

Helpful Resources for Families that Have Children and Young Adults with Disabilities

Compiled from information provided by Home School Coordinators Tracy Allen, Chokai Benton, Jennifer Burns, Toni Dautenhahn, Deanna Harris, Angela Hill-Mayes and Sara Lewis

We always hear that there are so many resources across the state for the young and the disabled, but finding those resources can be a difficult task. Thankfully, a few general resources in Missouri are readily available to serve children and young adults with disabilities. This article outlines a small sample of the resources available statewide. If your child's school has a home school coordinator, contact him or her to assist you in finding the types of resources in your area. Home school coordinators are there to help you locate and access the services that your child needs.

Missouri 211

Provided by the United Way, Missouri 211 gives free and confidential information and referrals for help with food, housing, employment, health care, energy costs, counseling, social service agencies and more. The organization will connect you with local resources to help put you on the right track. Dial 211 from a land line (some cell phone providers also participate). You can also find a service locator online at <http://www.211.org>.

State government

The state of Missouri provides services to families and disabled adults through the Department of Social Services (DSS) and the Department of Health and Senior Services (DHSS). Call your local DSS office for help with food stamps, temporary assistance or Medicaid. To locate the nearest office, call 573-751-3221. Call DHSS for assistance with in-home nursing care, WIC, health-related needs and adult care assistance. To find the nearest office, call 573-751-6400.

The Department of Mental Health (DMH) is an excellent resource for the disabled in Missouri through its Regional Centers. Most parents know it is important for disabled children to have a Regional Center service coordinator. While you might not need a service coordinator on a daily or monthly basis, maintaining an open case keeps you prepared for life's unexpected events. They provide funding and/or referrals for respite care, autism services, postgraduation placements and much more. To locate your area's Regional Center, call 573-751-8676 or visit <http://dmh.mo.gov/mrdd>.

Missouri Assistive Technology

Missouri Assistive Technology provides increased access to assistive technology for Missourians with disabilities. Funding is available to purchase equipment, along with a loan program and other services. To find out more, go to <http://at.mo.gov> or call 800-647-8557.

The Thompson Center

The Thompson Center offers health, educational and behavioral services for individuals with autism and other developmental concerns. Professionals from different disciplines strive to deliver family-centered care that is comprehensive and coordinated. A guide to available services can be found at <http://thompsoncenter.missouri.edu/about-center/TC%20guide%20to%20services%20on%20line.pdf>. Call 573-882-6081 for more information.

SB40 boards

Many counties throughout the state have a local Senate Bill 40 (SB40) board; these can be a treasure trove of supports. SB40 boards often work in tandem with your local Regional Center to provide funds for services for individuals with developmental disabilities. Some SB40 boards can provide direct supports and services. Other times, funds are funneled to various programs. Because each board operates separately, different types of services are offered in each county. To find out if your county operates an SB40 board, contact your DMH service coordinator or your home school coordinator. Visit <http://www.macdds.org> for additional information. ➔

Community action

Community action groups are a great resource and are available across the state. They offer housing assistance and energy assistance to low-income families through their area offices. To locate the office serving your area, call 573-634-2969 or go to <http://www.communityaction.org>.

Other resources

There are several resources for diapers or training pants that deliver throughout Missouri. Parents need to contact their insurance providers or Medicaid to determine if diapers or training pants are a covered service. The insurance provider will need a prescription from your child's medical doctor.

- Care Med Equipment (800-203-8432) delivers anywhere in Missouri and accepts Medicaid and private insurance. Care Med does not accept MC+.
- Children's Medical Services (877-984-5050) provides diapers for Medicaid recipients ages 4 through 20.
- HDIS (800-296-4663 or <http://www.hdis.com>) delivers anywhere in Missouri and accepts Medicaid.
- Home Medical Supply (573-686-5510) delivers anywhere in Missouri and accepts Medicaid.
- USA Drug (800-354-6334) provides diapers up to 5T.

Resources vary from area to area throughout the state. Home school coordinators are knowledgeable of your area and the array of resources available to you and your child. Utilize the home school coordinators – they have a wealth of knowledge of all types of services in your area, not just disability resources. They are available to assist you whenever you need help.

Parent Focus

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**Archie Derboven,
Superintendent**

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Information concerning other available resources, programs, etc., is not to be construed as an endorsement by Missouri Schools for the Severely Disabled for any specific product, organization, or philosophy.

Siblings of Children with Disabilities Experience Unique Challenges, Opportunities

By Julie Holmquist

The dynamics of any sibling relationship are complex, but the mix of siblings with and without disabilities in a family can create a unique set of challenges for parents and siblings alike.

Research has documented several concerns voiced by siblings of children with disabilities, including the loss of parental attention, the need for information about the disability, increased caregiver demands and concern about the future. Yet research has also shown that these siblings have a unique opportunity to develop insight into the human condition, maturity from coping with their special-needs sibling, appreciation for good health and other positive characteristics.

The type and severity of the disability, the number of siblings, how far apart they are in age, and how a family deals with disability are among the many factors that can shape the experience of siblings.

According to a 2006 study conducted by the Vanderbilt Kennedy Center's National Sibling Research Consortium, siblings of adults with disabilities are doing very well overall. In that study, siblings reported that, as a group, they spend a fair amount of time with, feel very affectionate and close to, and have benefited greatly from their brother or sister with a disability.

Jodee Kozlak, executive vice president of human resources at Target Corporation, and her youngest sister, Amy Stapleton, would agree with that positive viewpoint. They share their perspectives on the impact a child with a disability can have on siblings.

Prepare for the best

Jodee was 10 years old when her brother John, at 15 months old, had a brain injury. He now functions at a preschool level. "My parents were told they couldn't predict anything about John's future and to prepare for the worst," Jodee says. "They said if you can't predict anything, then we'll prepare for the best!"

Her parents' philosophy set the tone for this big Greek family. "My three sisters and I responded to John as a hero. I believe I was deeply influenced by my family and their viewpoint of looking at the situation as a positive one. You never give up, and our parents didn't give up on our brother. They believed in human capability and undying love, and being proud of John, not being embarrassed but celebrating his life."

That philosophy meant including John as much as possible in family life. "It was very important to us as a group to include John," Jodee says. "I remember taking him to the grocery store and the looks we ➔

got from people because of his unpredictable behavior. As a family, our response was to say, 'tough!' We deliberately included him."

As the oldest of five children, Jodee had a different experience than her sister Amy, who at age 38 is only one year older than John. He was "more of a playmate" for her, Amy says, but she also remembers the public reactions to her brother's behaviors.

"I remember our parents taking us out to a movie theater," Amy says. "John was hyperactive and would make noises and clap his hands. I remember getting so upset about the way people looked at us and wishing he had a physical disability so they would know."

John's disability did not stop Amy from inviting her friends to her home, however. "My best friends all just loved John. Even to this day they ask about him."

Restrictions, responsibilities

While both sisters remember their childhood years with John in a positive light, there were also certain restrictions and extra responsibilities that came with being John's sister.

"For me it meant very much taking on additional responsibilities so my parents had time with John," Jodee says. "We arranged things so we all had time with him and our mom would have a break." She remembers having to quit her first job so she could be home to care for her sisters and start dinner.

"I'm sure there were times when I thought, 'bummer,' but we all did our part," Jodee says. "As a family we came together and believed in the power of hope, love and attention."

She also remembers her sisters feeling disappointed when they couldn't do something because of John but said they never dwelled on it.

"Because there were four of us older sisters, there were two others who helped immensely," added Amy. "Even though it was difficult at times, we all just naturally pitched in and shared in helping care for John."

During John's middle school years, his bus trip home from school took one hour. "I remember being at home after school waiting for his bus," Amy says. "I couldn't be in after-school activities for that time period. That stands out. I had to be home to help get John off of the bus."

There were other inconveniences, Jodee recalls. "Sure, there were places you didn't go or vacations you didn't take, and we really had to respect his routines. But our home was the hangout place for our friends – that wasn't an issue. His disability was never something behind the scenes."

Positive influences

Despite these limitations and responsibilities, both Jodee and Amy attribute many positive character traits to growing up with John. "It causes you to be really resilient and less judgmental and gives you a wider scope of experience," Jodee says. "I'm just not fazed by things. I have huge tolerance and a righteousness that everyone belongs."

The time spent babysitting her siblings during her childhood, she notes, probably would have been her fate even if John had not been her brother.

"We are a big Greek family, so we had grandmothers, cousins, aunts and uncles around and in and out of the house all the time. As the oldest of five and often the one taking care of other cousins, I think I would have ended up in charge anyway."

Being John's sister helped Amy be more accepting and to appreciate others who were unique or who were cognitively challenged. "It definitely helped me to become a more patient person and also competitive in a sense," she says.

Both sisters remember how hard John worked, and how much he had to focus to accomplish something. "Here was a person with a disability, and there was nothing stopping him," Amy says. "Watching him encouraged me to try harder and not give up."

Amy believes that her parents were good at not letting John's disability become an obstacle for their other children. She recalls the once-a-year vacations to places such as Disneyland that would have been impossible without respite care for John. "I did not feel like I had less attention," Amy says of her childhood. "I almost felt that John being a special-needs child pulled the family together."

Today, their 37-year-old brother lives in a group home with three other men near their parents' house and works five days a week. Every Sunday he visits his parents, and his siblings call or visit on a regular basis.

Because John has a normal life expectancy and their parents are growing older, Jodee and her sisters are beginning to think about John's future care. "Just recently we've agreed that we need to get my parents out of the winter for a few weeks. They have been reluctant to travel because of John, but we are committing to take care of John when they are on vacation."

(This article originally appeared in the fall 2010 edition of the Pacesetter newsletter and is reprinted with permission from PACER Center Inc. All rights reserved. Visit <http://www.pacer.org> for more information.)

Tips for Parents on Handling Sibling Issues

- Be open and honest.
- Limit caregiving responsibilities of siblings.
- Use respite care and supportive services.
- Accept the disability.
- Schedule special time with your child who does not have a disability.
- Let siblings settle their own differences.

- Welcome other children into the home.
- Require the child with the disability to do as much for himself or herself as possible.
- Recognize each child's unique qualities and family contributions.
- Recognize special stress times for siblings and plan to minimize negative effects.
- Teach siblings to interact.
- Provide opportunities for normal family activities.
- Join sibling-related organizations.

From the National Dissemination Center for Children with Disabilities, News Digest, No. 11, <http://www.nichcy.org>

PARENT RESOURCES

ParentLink

ParentLink is a network of people whose mission is to strengthen Missouri's families and communities by linking parents and professionals to information and resources. The organization distributes quality parenting information and materials to achieve this goal.

ParentLink:

- connects parents to needed services and resources.
- operates a toll-free phone service for Missouri parents. The ParentLink WarmLine provides supportive conversation and guidance for parents regarding questions they might have. A WarmLine for Spanish speakers is also available.
- provides a free resource library of parenting materials. Adult residents of Missouri may borrow materials from the library for free but must pay for the cost of returning the materials. The items cover topics including general parenting concerns, developmental stages, teenage pregnancy, substance abuse,

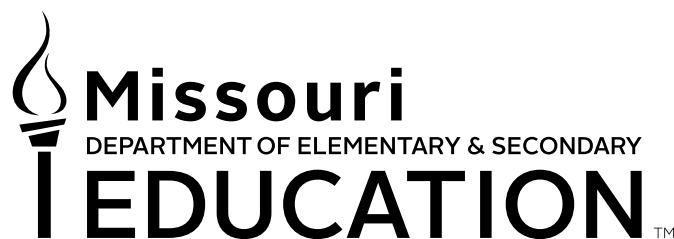
discipline techniques, toilet training, children with special needs and grandparents raising grandchildren. The library has books, videotapes, audiotapes, curricula, government documents and journals, as well as a selection of materials for African-American, Hispanic/Latino and Native American parents. New titles are acquired regularly.

ParentLink is based at the University of Missouri-Columbia, giving the organization access to the latest research, best practices and qualified experts.

For more information, contact:

- ParentLink
4800 Santana Circle
Columbia, MO 65211-8260
800-552-8522

For information in Spanish, call 888-460-0008. Business hours are 8 a.m. to 5 p.m. Monday through Friday. Visit the ParentLink website at <http://education.missouri.edu/orgs/parentlink/>.



MISSOURI SCHOOLS FOR THE SEVERELY DISABLED

Website: <http://dese.mo.gov/divspced/stateschools>

NOTE: If you have items of interest for Parent Focus, please call 573-751-0706, 800-735-2966 (Missouri Relay) or forward them to Debbie Stover, Missouri Schools for the Severely Disabled, P.O. Box 480, Jefferson City, MO 65102-0480; or send an e-mail to debbie.stover@dese.mo.gov.