

Family Matters.

A Guide for Adult Brothers and Sisters of People with Developmental Disabilities

Preface

"Having a sibling with special needs teaches you to look beyond your own needs to help another...makes you more aware of the world around you and less focused on yourself ...teaches that everyone can make a difference."

Kim Cushman, Sibling

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Introduction

Most people with developmental disabilities live with their families or within a support network of family members throughout their lives. Relationships between brothers and sisters are especially important, because they are among the longest and most meaningful relationships people have during their lives.

Children who grow up together form a unique bond, regardless of whether one has a disability. In fact, relationships between people with disabilities and their brothers and sisters can be identical to relationships between any siblings. They may be close and remain so into adulthood, or they may never develop a close relationship and grow apart as they get older. Family situations and circumstances, such as divorce or even cultural differences, can also affect the way sibling relationships develop. Many factors affect the way siblings relate to each other - not just the fact that one of them has a disability.

Bonds between brothers and sisters have a unique position within the range of family relationships - these bonds have the potential to last longer than any other human relationship. Because sibling roles are assigned rather than achieved, they remain part of individual identity regardless of changes in marital status, residence or lifestyle.

Growing up in a family with a brother or sister who has a disability is unique. Sometimes, however, having a brother or sister with a disability can create challenges that other families may not experience.

People with developmental disabilities may have great impact on their siblings' caregiving responsibilities, social relationships and well-being. Research shows that siblings of people with disabilities can be very mature, self-confident, independent and patient. They also can be very concerned for the welfare of others, more sensitive to humanitarian efforts, and have a greater sense of family closeness. Growing up with people who have disabilities may instill a greater level of understanding and development in people who don't have disabilities. They may develop excellent leadership skills, especially in areas where understanding and sensitivity to human issues are important.

Research also shows that most brothers and sisters of people with disabilities view sibling relationships as positive and as an enhancement to their family. However, at times, siblings of people with disabilities experience stress due to increased responsibilities, unbalanced attention and community reaction.

The increase in life expectancy for people with developmental disabilities means sibling relationships will last into adulthood. Parents once assumed they would outlive children with developmental disabilities. Now, most adults with disabilities outlive their parents. They may rely on brothers and sisters for support, and possibly for care, as they age. Adult brothers and sisters are often advocates, friends and/or guardians for people with disabilities.

Brothers and sisters offer a protective layer of support in families who provide care for adults with disabilities. They give direct emotional and instrumental support to people with disabilities and indirect support to parental caregivers.

Adult brothers and sisters of people with disabilities face a number of unique concerns and challenges. As parents age, the balance of responsibility for support to the person with a developmental disability often shifts to the sibling(s). Many individuals struggle with seemingly incompatible loyalty to their brother or sister with a disability and loyalty to their own families.

Many adults with disabilities live and work in their home communities. As parents age and die, brothers and sisters become significantly involved in their lives. Movement toward community life for people with disabilities, and scarcity of resources (e.g. residential options and employment opportunities) for adults with disabilities, will likely increase sibling roles and responsibilities.

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Brothers and Sisters Are Often Overlooked

Brothers and sisters of adults with disabilities are often overlooked by agencies who serve people with special needs, even though siblings generally have the longest family relationship and their numbers are vast.

Service providers and families must recognize the role of brothers and sisters in providing support to people with developmental disabilities. They must consider the willingness and capacity of siblings to expand their roles. It is critical that siblings have knowledge, information and guidance to assist people with disabilities in making decisions and long-range plans. Needs of people with disabilities remain a priority.

In offering support to siblings, professionals must recognize differences in the level and intensity of family involvement, in cultural and family values, and in personal resources. Offering support should strengthen the relationship between siblings and enhance their well-being.

Schools, community agencies and health care providers should provide support and information to help siblings and other family members address concerns and assist people with disabilities in making appropriate decisions. Brothers and sisters should be encouraged to participate in family support initiatives, staffings and training events — when appropriate and when desired by people with developmental disabilities and their families.

Concerns identified by Brothers and Sisters of Various Ages

Common concerns expressed by brothers and sisters of people with disabilities include:

Guilt. Siblings may feel guilty because they don't have a disability, or feel they did something to cause their brother's or sister's disability.

Embarrassment. Brothers and sisters may feel embarrassed about their sibling's behavior or appearance.

Fear. Some siblings may be afraid they will develop the disability or have children with a disability.

Anger or jealousy. If the person with a disability requires extra care, siblings may become angry or jealous of the attention given their brother or sister. Anger may also be directed at peers who mistreat people with disabilities.

Resentment. Siblings may resent time spent with a brother or sister with a disability. They may also resent different expectations parents hold for their children.

Confusion. Often, siblings are not given enough information about why their brother or sister has a disability, how it affects them and what the family can do to help. Siblings may be confused about their role as "surrogate parent" or about service priorities.

Isolation. Brothers and sisters may feel that no one else has the same feelings or experiences about having a sibling with a disability. They may feel isolated from peers and other family members.

Pressure. Siblings may feel pressure to achieve in order to "make up for" a brother's or sister's disability. They may also feel pressure to care for their brother or sister.

Burden. Siblings may feel the responsibilities of providing care are burdensome, especially if they conflict with activities planned with friends or family.

Concern. Siblings are concerned about their brother's or sister's future, especially if the brother or sister still lives at home.

Concerns of Adult Brothers and Sisters

Adult brothers and sisters of people with disabilities have unique concerns. Their concerns center around the following broad areas:

- **Genetics**
- **Long-term care Issues**
- **Ensuring a quality lifestyle**

Genetics

Most adult siblings are concerned about the possibility of having children with a disability - especially if their brother or sister has a genetic disorder or was born with a disability.

Many siblings of people with disabilities want to take advantage of genetic counseling and screening services. These services cannot make predictions with 100 percent accuracy or identify the presence of all disabilities, but they can help increase knowledge of present and potential risks (please see [Appendix A](#)).

Long-term Care Issues

When parents die or cannot care for a family member with a disability, responsibility often passes to siblings. Siblings need knowledge to face this responsibility. Many adult siblings are concerned about their financial responsibility in caring for their brother or sister. Proper estate planning can help address this issue.

Proper estate planning allows all members of the family to realize benefits from parental property. Parents should plan estate matters with a knowledgeable, experienced attorney and update them as needed (please see [Appendix B](#)).

Ensuring a Quality Lifestyle

Adult siblings can have a significant, positive impact on their brother's or sister's life by serving as advocates. An advocate promotes the interest of another and helps another enjoy a quality life. Sibling advocates can actively represent the interest of their brother or sister or an entire group of people with a disability.

- **Be interested** in the needs of their family member with a disability;
- **Have specific knowledge** of their family's needs and resources available to meet those needs;
- **Be willing** to secure services needed;
- **Be assertive**;
- **Want to promote** human rights of people with disabilities; and
- **Have courage** to help systems change in meeting the needs of people with disabilities.

Advocacy can occur at many levels, be pursued with varying intensity, and achieve a variety of outcomes. Advocacy focuses on the family member with a disability and attempts to ensure that they have a quality lifestyle (please see [Appendix C](#)).

Adult siblings face a delicate balancing act in meeting responsibilities to their brother or sister with a disability, themselves, their marriage partner, their children and other family members.

Needs of Adult Brothers and Sisters

Brothers and sisters share many, if not most, concerns parents have about the well-being of people with special needs. Needs of brothers and sisters include:

- **Respect.** Like everyone, adult siblings need to be recognized and respected as individuals. They need to be respected as individuals by parents, family, friends and service providers.
- **Understanding.** Adult siblings should feel their concerns are recognized and respected. They should feel that others understand their problems and are willing to help.
- **Information.** Adult siblings want to learn more about services for people with disabilities. They need information to help people with disabilities and their families make informed choices and plan for the future.
- **Peer support.** Often, adult siblings want to talk with someone facing a similar situation. Adult brothers and sisters of people with disabilities face issues that are not generally experienced by their peers in the community.
- **Advocacy.** Adult siblings want to advocate quality services for their brothers and sisters. Adult siblings know that system change for people with disabilities occurs when family members assist them as advocates. Since many siblings have an important role in the lives of people with disabilities, they want to gain advocacy skills.

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Adult Sibling Roles

Adult siblings can play an important, significant role in the lives of their brother or sister with a disability. Roles which they may choose to assume include:

- **Advocacy**
- **Financial planning** and/or support.
- **Caregiving** (direct and indirect).

Advocacy

Being an advocate may mean confronting authority. It may mean standing up for your sibling's rights. Following are tips for those who choose to become an advocate for their brother or sister and/or other individuals with disabilities:

- **Believe in your brother or sister.** You have a long, intimate relationship with them. Trust your knowledge.
- **Trust your insight and intuition.**
- **Educate yourself.** More skills and information will help you be a better advocate for your brother or sister and/or people with disabilities.
- **Be a change agent.**
- **Keep a notebook to document your progress.** Record the name, telephone number, title of the person you talk or meet with, and the date. Keep notes of questions you ask and answers you receive. After a telephone call or meeting, follow up with a short letter summarizing major points of the call or meeting.
- **Tell your family's story.** Stories are very useful if you meet with elected officials, if you are asked to testify at public hearings and meetings, or if you want to write letters.
- **Accept that you cannot change everything.** Many goals may take months or years to reach.
- **Be creative.** Different situations require you to develop different actions and strategy.
- **Take a moment to congratulate yourself** for each bit of progress, no matter how small.
- **If you must decide between being popular and being respected,** you have become an advocate.

[Appendix C](#) provides additional advocacy resources available through local disabilities and special needs boards.

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Strategies for Adult Siblings

Siblings need to be honest with themselves and others about their feelings. They may need assistance to deal with the pressures of having a brother or sister with a disability, including:

- **Collective action.** Family advocacy organizations provide real and personal opportunities for action;
- **Support groups.** Support groups allow siblings to talk with others who share similar feelings and find effective methods of coping;
- **Professional counseling;** and
- **Genetic counseling and screening services.** Siblings should seek genetic counseling if they are concerned about the possibility of having children with a disability.

Financial Planning/Support and Caregiving Roles

Proper estate planning ensures that all family members realize benefits from parental property. A Letter of Intent can help you understand your parents' future wishes for your brother or sister, as well as any special information you or others may need to know in caring for them.

As a sibling, it is important that you be consulted and included in any decisions that may have an impact on you in the future. It is also important that you learn about services and programs which would benefit your brother or sister, should you assume a more involved financial or caregiving role. Contact the service coordination staff at your local disabilities and special needs boards for more information about services and programs for people with disabilities (please see [Appendix E](#)).

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Strategies for Professionals

Family members are constant figures in the lives of people with disabilities. No professional will follow the individual with a disability throughout a lifetime, across a range of needs. Only families have a broad enough perspective to see the "big picture" for service needs.

Family harmony is greatest when siblings view their lives as enhancing and personally rewarding, overshadowing inevitable times of embarrassment, personal isolation and frustration.

Professionals should assist adult siblings in various ways:

- **Professionals should reach out** to adult brothers and sisters. They should target family members who will have increasing involvement in the lives of people with disabilities and make a special effort to invite siblings to staffings and advocacy group meetings. Advocacy groups provide real and personal opportunities for action.
- **Professionals should seek siblings to serve** on boards of directors or advisory councils. These individuals provide a unique and important perspective and reinforce board members' concern for siblings with a disability.
- **Professionals should educate staff** about issues facing brothers and sisters of people with disabilities.
- **Professionals should host programs specifically for brothers and sisters.** Siblings of people with disabilities have unique questions about their personal circumstances: "How will a spouse feel about my brother or sister with a disability?" "What will I do when my parents die?" "How can I advocate?" "Will my own children resent the time I take with my brother or sister?" Support groups allow siblings to talk with others who have already faced these questions ([Appendix D](#) includes additional discussion questions as well as information about peer support).
- **Professionals should adopt a policy statement** on the role of siblings in serving people with disabilities.
- **Professionals should use broad terminology.** Professionals should not refer to "parents" if "families" or "family members" is more appropriate. Siblings and other family members are very active in the lives of people with disabilities - they should not be excluded.
- **Professionals should provide employment opportunities** to qualified siblings. Many siblings share their knowledge and concern for people with disabilities by working as professionals in the human services field.

Strategies for Family Members

Family members can reap many benefits if they help siblings of people with disabilities handle unique pressures. Positive family actions include:

- **Treating each child as an individual.** Not demanding or expecting siblings to take on responsibility unless they are prepared.
- **Valuing each child individually.** Recognizing each child's qualities and family contribution.
- **Remembering the feelings of siblings.** Taking time to talk with them about their feelings and encouraging them to express their feelings openly.
- **Involving siblings.** Becoming involved in making decisions about their brother or sister with a disability.

Family members can involve siblings by:

- **Inviting them** to attend meetings/staffings.
- **Discussing future plans.**
- **Soliciting ideas** on service needs.
- **Having them visit professionals** who serve their brother or sister.
- **Discussing family matters** with their children, especially if the children will be affected. Ask for and value their opinions.
- **Being an active listener.** As siblings mature, they will have observations, comments and suggestions about their brother or sister with a disability. Their statements and concerns should fall on attentive ears.
- **Giving their children information** about their brother's or sister's disability.
- **Recognizing family uniqueness.** Feeling good about about your family and your children will help.
- **Helping establish an adult sibling group.** Families should recognize the advantages of sibling groups and should support the efforts to provide these

opportunities.

- **Recognizing stressful times** for siblings and trying to minimize negative effects.

For older siblings, stress may be greatest when:

- **The sibling starts to date.**
- **Friends ask questions** about the brother or sister with a disability.
- **The brother or sister becomes critically ill.**
- **Problems related to the brother or sister are handled in secrecy.**
- **The brother or sister moves from home.**
- **Siblings marry.**
- **The children of siblings are born.**
- **Parents die.**

Stress can be reduced, if potential problems and possible solutions are recognized and discussed frankly and openly. Adult siblings may not always recognize why they feel more angry, resentful, frightened, sad or lonely.

Parents can help by opening the door for discussion and mutual problem solving:

- **Families should have reasonable expectations.** Like all people, siblings occasionally lose their patience and understanding. They may become angry at people with disabilities. Family members need to understand the boundaries of normal sibling feelings and not expect extraordinary behavior.
- **Families should develop an estate plan and prepare a Letter of Intent.** A Letter of Intent will help a son's or daughter's future caregivers understand the family's wishes (Please see [Appendix B](#) for guidance in developing a Letter of Intent).

Bonds between family members deepen as families work together to find solutions for needs and concerns they share.

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Appendix A

Genetic Resources

DDSN has a special working relationship with Greenwood Genetic Center. The Center provides genetic services to families of people with developmental disabilities served by our agency.

Families of people with mental retardation or related disabilities may receive services from Greenwood Genetic Center without charge. Services emphasize prevention programs, which reduce the risk of having children with mental or physical disabilities.

Genetic case workers coordinate services at the regional level. Services are provided through a central clinic and laboratory in Greenwood and a network of satellite clinics. Services are also available through local DSN boards. For more information about genetic services, contact the appropriate regional genetic case worker or the central clinic in Greenwood:

Upper Piedmont Region

(Cherokee, Chester, Greenville, Oconee, Pickens, Spartanburg, Union and York counties)
455-8471

Lower Piedmont Region

(Abbeville, Anderson, Edgefield, Greenwood, Laurens, McCormick, Newberry and Saluda counties)
941-8100

Midlands Region

(Aiken, Allendale, Bamberg, Barnwell, Calhoun, Fairfield, Kershaw, Lexington, Orangeburg and Richland counties)
737-6346

Pee Dee Region

(Chesterfield, Clarendon, Darlington, Dillon, Florence, Georgetown, Horry, Lancaster, Lee, Marion, Marlboro, Sumter and Williamsburg counties)

679-0927

Coastal Region

(Beaufort, Berkeley, Charleston, Colleton, Dorchester,
Hampton and Jasper counties)
881-2404

Central Clinic and Laboratories

941-8100

Greenwood Genetic Center

941-8100

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Appendix B

Planning for the Future

Most parents hope that after their death, their child with a disability will continue to be as happy, healthy, productive and independent as possible.

It is important that parents make sure their wishes are known and carried out. Failure to make these arrangements known can create unnecessary problems for other family members, as well as professionals.

Families should be careful to consult an attorney who is knowledgeable and experienced in estate planning for individuals with disabilities. Several publications about estate planning are available to families without charge. These publications include:

Now...and the Future:

A Guide for Families of Children or Adults with Disabilities

South Carolina Developmental Disabilities Council
Office of the Governor
Room 372, 1205 Pendleton Street
Columbia SC 29201
(803) 734-0465

Estate Planning News Digest

National Information Center
for Handicapped Children and Youth

P0 Box 1492
Washington, DC 20013-1492
(800) 695-0285
TDD (202) 884-8200

A Family Handbook on Future Planning

The Arc
500 E Border Street, Suite 300
Arlington, TX 76010
(800) 433-5255

Letters of Intent

A Letter of Intent is written by the parents, guardians or other family members to describe the history and current lifestyle of an individual with a disability and hopes for the future. People with disabilities, family members and professionals should be included in writing this letter. The letter should be shared with all individuals who will share responsibility in caring for a person with a disability when parents become ill, disabled or die.

Although a Letter of Intent is not a legal document, it provides guidance to the court system, family members and professionals in understanding who will be involved in caring for the individual with a disability and the wishes of the family.

Purpose

A Letter of Intent describes the history and lifestyle of a person with a disability, describes wishes and desires for the individual's care and provides advice for future caregivers. The letter also provides valuable information about the individual's personality, preferences, talents, strengths and concerns. The letter can be used by lawyers and financial planners to draft legal documents which ensure these wishes will be carried out, and to provide advice for possible care alternatives.

What to Include

The letter may be handwritten or typed. It should be addressed, "To Whom It May Concern." The first paragraph should list names, addresses and telephone numbers of those to be contacted in an emergency. A family history - including names, birth dates and addresses of family members — should be listed next.

The second section should include information about the family member with a disability: housing/residential care, education, employment, medical care, behavior management, social

opportunities and religious activities. Describe the person's present status, as well as wishes, hopes and desires for their "best" future in each of these areas. Three or four options should be given for each area regarding the future (please see [Worksheet for Letters of Intent](#)). Parents should discuss these ideas with their children.

After you write a Letter of Intent, make sure you tell family members and professionals that you have written the Letter of intent and tell them where it can be found. Mark the letter clearly and keep it in a safe place where it can be easily located.

It is important to update the letter on a regular basis. It may be helpful to choose a date each year to review the document with your family and add important information, If your child's life changes significantly, update the letter immediately.

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Worksheet for Letters of intent

For each applicable area, consider your family member's future. List three or four options to guide future caregivers in making decisions and interacting with your family member.

- **Residence:** If something should happen to you tomorrow, where will your family member live?
 - 1.
 - 2.
 - 3.
 - 4.
- **Education:** What are your perspectives for your family member's education?
 - 1.
 - 2.
 - 3.
 - 4.
- **Employment:** What does your family member enjoy? What are the goals, aspirations, limitations, etc.?

- 1.
 - 2.
 - 3.
 - 4.
- **Medical Care:** What has and has not worked with your family member?
What should future caregivers know?
 - 1.
 - 2.
 - 3.
 - 4.
 - **Behavior Management:** What approaches have worked best in your absence during difficult transition periods for your family member?
 - 1.
 - 2.
 - 3.
 - 4.
 - **Social:** What activities make life meaningful for your family member?
 - 1.
 - 2.
 - 3.
 - 4.
 - **Religious:** Is there a special church or synagogue your family member prefers for fellowship?
 - 1.
 - 2.
 - 3.
 - 4.

Additional Considerations

- **Advocate:** Who will look after, fight for, and be a friend to your family member?
- **Guardian:** (List 3-4 options)
- **Trustee(s):** Who do you trust to manage your family member's supplementary funds?

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Appendix C

Advocacy

All local disabilities and special needs boards and regional facilities are required to have local family/consumer organizations, and to have in place a process for consumers and families to participate as advocates and review specific programs.

Family/consumer organizations monitor community residences and regional facility residential programs; assist foundations to provide private funds; assist volunteer organizations; provide self-help groups, advocacy, information and public education; and cooperate with statewide coalitions.

For more information about these organizations, please contact your county DSN board or regional facility. Listings of DSN boards and regional facilities are provided (please see [Appendix E](#)).

DDSN has a statewide consumer/family organization which meets quarterly to advise the agency on programs, services and needs of people with disabilities and special needs.

Members include representatives of each DSN board consumer/family organization, presidents of regional facility consumer/family organizations and representatives of other statewide consumer/ family organizations. For more information about the Consumer/Family Organization Council, contact your DSN board or regional facility.

State and national organizations also provide leadership to families of people with disabilities. DDSN offers a services directory with information about various state and national organizations that serve people with disabilities and their families.

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Appendix D

Discussion Questions

- **How does your relationship with the sibling who has a disability compare to the relationship your other brothers and sisters have with this sibling?**
- **What are family plans for your sibling's future?** What is your role? Were you involved in this planning? Are you satisfied with these plans?
- **Do you have problems explaining your brother's or sister's special needs to your children, "significant other" or spouse?**
- **What do you consider important issues in growing up with a sibling who has a disability?**
- **What are your sibling's greatest needs right now? When you think about your sibling's future, what do you see?** In retrospect - and in regards to raising a child with special needs - what did your parents do especially well? Is there anything you wish they had done differently?
- **What should parents and professionals know about brothers and sisters of people with special needs?**

Peer Support

Support groups give adult siblings an opportunity to meet each other, share common interests and discuss concerns. Support groups also provide information about programs and services and discuss ways to resolve common issues faced by brothers and sisters.

Family Connection and Caring Connection offer support groups in South Carolina. These organizations also offer assistance in starting local support groups.

Family Connection of South Carolina, Inc.

2712 Middleburg Drive, Suite 103B
Columbia SC 29204
(803) 252-0914

Caring Connection

101 Thompson Hall
The Citadel
171 Moultrie Street

Charleston SC 29409
(803) 953-1823

Parents Reaching Out to Parents is a parent training and information center for children with special needs. PRO-Parents can provide disability-specific information as well as national, state and local information and resources.

Parents Reaching Out to Parents of South Carolina

2712 Middleburg Drive, Suite 102
Columbia SC 29204
(803) 799-3859 (Voice, TDD)
1-800-759-4776 (Voice, TDD)

Other Resource materials include:

Brothers and Sisters: A Special Part of Exceptional Families

By Thomas H. Powell and Peggy Gallagher (1993)
Paul H. Brookes Publishing Co.
PO Box 10624
Baltimore MD 21285-0624

The Effects of Mental Retardation, Disability and Illness On Sibling Relationships: Research and Challenges

By Zolinda Stoneman and Phyllis Waldman Berman (1993)
Paul H. Brookes Publishing Co.
PO Box 10624
Baltimore MD 21 285-0624

The National Association of Siblings Programs Newsletter

The Sibling Support Project
Children's Hospital and Medical Center
PO Box 5371, CL-09
Seattle WA 98105-0371

Sibling information Network

The A. J. Papanikou Center
991 Main Street
East Hartford CT 06108
(203) 282-7050

The Arc's Family Support Project

PO Box 1047
Arlington TX 76004
(800) 855-1155

"The Next Step"

(A 20-minute videotape presenting the views of over 20 adult siblings)

Publications Office

Nissonger Center University Affiliated Program

434 McCampbell Hall

The Ohio State University

1581 Dodd Drive

Columbus OH 43210

(614) 292-0825

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Disabilities and Special Needs Boards, and Service Organizations

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