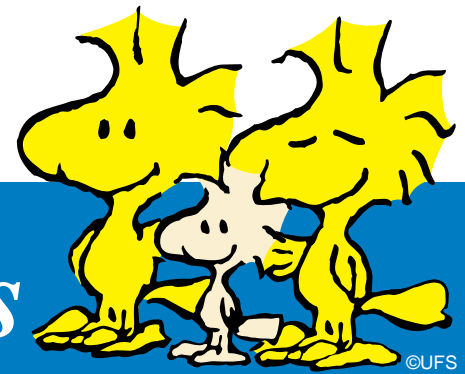


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MetDESK® News

Information and Support for the Special Needs Community

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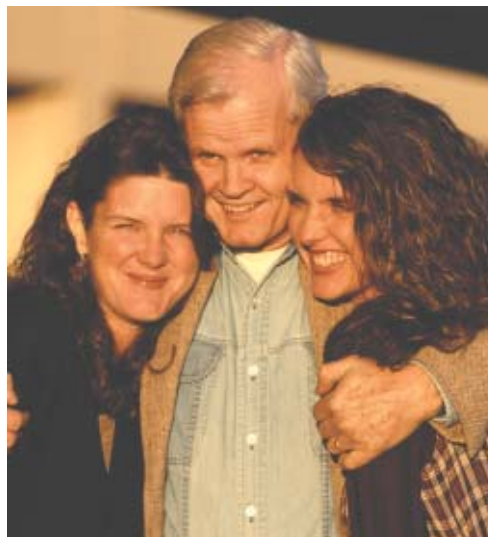
Understanding the Sibling Experience

Written by By Thomas Fish, Ph.D., Tammy Savage, Director, Ohio SIBS, The Ohio State University Nisonger Center

Why it is important to involve adult siblings in the future planning needs of families with a child with a developmental disability.

Conservative estimates put the number of adults who are currently or will soon be serving in the supporter, caregiver or advocacy role for their siblings with a disability at 5 million. The number will continue to climb as parents age and are unable to care for their children. Adult siblings are striking a delicate balance between managing their own lives, their parent's lives and the lives and of their sibling with a disability.

As one adult sibling stated, "I am one of the 5 million. You know me. I am the woman at the grocery store pushing the wheelchair in front of me and pulling the cart full of groceries behind me. I am the woman driving the mini-van without seats, but with a wheelchair lift and anchors. I am the woman who carries a "diaper bag" full of baby-related products and items, yet I have no baby. But what I do have, is my sweet, spoiled, adorable and affectionate younger sister who means the world to me. I am not her mother, but because our parents included me in her care and plans from the day she was born I have the knowledge, the



Adult siblings should realize that they are not alone as they go through life and the many unexpected twists and turns that occur when having a brother or sister with a disability.

love and the desire to provide for her the life and level of care that she not only needs but also deserves. I would want nothing less for myself, were the situation reversed and I had the disabilities."

Adult siblings can bring a fresh perspective to the issues and concerns regarding their siblings with disabilities. Often, it is the adult sibling who can see clearly past the emotional turmoil many parents face when making decisions about the sibling with a disability. Families who are fortunate

enough to have an involved adult sibling can often benefit from the different perspective.

PARENT PERSPECTIVE

Why do they do what they do?

Many parents of children with disabilities take extra steps to ensure that they do not "burden" their other children with the care or responsibilities for the child who has a disability. This is especially true, when the children are close in age. Often, parents feel that when the disability is diagnosed, it is too complex for young child to understand. What begins as a genuine desire to protect the typically developing child from anything negative evolves into a lifetime of non-communication regarding their sibling with disabilities. If parents truly wanted to avoid putting their typically developed children into the "burden" trap, then they would include all their children in open, honest discussions regarding the future plans of our brothers and sisters. After all, what greater "burden" is there than the fear that weighs on adult siblings when faced with navigating the unknown? Parents may think they are helping and still protecting them by remaining silent, but they are only making the situation worse and potentially

jeopardizing the sibling's special needs and health care.

Many parents remain silent out of fear. As the aging process begins to take its toll on their minds and bodies, the realization soon hits that they too, may need someone to assist with their daily care. Parents may also fear relinquishing control of the sibling's affairs. After all, this is their child and they have invested years of worry, care and devotion to their child's needs.

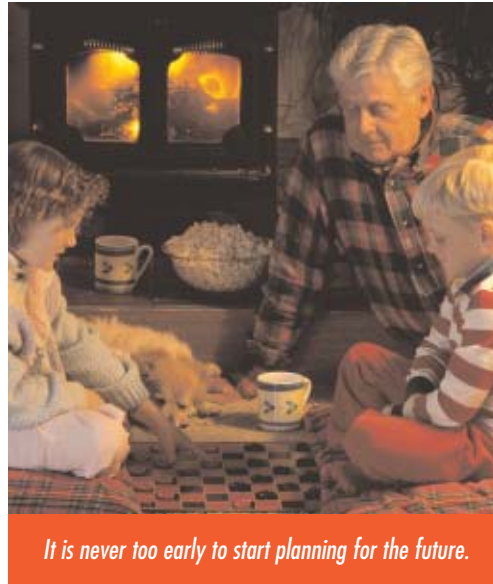
GETTING STARTED

Searching for answers when there are no easy answers.

It is never too early to start planning for the future. Future planning can be an intimidating process, but adult siblings can begin by following a few, simple guidelines. Adult siblings should be encouraged to talk with their parents and if possible, include the sibling with a disability in the conversation. It is amazing the number of times parents (who mean well) make choices and decisions without consulting the one person it actually impacts.

Begin by asking questions. Try to address the most basic needs first. Where is my sibling going to live? Where will my sibling work? What types of transportation services are available? What will my sibling do for fun and entertainment? How will my sibling's living expenses be paid? These questions are in no way all inclusive, but they will certainly provide a foundation to get adult brothers and sisters headed in the right direction. Ask your parents and other siblings, workshop supervisors, teachers, MRDD professionals and other adult siblings of people with mental retardation and developmental disabilities. The more information an adult sibling obtains, the more questions they may have. This is not uncommon, especially in situations where adult siblings have never been involved in the care of their special-needs sibling. Many adult siblings may be surprised by the answers they receive. Often the perception adult siblings have of what parents want is vastly different from the reality of the parent's desires for the future care of the brother or sister with a disability. In addition, adult siblings should be prepared for some resistance when first

attempting to address these topics with their families. Resistance may manifest in strange, unfamiliar forms and patterns, but it is important to remember that even if everyone disagrees, the motivating factor is still the sibling with disabilities.



It is never too early to start planning for the future.

Remember, every family is unique and each adult sibling must decide the best approach to begin the necessary dialogue with their particular family.

EXPERTS AND PROFESSIONALS

How can professional planners help?

Successful future planning usually involves more than one expert. Typically, a financial planner and/or an attorney will be involved in the process. Laws vary from state to state and it is crucial that families work with experts who are competent and knowledgeable in the areas of disability law, tax law and estate planning. Such experts or referrals to experts can be found by contacting a MetDESK Specialist at 1-877-MetDESK (1-877-638-3375) or visiting www.metlife.com/desk. MetDESK® is MetLife's Division of Estate Planning For Special Kids. Remember also, that there may be more than one state involved if the parents live in one state and the sibling will ultimately live in another.

The professionals must also understand how those laws and issues translate into actions and plans that accommodate each individual family's needs and desires for the future care of the sibling with a disability. Every family is different and what works for one family, may very well cause

chaos in another. Professionals need to be curious enough to ask the right questions of the family; creative enough to work with the answers and compassionate enough to realize that these are difficult issues for any family, even more so when an individual with disabilities is involved.

SIBLING SUPPORT

Adult siblings are not alone.

Adult siblings should realize that they are not alone as they go through life and the many unexpected twists and turns that occur when having a brother or sister with a disability. Connecting with other adult siblings who have similar experiences, issues and feelings can provide the adult sibling with a sense of validation and confirmation that they are an integral part of the family's success.

Ohio SIBS (Special Initiatives by Brothers & Sisters) is a unique organization leading the Adult Sibling movement. Ohio SIBS is an association of volunteer adult siblings and MRDD professionals dedicated to helping adult siblings of brothers and sisters with mental retardation and developmental disabilities become the next generation of caregivers, supporters and advocates. In addition to preparing for its third annual adult sibling conference in October, Ohio SIBS is working towards establishing itself as a state-wide resource and referral network; becoming an advocacy voice for adult siblings and their siblings with disabilities and also serving as an emotional support system for adult siblings. For more information on Ohio SIBS or to register for the conference, please contact Tammy Savage, phone: 614.688.8162, e-mail: tsavage@ohiosibs.org or Tom Fish, phone: 614.292.7550, e-mail: fish.1@osu.edu or visit www.ohiosibs.org

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