages. We both have very different relationships with Sarah, but Leah and I are also close, we still have that silent understanding of taking care of our little sister. When I talked to Leah about this “tool kit”, she thinks this is “awesome” that there is so much understanding for siblings of children with special needs, but she was quick to clarify that she would never want Sarah to feel badly about being a different kind of sibling.

Recommended Books:

For parents:

- It Isn't Fair! Edited by Stanley D. Klein and Maxwell J. Schleifer
Presents a wide range of perspectives on the relationship of siblings to children with disabilities, written by parents, young adult siblings, younger siblings, and professionals. The issues of fairness, expectations, rewards, punishments, caretaking responsibilities, and negative feelings are all thoroughly discussed.
- Living with a Brother or Sister with Special Needs: A Book for Siblings, by Donald Meyer and Patricia Vadasy
May be useful for both parents and children to read.
- Brothers and Sisters: A Special Part of Exceptional Families, by Thomas Powell and Peggy Gallagher
- Siblings Without Rivalry, by Adele Faber and Elaine Mazlish
A real classic—a quick and easy read with powerful techniques you can start using right away.
- How to Cope with Mental Illness in Your Family: A Self Care Guide for Siblings, Offspring and Parents, by Diane Marsh, Rex Dickens and E. Fuller Torrey
- How to Talk So Kids Will Listen and Listen So Kids Will Talk by Adele Faber and Elaine Mazlish
- When Madness Comes Home: Help and Hope for the Children, Siblings and Partners of the Mentally Ill, by Victoria Secunda

For children:

- We'll Paint the Octopus Red, by Stephanie Stuve-Bodeen
Ages 3-7. Emma's baby brother Isaac is born with Down syndrome.
- Ben, King of the River, by David Gifaldi
Ages 5-8. Chad, the older brother of a developmentally disabled boy, narrates this story about the family's first camping trip. Chad's frank story-telling gets across the highs and lows of the trip and of life with Ben, and his mixed emotions. Includes a page of tips for siblings of kids with special needs.
- My Brother, Matthew, by Mary Thompson
Ages 4-11. Offers a sibling's point-of-view of the ups and downs of life when your brother is born with a disability. David, the older brother, wryly shares the worry, impatience, feeling left out, being talked down to by grown-ups—and the positive ways in which he has built a unique relationship with his brother.
- Way to Go, Alex!, by Robin Pulver
Ages 4-8. Carly feels the dual emotions that many siblings of special-needs children may feel. Her older brother Alex participates in the Special Olympics.
- Sara's Secret, by Suzanne Wanous
Ages 7-9. Sara's secret is her little brother Justin, who has cerebral palsy and mental retardation. Her love for him and the discomfort he causes her at school are realistically portrayed.

- My Sister Annie, by Bill Dodds
Ages 8-15. Twelve-year-old Charlie's sister Annie has Down syndrome. This is a thoughtful novel about his growing pains and struggle to accept a sister who is "different".
- Views from Our Shoes: Growing Up With a Brother or Sister With Special Needs, edited by Donald J. Meyer
For ages 7 and up. 45 children aged 4-18 contributed to this book. They share their experiences as the brother or sister of someone with a disability—the good and the bad, as well as many thoughtful observations.
- The Summer of the Swans, by Betsy Byars
Ages 9-15. A 14-year-old girl's mentally retarded little brother gets lost, and the family realizes how much they really appreciate him.
- A Real Christmas This Year, by Karen Williams
Ages 9-15. Megan's special-needs little brother makes life harder on her family, just when she already has lots of things going on in her own life. Realistically portrays the life of the family in caring for a disabled child.
- Welcome Home, Jellybean, by Marlene Shyer
Ages 9-15. Neil's sister, Gerri, comes home from an institution to live with their family.
- Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters, by Brian Skotko & Susan Levine
Written for teens who have a brother or sister with Down syndrome. In an easy-to-read, question & answer format, it tackles a broad range of their most common issues and concerns.

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