

DOWNLOAD PDF PROVIDING INFORMATION TO CHILDREN WITH SIBLINGS WITH DISABILITIES

Chapter 1 : How to Plan (& Provide) for a Child with Special Needs - The Simple Dollar

Keep in mind that growing up with a special needs sibling teaches valuable skills and empathy, notes Dr. Silverman. "Sometimes children who have siblings with special needs have a level of compassion that makes them especially good friends, and they have a lot of friends, because they are patient and positive and understanding."

The responses and feelings of the non-disabled sibling toward the sibling with a disability are not likely to be static, but rather tend to change over time as the sibling adapts to having a brother or sister with a disability and copes with day-to-day realities. The younger the child the more difficult it may be for him or her to understand the situation and to interpret events realistically. Non-disabled 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 non-disabled sibling may mimic the physical or behavioral actions of the child with a disability, or the non-disabled sibling may regress in behavioral development. 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. 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.

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Family stress factors The birth of a child with a disability, or the discovery that a child has a disability, can produce stress among family members. Stress can also be caused by a number of ongoing factors, or by special circumstances. Siblings need an explanation for the tensions within the family and the cause of the tensions. Some families are stressed by the amount of financial resources required to meet the needs of the child who has a disability. Some parents may expect non-disabled siblings to accept the brother or sister with a disability as "normal. Parents have to sit down and talk to the brothers and sisters who are non-handicapped about what the handicap really means. They may be acting as a surrogate parent, assuming more responsibility than would be usual in the care of a family by providing their parents with assistance and support, which they otherwise might not have, in the care of the child with a disability. The non-disabled child may experience jealousy because he or she may be required to do family chores, whereas, the sibling with a disability is not required to do them -- despite the fact that the sibling with a disability may be unable to do them, or would have great difficulty doing them. The non-disabled sibling may resent having to integrate the sibling with a disability into the neighborhood peer group, and may experience or perceive peer rejection because of having a sibling with a disability. Siblings with disabilities, on the other hand, 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 non-disabled 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. When parents have a double standard for disabled and non-disabled children, conflicts can arise. Even though the child with the disability, in fact, may need and receive more parental attention, the amount given may be perceived as unfair by non-disabled siblings. Some parents, on the other hand, may tend to overindulge the normal sibling in an effort to compensate for a brother or sister with a disability. The normal rivalry between all siblings may cause the non-disabled sibling to perceive incorrectly that the parents favor or love best the sibling with a disability. Mary expressed the resentment she feels when her brother is dealt with lightly in comparison to her punishments: McKeever tells us that siblings generally are poorly informed about disabilities. It is important to bear in mind that they have limited life experiences to

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assist them in putting a disability into perspective Featherstone, Non-disabled siblings may require information throughout their lives in a manner and form appropriate to their maturity. For many siblings, anxiety-producing feelings often are not expressed in day-to-day family interactions and discussions, and are shared even less at school. These internalized feelings complicate sibling relationships, for children need to vent their emotions. Most importantly, the need for information and understanding does not have to be addressed solely by the parents. For example, some progressive clinics and hospitals have designed programs that include siblings from the beginning. These programs offer Family Support Groups which bring entire families together as a means of sharing information and mutual support. Educators can do much to promote positive sibling interactions as well as acceptance of disabilities in all children. During the school years, especially the early years, teachers can help to promote sibling awareness and interaction by providing opportunities for siblings to learn about disabilities. For example, conducting a "sibling day" or a sibling workshop can be an excellent way of introducing siblings to a variety of disabilities. A "sibling day" can be held on a school day or on a weekend. On this day, activities can include a presentation by "Kids on the Block," disability simulation games, sign language instruction, and sharing positive experiences about having a sibling with a disability. For example, siblings of students with orthopedic impairments might see a physical therapy room and go through activities a student might perform in physical therapy. Siblings of students with hearing impairments might learn a song or poem in sign language. Information puts fears into perspective. In most instances, simply knowing the facts about a disability or chronic illness takes away the sting of embarrassment, as well as uncertainty and fear. While embarrassment can and does occur in many situations over the years, knowledge can help one cope. Ask parent groups, social workers, therapists, doctors, teachers, or counselors about the availability of support groups and other sibling resources in your area. Back to top

The impact on a sibling with a disability or chronic illness Most of the sibling research has focused on the effects of a child with a disability or chronic illness on non-disabled siblings. Also important is the influence of the non-disabled sibling on the child with a disability or chronic illness. While very little work has been done in this area, researchers do stress the reciprocity of sibling relationships. Back to top

Planning for the future: Sibling concerns Planning for the future raises many important issues for the family of a child with a disability. Powell and Ogle note that the most challenging of these dilemmas is the care of the adult sibling who has a disability. Even though non-disabled adult siblings have lives and often families of their own, they face unusual, additional responsibilities because of their unique relationship with their brother or sister with a disability. The amount of responsibility that adult non-disabled siblings assume for their adult sibling with a disability varies with individuals and with circumstances. It is dictated by a consideration of family and job responsibilities, personal choice, and available community support. Perhaps the most challenging issue families face is, on the one hand, encouraging and fostering the independence and self-determination of the person with a disability and, on the other hand, facing the reality that, at some level, assistance may be necessary. Even after careful planning and the appointment of a guardian or co-guardians, plans should be made for emergencies. A file should be kept in a safe place, known to all family members. The following ideas should be addressed when making future plans and the information should be included in this accessible file: Develop financial plans for future care. If the family is considering establishing a trust for the family member with the disability, it should consider the incomes of the children in the family, including the sibling with a disability. Make a will only with an attorney experienced in devising wills for those who have an heir with a disability. Inheritances must be treated with caution. It is especially important to investigate the continued eligibility for certain social services if assets from an estate, pension, or life insurance are left to the child with a disability. Establish whether the sibling with a disability requires no, partial, or full guardianship. This information should be in writing, and, if possible, make contingency plans in case the first-choice guardian is unable to assume that role. Be aware of the consequences in your state of not having a guardian appointed. Non-disabled siblings should know where to access the needed educational, vocational, and medical records of the disabled sibling, and be ready to anticipate his or her changing future needs. Families

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should consider the future health and care of the disabled child. Parents should document where he or she can receive medical care and the financial resources and arrangements necessary for this care. Families should gain an understanding of the legal and eligibility requirements of programs available to the family member with a disability. Families should discover the types of community resources available. The range of services and resources varies considerably according to place of residence. Keep abreast of any changes in the availability of these services. Be aware that, as families grow and develop, the members within it change. Living with and caring for a child with a disability is different from living with and caring for an adult with a disability. Family members should continually ask themselves the following questions: What are the needs of the sibling with a disability? How will these needs change? What can be expected from local support groups in the community? What is and will be my level of involvement? Is the involvement financially, emotionally and psychologically realistic for me? How will the responsibility be shared with other family members? Are my career plans compatible with my responsibilities for my brother or sister with a disability? Will my future spouse accept my brother or sister? The care of a sibling with a disability or chronic illness is, in large part, a family affair and a responsibility that should be shared as evenly as possible. By planning effectively for the future, parents can help ease the responsibility and the feelings of stress that uncertainty about the future can bring. Suggestions to parents 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 non-disabled 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. Care giving responsibilities for the child with a disability or chronic illness should be shared by all family members. It is especially important that the burden for care giving 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. Examples include recreation activities, respite care, and parent support groups.

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Chapter 2 : Developmental Disabilities

Siblings may have similar questions about the sibling with the disability as do parents but have little information or resources available to them. During doctor visits, they are often left in the.

She was angry that she would be punished for misbehavior that he could get away with. She was healthy; her brother was mentally retarded and had cerebral palsy and other neurological problems. They have found that the relationship is far more complex than they had anticipated, but that a few simple things can help both the children and the parents make the most of the situation. Psychologists used to assume that having a child with a disability at home was damaging to the other members of the family. It can lead instead to creative problem solving and personal growth. Children who have disabled siblings can gain a greater appreciation of the value of different kinds of people and become more understanding of human differences. To handle the stress successfully, children need increasing amounts of information about their disabled siblings and other family issues. This information has to be presented in ways that match their own developmental needs and abilities. This may be the first generation in which people with disabilities are routinely outliving their parents. Having a disabled sibling can distort the natural rivalry between brothers and sisters. Competition for attention and individual recognition takes on a different tone, not only at home but also at school. Siblings of disabled children are often asked to assume responsibilities years before their classmates are. Some requests are made by their parents, like asking them to baby-sit for their brother or their sister every day after school. Other duties are self-imposed and based, in part, on how they view their roles within the family. Many of these children feel a strong pressure to achieve. They need to be the scholar, the athlete, or the prom queen because they feel that their parents are disappointed by what their other child cannot achieve. This added responsibility can breed resentment, at least temporarily. She felt they were taking away her rights as a child. As she grew older, however, she began to see that her parents were the ones who stayed with him during the weekend and got up with him in the middle of the night. She had only seen what she was giving up. Helping the Healthy Child A child who has an emotionally, mentally, or physically disabled brother or sister often feels isolated, especially in preadolescence, when fitting in with a peer group is of growing importance. Although social service agencies have long provided support groups for parents, only recently have such groups been available to siblings. Here are a few other things that parents should keep in mind: Arrange to spend time alone with each of your children. This is important for all families, but especially for those in which one child has some special needs. This lets all your children know that you recognize and respect their needs. All articles appearing here originally were published on [www. When A Sibling Is Disabled](http://www.WhenASiblingIsDisabled.com). Retrieved on November 9, , from <https://www.whenasiblingisdisabled.com>

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Chapter 3 : Siblings of Kids with Special Needs: Your Child: University of Michigan Health System

information on the topic of siblings of children with disabilities available to parents, special educators, child psychiatrists, counsellors and marriage and family therapists.

According to the CDC, autism affects 1 in 88 children. Every child is unique. However, there are things you can do after the birth of your child, and even before, that can make a huge difference down the road. Ask about Early Intervention The sooner you can ask your pediatrician about Early Intervention , the better. Early Intervention services can entail teaching physical and cognitive skills such as crawling and problem-solving, along with communication and social skills like listening and playing. Your local pediatrician might be able to point you in the direction of services available in your area. You can also explore online resources for more information. If the will bequeaths a substantial sum of money to your child, it could disqualify your child from receiving any additional government aid. In order to avoid this, many parents opt for special needs trusts , which appoint a trustee a designated friend, family member, or lawyer control over the estate left to the beneficiary your child. Because the trustee has total control over the funds, your child can continue to be eligible for government aid if he or she needs it, without losing access to the trust. Whichever path you decide to take, make sure you consult with a financial professional for advice specific to your situation. After all, you want to make sure your child is provided for in the event of your passing. Take some of the stress out of choosing a policy by finding a reputable financial advisor and asking about terms of payment upfront. As to how much of a policy to take out, this will depend on what you need covered. Again, a financial advisor can help walk you through this. Start thinking about designating a legal guardian. As your child continues to grow, you will gain more insight into their special needs and be able to adjust your financial plans accordingly. Build bridges with your community Take the time to meet with your community leaders and establish a rapport with the local school faculty. Accidents happen, and if your child is unable to speak for themselves or articulate their feelings, a simple misunderstanding could turn disastrous. There are resources available online that go over what your child needs to know about the police and ways you can introduce yourself to them. In fact, you might find there are plenty of families in your area going through something similar. This is a great way to develop bonds with other like-minded individuals as well as gain some important insight from parents of older children. In turn, this will assist you in determining the proper amount of financial aid your child will need. Review finances regularly About every 2 or 3 years, you should review your finances to determine if you are on track to achieve your goals. You may find that you no longer require such a large life insurance policy, or you may discover that more is required. Plan and project for the worst case scenario, since you never know what unexpected expenses may arise. Also, remember to budget for the rest of your family and your retirement. For more information on applying for SSI and Medicaid, consult the following: In the event that you feel your child cannot make important life and financial decisions on their own, a guardian will need to be appointed. Most states have their own preferences and legal requirements for what constitutes a legal guardian. In most cases, the preference will be for an adult parent to take on the role or, if this is not possible, an adult sibling or a close family friend. Guardians are supervised by the court to prevent any potential abuse of trust. Spend some time online looking into additional special needs support programs. Think long and hard about who you would designate as a legal guardian. There are plenty of guides online that can help you make this decision as well as suggest alternatives to guardianship. Spreading their wings Age 18 - 22 Your child is no longer, legally, a child. Depending on their diagnosis, they may even be ready to enter the world of college. This is also a great time to review items we have previously touched upon. Appoint a guardian or an alternative If your child needs help making important decisions, financial or otherwise, and you have not yet appointed a guardian, then now is the time. However, just as there is no one-size-fits-all solution to special needs funding, there are degrees of need when it comes to guardianship. In fact, you might not even need a guardian when a durable power of attorney may suffice. This is perfect for situations where your child can

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make decisions on certain matters but may benefit from occasional guidance. Speak with your local school administration to determine if there are any opportunities to attend employment or educational workshops. Organizations like The Douglas Center offer these and more, and there are many others like it that can give your child the opportunities to lead full and productive lives. The cost of tuition for enrollment in organizations such as these will vary. Will they be staying overnight? Financial aid opportunities are available to help defer these costs. In the event that this occurs, look into ways of shrinking those assets or transferring them to a trust. Get acquainted with any local organizations that work with the government to provide aid. Learn how these organizations work so you can strengthen your voice of advocacy for your child. In some cases, a child with special needs can live in their own space. Now is as good a time as any to start equity on a second home. In addition to any residential needs, you should also evaluate whether or not your child has any transportation requirements. If your child is eligible to drive, make sure you budget for that as well. Do not be afraid to consult with a financial expert on these matters, as well. It never hurts to double-check these things. Instead, consider a special needs trust. Take account of expenses and liabilities Itemize all of the expenses you can think of that your child will have to handle or manage in your absence. By organizing this information, you can gain a better perspective on what your child will deal with financially and make any necessary adjustments to your financial trajectory. Additional takeaways Continue to include any other siblings even those without special needs into your financial planning. Maintain a healthy balance between providing for your special needs child and your own eventual retirement. If you have been reviewing your estate plans and your finances, your child should have the tools necessary to carry on after you have passed away. Additional takeaways Consider utilizing a special needs trust as a means of dispensing a sizable inheritance. By doing this, you ensure your child receives all that they are owed without the government withdrawing their aid. While ensuring your child has what they need, you may have to push your retirement date back a few years. Providing a healthy life It can be difficult to determine what your child will need when they are first born. Keep a careful record of your spending and your income and consult with financial professionals on matters regarding your estate and life insurance policies. And remember that this guide is not a substitute for a professional consultation. Additional checklist We have also put together an additional checklist that condenses this guide into a series of the more pressing items and matters to consider. You can download the checklist by clicking below.

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Chapter 4 : Research Related to Siblings of Individuals with Disabilities - Sibling Leadership Network

As a parent, you want to give equal attention to all of your children. But when parenting a child with special needs, that can be hard. Your child with a disability needs you. But so do his or her siblings. It may feel like there's never enough of your attention to go around "and your other kids.

Easter Seals What they offer: Resources for autism, seniors, children, adults, military and veterans, employment and training, medical rehabilitation, camping and recreation, brain health. Children and adults with disabilities and special needs find highest-quality services designed to meet their individual needs when they come to Easter Seals. Teams of therapists, teachers and other health professionals help each person overcome obstacles to independence and reach his or her personal goals. Easter Seals also includes families as active members of any therapy program, and offers the support families need. Special Olympics What they offer: Real sports, building communities, youth activation, healthy lifestyle promotion, leadership, research. Through the power of sports, people with intellectual disabilities discover new strengths and abilities, skills and success. Our athletes find joy, confidence and fulfillment " on the playing field and in life. They also inspire people in their communities and elsewhere to open their hearts to a wider world of human talents and potential. United Cerebral Palsy What they offer: My Child Without Limits , My Life Without Limits , family support, employment guides, health and wellness tips, housing help, financial assistance, international resources. UCP educates, advocates and provides support services to ensure a life without limits for people with a spectrum of disabilities. UCP works to advance the independence, productivity and full citizenship of people with disabilities through an affiliate network that has helped millions. The Arc What they offer: Information and referral services, individual advocacy to address education, employment, health care and other concerns, self-advocacy initiatives, residential support, family support, employment programs, leisure and recreational programs. The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. We encompass all ages and more than different diagnoses including autism, Down syndrome, Fragile X syndrome, and various other developmental disabilities. Friendship Circle International What they offer: Volunteer home visits, Torah circle for children, holiday programs, camp experiences, sports, sibling support, life skills. With over 80 locations worldwide, the Friendship Circle has cultivated friendships between 5, special children and close to 11, teen volunteers. These shared experiences empower the children, our special friends, while enriching the lives of everyone involved. The teen volunteers learn the priceless value of giving, the curative power of friendship, and the vital importance of integrating children with special needs into our communities. The parents and siblings receive much-needed respite and support from the Friendship Circle community, and all those who assist us. Each independent Friendship Circle is operated by its local Chabad Lubavitch Center, and entirely supported by each local community to benefit local children with special needs. Goodwill Industries International What they offer: Financial coaching, savings and loan support, tax preparation, education programs, community services, financial aid, transportation, after school programs, housing assistance, clothing assistance, medical rehabilitation. Goodwill works to enhance the dignity and quality of life of individuals and families by strengthening communities, eliminating barriers to opportunity, and helping people in need reach their full potential through learning and the power of work. Last year, Goodwill helped more than Parents Helping Parents What they offer: Support groups, family and community services, crisis support, early intervention, assistive technology services. This includes children of all ages and all backgrounds who have a need for special services due to any special need, including but not limited to illness, cancer, accidents, birth defects, neurological conditions, premature birth, learning or physical disabilities, mental health issues, and attention deficit hyperactivity disorder, to name a few. Federation for Children with Special Needs What they offer: The Federation for Children with Special Needs FCSN provides information, support, and assistance to parents of children with disabilities, their professional partners, and their communities. They are

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committed to listening to and learning from families, and encouraging full participation in community life by all people, especially those with disabilities. FCSN believes that individual differences in people are a natural part of life, and that disabilities provide children and adults with unique perspectives, insights and abilities which contribute to the overall well-being of society. The Federation also promotes the active and informed participation of parents of children with disabilities in shaping, implementing, and evaluating public policy that affects them. The Federation believes in the power of parents helping parents and has infused a proven model of peer support throughout all its work. Most Federation staff members are parents or family members of children with disabilities and people with disabilities.

Special Needs Alliance What they offer: Connection to attorneys in your area that practice disability and public benefits law, covering special needs trusts and wills, Medicare, SSI, estate and tax planning, personal injury, health care, financial planning, guardianships and conservatorships, The Special Needs Alliance SNA is a national, not for profit organization of attorneys dedicated to the practice of disability and public benefits law. Individuals with disabilities, their families and their advisors rely on the SNA to connect them with nearby attorneys who focus their practices in the disability law arena. The SNA is an invitation-only organization. SNA membership is based on a combination of relevant legal experience in the disability and elder law fields, direct family experience with disability, active participation with national, state and local disability advocacy organizations, and professional reputation. As a result, an SNA member will have an average of 18 years of relevant legal experience, with no member having practiced law for less than 5 years.

Family Voices What they offer: Throughout our national grassroots network, we provide families resources and support to make informed decisions, advocate for improved public and private policies, build partnerships among families and professionals, and serve as a trusted resource on health care. Latest Special Needs Products.

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Chapter 5 : The Arc | FSRTC

Siblings of children with special needs—From the NYU Child Study Center, with information about feelings, what kids can understand at different ages, and general parenting tips. When special needs spark sibling rivalry —with tips for minimizing rivalry when one child has special needs.

Purpose The purpose of this White Paper is to provide a summary of key research findings on siblings of individuals with disabilities and an initial set of guidelines and recommendations to guide new research in this area. The research work group drew up principles that should guide research on siblings, identified gaps in the research, and proposed recommendations and action steps for moving a research agenda on siblings forward.

Principles Guiding Research Siblings with and without disabilities should be involved in all phases of research from conceptualization to dissemination. It is important to get the perspectives of siblings both with and without disabilities. They are also the persons who can best identify strategies for getting the word out to families and policymakers. Research should be inclusive, representative of diversity, and culturally competent. Most of the research focuses on convenience samples lacking minority families, as it is often difficult to find siblings. We need to find ways to reach these siblings. There is a place for both description and intervention research, using the range of state of the art research methods. To date most of the research has been descriptive with very few intervention studies. Both types of research are needed to help identify the issues and to test models of providing support to siblings. Research on perspectives and outcomes for siblings with and without disabilities is of interest. Siblings with and without disabilities may have a very different perspective on family relationships and supports needed. They may also have very different perspectives than parents, who are most often the family members targeted in research studies on families of people with developmental disabilities. Research should address lifespan issues and critical contexts for their families. Siblings play varying roles and face varying issues at different life phases and at transition points. As parents age the roles and responsibilities of siblings in supporting their siblings with a disability likely increase.

Summary of Sibling Research to Date Siblings provide the most long-lasting relationships for adults with developmental disabilities. Over 30 years of research on siblings has provided key information about the effects of being a brother or sister of an individual with a disability. Generally siblings across the lifespan often regard their experiences as a sibling positively. Siblings report affection and positive regard for their brothers and sisters with disabilities, attribute high levels of empathy and altruism as deriving from their relationship with sibling, and on the whole, appear to be as well adjusted and successful as individual who have typically developing brothers and sisters. While sibling relationships may be more asymmetrical due to the abilities of the brother or sister with disability in childhood and later on, the resulting differences are somewhat predictable and seldom regarded by typical siblings as negative. The quality of the sibling relationship and level of involvement of the typical sibling is related to childhood experiences and as well as to gender of each member of the sibling pair, the relative ages of the siblings, and continued geographic proximity. Relatively little is known about family, cultural, and psychological factors contributing to individual differences in sibling relationships and sibling outcomes. Understanding what allows siblings to cope and do well and what constrains sibling relationships and sibling well-being requires research. Almost all findings about sibling relationships are based on reports of the typical sibling or the parent. The views of the sibling with disabilities are notably absent. This is especially problematic in considering adult sibling relationships where there are few studies examining the relationship from the perspective of both siblings. There is a great need for a lifespan perspective on sibling relationships, capturing the perspectives of both siblings. The relatively limited research on support provided to siblings during childhood suggests that information, meeting other siblings, and having opportunities to process concerns about family and sibling issues can have long-term positive benefits. There are relatively few studies of interventions at any point in the lifespan designed to enhance positive outcomes for the sibling with a disability, the typical sibling or the family as a whole. The need to describe and promote healthy, positive

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sibling relationships in adulthood is primary. Key Research Recommendations The research work group developed the following recommendations for future research on siblings of individuals with developmental disabilities: Make findings from past research studies easily accessible to families, service providers and policy makers. Include the voice of the sibling with disability in research How do siblings with disabilities experience their relationships with their brothers and sisters across the lifespan? How could these relationships be strengthened from the perspective of the sibling with disabilities? Examine the contributions that individuals with disabilities make to the everyday lives, and longer term health and psychological well-being of typical sibling From the perspective of the typical sibling From the perspective of the sibling with disabilities Focus on how sibling relationships, roles and experiences affect the sibling with a disability. Specifically identify positive effects of the sibling relationship on everyday lives, and longer term health and psychological well- being outcomes for sibs with disabilities across the lifespan. Determine how sibling involvement may affect community participation and inclusion, self-determination, employment of the sibling with disabilities. Broaden the scope of sibling research during adulthood. Study siblings across the adult lifespan to better understand the course of sibling relationships. Focus on key transition points where siblings may play key roles in the lives of their brothers or sisters with disabilities.

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Chapter 6 : Province of Manitoba | fs - For Parents of a Child with a Disability

Siblings of children with disabilities may experience a "wide range of emotions." 5 Some feel guilty because they wonder if they caused the disability. They may feel guilt about being resentful or.

Siblings of Disabled Kids May Show Emotional Effects Study found stress, care schedule may squeeze out parental time with brothers, sisters Please note: This article was published more than one year ago. The facts and conclusions presented may have since changed and may no longer be accurate. And "More information" links may no longer work. Questions about personal health should always be referred to a physician or other health care professional. But exhaustive, time-consuming and sometimes expensive treatments and tasks associated with caring for a child with such challenges can draw attention, energy and resources away from siblings. The study found that healthy siblings of children with a disability experienced more problems with interpersonal relationships, psychological issues, functioning at school, and getting involved with sports and hobbies than did kids without such siblings. The problems, the researchers speculate, lie partly in the lifestyle itself. There is financial, psychological and emotional stress," explained study author Anthony Goudie, an assistant professor in the department of pediatrics at the University of Arkansas. Siblings in larger families where a healthy child has another healthy brother or sister seem to fare better: That suggests that having other people in the household to talk to and play with may help siblings develop the social skills and confidence necessary to succeed outside the home -- in the classroom and on the playground, he explained. Agency for Healthcare Research and Quality to randomly survey households around the country. Parents were asked about the level of problems experienced by their children between the ages of 5 and 17 years in the 12 months before the interview. In total, there were more than 6, siblings identified living in homes with only typically developing children and siblings who lived in homes in which at least one other child had a disability. The researchers found that compared with siblings of typically developing children, parents said that siblings of children with a disability were less likely to have a very good or excellent mental health status; felt the sibling gets sick more easily; had interpersonal problems with their mother, siblings or adults in general; were more likely to seem unhappy, sad, nervous or afraid; and had more problems with schoolwork or in leisure or sports activities. To counter those problems, Goudie suggested that parents look for signs of problems related to school behavior, mood, interests, activities and relationships. Parents may also need to seek respite care that would allow them regular time away for a day or longer with the sibling, find support groups and get other forms of practical help, said Goudie. Nip it in the bud," he advised. One expert said the findings rang true, but noted limitations to the study. In some ways, the study may have underestimated the impact of having a disabled sibling, Carle added. More information Learn more about children with disabilities from the National Dissemination Center for Children with Disabilities.

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Chapter 7 : A Sibling's Role in the Social and Academic Development of a Child with Disabilities

Siblings of children with disabilities are more likely than those with typically developing brothers or sisters to struggle with relationships, schoolwork, behavior and leisure time, a new study suggests.

This approach incorporates the strengths, priorities and cultural influences of families into services provided. What are my rights as a parent? What are my responsibilities? Parents have the right to be informed about the full range of services and supports that are available. This will help them make informed choices about the types of services they feel will best meet the needs of their family. When working with service systems, parents have rights that protect the privacy of their child and their family. Information given to a service provider is confidential and cannot be shared without the consent of the parent. Parents must also ensure that information about their child and family remains current. Report any changes right away. Your Rights

Right to request and receive information – You have a right to receive information about the options available to your child, possible courses of action and assessment results. **Right to provide consent** – Your consent is needed for any specialized assessments or services your child receives. **Right to have a central role in the planning process** – In family-centered service, parents are an essential part of the planning process for the child. Your Responsibilities

Provide information – Providing information to service providers is important. It will help determine which services are the most appropriate for your child. **Return to Top** How can I advocate for my child and maintain good relationships with service providers? Each person involved in service planning has a vital role to play. Professionals bring specialized knowledge in their areas of expertise. As the child gets older, he can contribute important information about how the program is meeting his needs. The best plan can be created when everyone works together. The following tips can help to ensure your child is receiving the necessary services: **Learn about the disability** – Having a good understanding of the disability, its possible impacts and available equipment and devices can be very helpful. **Learn about available services** – There may be a wide range of services available from various agencies in the community. Ask the service providers you work with about the services that could help your child. Anyone who is involved with disability-related issues – people with disabilities, family members of people with disabilities and advocacy organizations – can provide valuable information. Be sure to ask questions whenever possible. **Share information** – Provide information on the progress your child is making in various situations and activities. For any interventions that take place, note whether the results have been positive, or have had no effect. **Ask about information sharing between agencies** – It can be helpful if assessment results and recommendations are shared among the professionals who provide services for your child. This information can help service providers deliver consistent and appropriate services for your child and family. You may prefer to give information to the professionals yourself. **Take notes** – Take notes at all meetings with service providers, school staff and physicians. This record can be helpful at a later date. **Ask questions** – If you are unsure of terminology, the diagnosis, recommendations or parts of the service plan, it is important to ask questions to get a clear understanding of the information. **Ask about the services you may be eligible to receive.** Communicate respectfully – If you have a concern, speak to the person involved directly and try to come up with solutions together. Is there someone who can help if I am having difficulty advocating for my child? There are a few options that are available to support you in advocating for your child: **Community Living Manitoba** – Community Living Manitoba is a non-profit organization that promotes full inclusion for people with intellectual disabilities. Staff can assist with advocacy in various situations. To contact Community Living Manitoba and connect with services in your area: **Does The Human Rights Code allow for an accommodation change in this situation?** Each situation is unique. Since there may be additional responsibilities involved in caring for a child with a disability, The Human Rights Code, under the characteristic of Family Status, provides protection for parents who are in this situation. However, the need must go beyond what parents of children without a disability would experience. An accommodation is a change in the way that something is

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usually done because of a special need. There are many types of workplace accommodations that are available, including: Undue hardship is an unreasonable or unmanageable burden on an organization. Although there are times when an employer may not be able to provide an accommodation, they must still follow a process to explore the possibilities. When considering an accommodation, there are many factors that are taken into consideration: If an employer cannot provide the preferred accommodation, people can explore with their employers how their needs can be met, while making sure the workplace can continue to function effectively. Ted and Nancy are working parents of a child with complex health needs requiring full time nursing care. Sometimes, they are called to return home when their child is experiencing a major health issue. The employers of both parents explored options that allow the parents to be with their child, while not affecting their workplaces. Return to Top If I am making a request for an accommodation, is there a process I need to follow with my employer? When making a request for your employer to make an accommodation, follow these steps outlined by the Manitoba Human Rights Commission: Explain your needs “ When requesting accommodations, let your employer know about the situation and the needs you have as a result. When suggesting accommodations, try to balance your needs with the needs of your employer. For example, try to limit time away during busy times of the day or year. Work with your employer to arrange the most effective accommodation for both you and the organization. While you bring information about your needs and how to best address these needs, your employer has insights and a big picture view of the organization. Participate in whatever accommodation you agree to “ It is important that both parties demonstrate good faith once an accommodation has been reached. For more information, contact the Manitoba Human Rights Commission at in Winnipeg or toll free. What can I do if I think my child is being discriminated against? Being treated differently can happen for a variety of reasons, including a person being unaware of how to interact with someone who has a disability. If you feel comfortable discussing the issues with the people involved, let them know the specific behaviours that are creating unequal treatment or causing a barrier for your child. Discuss ways that your child can have an inclusive experience. If you do not feel comfortable approaching the people, or have tried unsuccessfully to address the matter, you can contact the Manitoba Human Rights Commission. The commission is the agency that administers The Human Rights Code. It is authorized to mediate and investigate complaints of discrimination and refer matters to adjudication when it has been determined there is enough evidence. Their role includes promoting human rights and educating the public. For more information, contact the Manitoba Human Rights Commission:

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Chapter 8 : Caring for Siblings of Kids With Special Needs

Siblings to children of disabilities are a key element to the social development of their handicapped sibling. Brothers and sisters have a lifelong relationship with one another that tends to.

What are some recommended books on parenting siblings of kids with special needs? 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*: May be useful for both parents and children to read. A real classic—a quick and easy read with powerful techniques you can start using right away. *When Madness Comes Home*: What are some titles of books for kids about special siblings? Sometimes reading a book with your child can open up a dialog about issues they are facing. Check out some of these books and see if they help get your kids talking about their feelings and experiences. Below are listed a few titles. Many more books for kids and adults are listed in the Sibling Support Project Store. *Ben, King of the River*, by David Gifaldi. Includes a page of tips for siblings of kids with special needs. 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!* Carly feels the dual emotions that many siblings of special-needs children may feel. Her older brother Alex participates in the Special Olympics. Her love for him and the discomfort he causes her at school are realistically portrayed. *My Sister Annie*, by Bill Dodds. This is a thoughtful novel about his growing pains and struggle to accept a sister who is "different". *Views from Our Shoes: Meyer* For ages 7 and up. 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. Realistically portrays the life of the family in caring for a disabled child. *Welcome Home, Jellybean*, by Marlene Shyer. Written for teens who have a brother or sister with Down syndrome. Written and compiled by Kyla Boyse, R. Reviewed by Brenda Volling, Ph.

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Chapter 9 : When A Sibling Is Disabled

During the school years, especially the early years, teachers can help to promote sibling awareness and interaction by providing opportunities for siblings to learn about disabilities. For example, conducting a "sibling day" or a sibling workshop can be an excellent way of introducing siblings to a variety of disabilities.

Many camps offer specialized medical care for specific disabilities or one-on-one buddies, while other camps provide tutoring for individuals with learning disabilities in addition to outdoor activities. In the social skills day camp, children are placed in small groups headed by a volunteer. In the other programs, each child is matched with a one-on-one volunteer. The Friendship Circle also has 83 locations worldwide, each with its own menu of summer programs. Miracle League fields are fully accessible to wheelchairs, and each player is paired with a non-disabled volunteer. The rules of the game are modified to give every player the opportunity to participate fully. The Coalition covers all expenses, including travel, for the campers. Since its beginning in 1984, the camp has hosted more than 100,000 campers with limb loss or limb difference. Recreational, competitive and team-building programs are available in skiing, adventure learning, aquatics, water sports, archery, cycling, snowboarding, snowshoeing, sled hockey, climbing and equestrian sports. Camp Greentop Camp Greentop, located in Catoctin National Park, near Thurmont, Maryland, has been welcoming children and adults with disabilities since 1978. Day and overnight camps offer a structured schedule of canoeing, fishing, swimming, horseback riding and campfire singalongs. Siblings and buddies age are invited to join each camper. Some camp sessions provide one-on-one support around the clock, some are small group sessions for campers with mild to moderate impairments and some are planned for individuals with autism and Asperger Syndrome. Children and young adults with disabilities age participate in traditional camp activities alongside Boy Scouts. Each camp session is one week long. Children with and without disabilities ages can learn English or Western riding, and everyone participates in a horse show on the last day of camp. Talisman Programs Talisman Programs in Zirconia, North Carolina cater to children and teens with ADHD, learning disabilities, Asperger Syndrome and autism with special attention to nutrition, life skills and daily routines with built-in downtime. The overnight camps are either campus-based or adventure-based, and all programs are multi-sensory. Grace Bentley Camp Grace Bentley, located in Burtchville, Michigan on the shores of Lake Huron, hosts campers ages with mild to moderate special needs. Each counselor is assigned to 3 campers, and each session is 9 days long. Activities include swimming, team sports, dances, bonfires, talent shows, carnivals, various games, arts and crafts, indoor games and movie nights. The six day, five night summer camp sessions are for children and adults with special needs as well as their siblings. Traditional summer camp activities such as canoeing, swimming, horseback riding and outdoor sports are modified so that people of all abilities may participate. In addition to traditional summer camp activities, the camp incorporates a curriculum of life skills, language skills, music and movement, social skills and vocational training. Children with mild to moderate learning or developmental disabilities participate in a 7 week residential camp. Children with special needs ages enjoy traditional camp activities on the wooded lakefront campus: The camp was founded by medical students at the University of Colorado, and each camper is paired with an adult volunteer. All camp counselors are volunteers, many of whom are active or retired firefighters or medical personnel trained in treating burns. Camp activities include campfire singalongs, hiking, fishing, archery, boating, and a ropes course. The camp infirmary is staffed by nurses. The nursing staff also teach a heart class so that the children can learn more about their health conditions. Camp activities include swimming, non-contact sports such as volleyball, art class and a talent show. These camps are for children with limb loss and their families. Families learn about prosthetics and adaptive equipment while participating in art, music, sports, recreational activities and therapy. Deaf Camp Deaf Camps, Inc. Separate camps are offered for siblings. The camps are free for participants and parents only pay the cost of transportation to and from camp. Each applicant is screened by a medical team, and the camps have medical clinics staffed by volunteer doctors and nurses. The camps are staffed by West

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