

CHS Community News

Editor:

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SIBLINGS: Supporting Brothers & Sisters without Disabilities

This special edition of the CHS newsletter celebrates the often forgotten family members of individuals with disabilities, brothers and sisters. Although the support needs of parents and caretakers may be addressed by the service system, far less attention is paid to the support needs of siblings.

Why are the needs and concerns of siblings so important? Siblings are part of the family unit and as such are directly affected by the addition of a family member with special needs. The wishes of siblings may be overlooked due to the enormous time and energy spent by parents caring for the child with disabilities. Siblings will spend the most amount of time involved in the life of the family member with disabilities; and they will be essential to the well being of the family member after the parents are gone. Don Meyer, Director of the Sibling Support Project has written extensively about the importance of siblings for the well-being of people with special needs. He summarizes his concerns about sibling involvement in his article "I'm Constantly Thinking About Bev and Her Future: Siblings Speak About Aging," where he states:



In the United States, there are over 4.5 million people who have special health, developmental, and mental health concerns. Most of these people have typically developing brothers and sisters. Brothers and sisters are too important to ignore, if for only these reasons:



- **Brothers and sisters will be in the lives of family members with special needs longer than anyone. Brothers and sisters will be there after parents are gone and special education services are a distant memory. If they are provided with support and information, they can help their sibs 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 care giving demands. Brothers and sisters also face issues that are uniquely theirs including resentment, peer issues, embarrassment, and pressure to achieve.**

In this issue we will explore the needs and concerns of siblings at all ages — young children, pre-teens, adolescents and adults. We have also listed some excellent resources and websites for further information. Our goal is to help parents, caretakers, teachers, social workers and other service providers to not only recognize the critical role that siblings have in the family unit, but also to incorporate sibling needs, concerns and input as an integral component of service planning and delivery.



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.

Brothers and sisters can give parents some of the extra help and support they need; the special relationship of brothers and sisters, disabled and non-disabled, is often lifelong. This special and unique bond among siblings can foster and encourage the positive growth of the entire family.

(NewsDigest, National Center for Children and Youth with Disabilities).

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“Supporting siblings is critically important for people with disabilities and their families. I can’t think of anything more vital to the quality of life over time than strengthening relationships with siblings.”

Kevin J. Leahy
Executive Director
Cooperative for Human Services, Inc.

Advice From Siblings to Parents

Siblings offer important suggestions, reflections and advice developed from their own, first hand experience for parents, other family members, care providers and provider organizations. Below they list some of their suggested strategies for interacting with the nondisabled sibling: (Source: National Information Center for Children and Youth with Disabilities.)

- Be open and honest.
- Limit the care giving responsibilities of siblings.
- Use respite care and other supportive services.
- Accept the disability.
- Schedule special time with the nondisabled sibling.
- Let siblings settle their own differences.
- Welcome other children and friends into the home.
- Praise all siblings.
- Recognize that siblings are the most important, most powerful teachers of their children.
- Listen to siblings.
- Involve all siblings in family events and decisions.
- Require the disabled child 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.

New Beginnings — Childhood Needs



The family structure changes with the addition of each new child, whether or not the newborn has a disability. When the new family member has special needs, however, the difference for siblings can be profound and life long. Usually the parents must focus all of their attention on caring for the child with a disability, often leaving little or no time for attention to the other siblings.

For young siblings, it is especially important for parents to re-assure them constantly that they are loved. Constant attention to the family member with special needs is very hard for them to understand — they have their own needs for attention, information about the sibling’s disability and help understanding their parents’ grief as well as their own feelings.

Other issues arise when siblings become school age. Although the bond between siblings can be very strong and meaningful, it is important to make sure they are not overly burdened with watching over their sibling with a disability at school. Taking care of the sibling at school can be stressful and can deprive the brother or sister of free time necessary for making friends and socializing with their peers — very important factors in their lives. Other concerns for the school aged child often involve how to talk about their sibling with special needs with their friends, competition with siblings for attention, how to respond to inappropriate teasing and other difficult social situations.

Support groups for siblings are also an important resource to explore. Organizations that provide support services to families with special needs may also provide support groups for siblings. One of the models developed across the U.S. is SIBSHOPS, a workshop structure developed by Don Myers, Director of the Sibling Support Project. These workshops are lively programs developed just for young brothers and sisters.

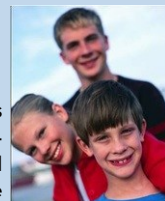
(To find a Sibshop near you: www.siblingsupport.org/sibshops/find-a-sibshop)

HOW DO SIBLINGS FEEL?

“It’s the same as in any brother or sister relationship, only the feelings are exaggerated.”

Sibling

Sibling Resources



Sibling Support Project www.siblingsupport.org/ The Sibling Support Project provides web-based resources and education for siblings of all ages. You can find information about Sibshops and a great collection of books and other resources that you can order. The Sibling Support Project has several online groups and listservs to help siblings connect and stay in touch with one another. SibNet and SibTeen are Yahoo and Facebook groups for adult and teen siblings. SibKids is a Yahoo group for kids—and parents who would like to learn from kids. SibParent is a group for parents who want to share about siblings of children with special healthcare needs. You will find more information about these groups under “Connect with Other Sibs” on the Sibling Support website.

Massachusetts Sibling Support Network The MSSN is the only organization in Massachusetts focused on supporting siblings of people with disabilities across the siblings’ life span. The network is made up of adult siblings, parents of young siblings, service providers, educators, mental health and medical professionals. The MSSN provides information and education on sibling issues, referrals to sibling services across the state, and social connections for siblings of all ages. Visit the Sibling Resources page to get list of sibling workshops and support groups at www.masiblingsupport.org

Growing Up with Someone with a Disability, Revised Edition, 2002, Mary McHugh, 2002, Paul H. Brookes Publishing Co.

Brothers and Sisters: A Special Part of Exceptional Families, Third Edition, 2006, Peggy A. Gallagher, Ph.D., Thomas H. Powell, Ed.D., & Cheryl A. Rhodes, M.S., L.M.F.T., Paul H. Brookes Publishing Co.

Sibshops, Workshops for Siblings of Children with Special Needs, Revised Edition, 2008 [Don Meyer M.Ed.](#), [Patricia F. Vadasy Ph.D.](#)

Thicker Than Water: Essays by Adult Siblings of People with Disabilities, Edited by Don Meyer and written by 39 adult siblings, 2009—A collection of essays in which adult siblings share the highs and lows of growing up with a brother or sister with disabilities, as well as the ways their siblings have shaped their adult lives.

“Caring for Siblings of Seriously Ill Children,” Guidelines to support parents and caregivers in caring for the siblings of seriously ill children. View this article at: http://kidshealth.org/parent/positive/talk/sibling_care.html#

“Siblings of Children with Chronic Illnesses,” This article helps parents understand how siblings might feel and what they can do to help. View this article at: <http://www.healthychildren.org/English/health-issues/conditions/chronic/Pages/Siblings-of-Children-with-Chronic-Illnesses.aspx>