

Spina Bifida



A NEW WAY TO SUPPORT FAMILIES

Welcome to the Missouri Developmental Disability Resource Center (MODDRC). You are receiving this letter with an enclosed packet of information because a request was made by you (or someone on your behalf) to the MODDRC.

We have compiled information from a number of sources and have included them in this packet, which is divided into the following sections:

- **Overview of a specific disability, special health care need, or other major topic**
- **Current practices**
- **Personal Stories**
- **Family support, advocacy and services**
- **Missouri Service Systems**

The MODDRC, which has now expanded to include Missouri's Family-to-Family Health Information Center, seeks to inform and connect individuals with disabilities or special health care needs and/or their families to peer support. We also provide opportunities for leadership development and volunteerism. When contacting the MODDRC, you are connecting to staff that have first-hand knowledge about disability related issues because they have the experience of living with the disability, either as an individual, parent or family member.

Thank you for using the MODDRC. This packet of information is one of the many ways that the MODDRC can support you in your journey with disability. We hope you will connect with us again.

Missouri Developmental Disability Resource Center/Family-to-Family Health Information Center is housed within Missouri's University Center for Excellence in Developmental Disabilities Education, Research and Services (UCEDD) at the University of Missouri-Kansas City, Institute for Human Development.

This packet was developed with funding from the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs, grant number H84MC08005 as well as Federal Funding from the Missouri Planning Council on Developmental Disabilities as established through the - P.L. 106-402



Overview

The purpose of this section is to help you gain a better understanding of a specific disability or special health care need. It is intended to provide a basic explanation of the disability and possible causes and characteristics.

If you would like more in-depth information on this topic, other topics of information or if it is not the topic you requested, please feel free to contact us again.



Overview: Spina Bifida

Sometimes a baby's spine and back bones do not close all of the way before birth. This is called Spina Bifida. It is more common than any other life-long disability that begins while the baby is still developing. Every day in the United States, around eight babies are born with Spina Bifida or a similar condition of the spine or brain¹, about 1 in every 2,500 babies.² There are different kinds of Spina Bifida. They each cause their own kinds of challenges for the person born with it.

Occult Spinal Dysraphism (OSD):

Babies born with this kind of Spina Bifida have a dimple in the lower part of their back. Some infants are born with a dimple, but do not have Spina Bifida. To be sure, doctors must check to see if it is OSD with special tests. They also look for other signs of OSD, like small lumps, red marks, or patches of hair on the lower back. With OSD, a child's spinal cord may not grow the way it should. This can cause serious problems to happen later. Babies who have OSD, or might have it, should be seen by a doctor.

Spina Bifida Occulta:

This kind of Spina Bifida is more common than most people know. Many healthy people have this kind of Spina Bifida, but don't find out unless they have a reason to get an X-ray taken of their back. It does not cause problems and has no signs, so it is sometimes called "hidden Spina Bifida." Their spinal cord is not harmed.

Meningocele:

When a child is born with this form of Spina Bifida, part of their spinal cord has come out of their spine in a sac. It is filled with nerve fluid, but usually does not cause nerve damage. Meningocele causes minor disabilities.

Myelomeningocele (Meningomyelocele):

This kind of Spina Bifida causes the most serious problems. When part of a baby's spinal cord and

nerves come through an opening in the spine, nerves are damaged. Up to 90 percent of children born with this type also have extra fluid on their brain.³ This is called hydrocephalus (hi-dro-sef-a-lus). When this happens, fluid that protects the brain cannot drain like it should. The fluid may build up too much, causing pressure and swelling, which can be dangerous. Doctors can help this problem with surgery, preventing brain damage. (See Current Practices section.)

Certain difficulties go along with having Spina Bifida. Some children and adults have problems walking, going to the bathroom, or digesting food. Others may struggle with obesity, latex allergy, learning disabilities, ADHD, depression, tendonitis, skin breakdown, or sexual issues. Sometimes cognitive and social issues also go along with Spina Bifida.

Every person with Spina Bifida is different. Some may be able to get around without help. Some may need to use a wheelchair, braces, or crutches. For some who have trouble using the bathroom, help from doctors, nurses, and parents may help them learn ways to take care of their own toileting needs.



¹ (Liptak, 2008)

² (Centers for Disease Control and Prevention, 2010)

³ (Liptak, 2008)

Preventing Spina Bifida

Studies have found the best way to prevent Spina Bifida is by making sure pregnant women get enough folic acid (also called folate) both before and during pregnancy. Because half of pregnancies happen without being planned, doctors strongly encourage all women and girls of child-bearing age to take 400 mcg (0.4 mg) of folic acid each day.⁴ Women should check their daily multi-vitamin to make sure it has at least this much folic acid.

Other sources of folic acid are dark green vegetables, egg yolks, and some fruits. Certain foods may have folic acid added to them, like some breakfast cereals, pastas, breads, and grain products. To be safe, women should eat a healthy diet and take a complete multi-vitamin with folic acid/folate.

Women who have a brother or sister with Spina Bifida, or already have a child with the disability, should take 4000 mcg (4 mg) of folic acid for one to three months before pregnancy and for the first three months after becoming pregnant.⁵

Hispanic babies are at an increased risk for Spina Bifida, as well as mothers who are seriously overweight before becoming pregnant.⁶

Life with Spina Bifida

With help, kids and adults with Spina Bifida can lead happy, full lives. They can make great friends, learn and grow, be active, and even play sports. They can learn to take care of themselves, each to his or her own ability.

Learning about Spina Bifida can be confusing. Don't be afraid to ask questions of your doctors, other families who have gone through it too, and our staff here at the Missouri Developmental Disability Resource Center/Family-to-Family Health Information Center. We're here to help.

⁴ (National Institute of Neurological Disorders and Stroke, 2007)

⁵ (Liptak, 2008)

⁶ (Centers for Disease Control and Prevention, 2010)

Works Cited

Centers for Disease Control and Prevention. (2010, May 4). Retrieved May 31, 2010, from Department of Health and Human Services: <http://www.cdc.gov/ncbddd/birthdefects/SpinaBifida>

Liptak, G. S. (2008, June). *Spotlight on Spina Bifida*. Retrieved May 31, 2010, from Spina Bifida Association: <http://www.spinabifidaassociation.org>

National Institute of Neurological Disorders and Stroke. (2007, March). Retrieved May 31 2010, 2010, from National Institutes of Health: http://www.ninds.nih.gov/disorders/spina_bifida





Current Practices

The purpose of this section is to provide you with the most current techniques and procedures for supporting people with developmental disabilities or special health care needs. These could include such things as:

- Information on therapies
- Medical treatment
- Accommodations
- Interventions

If you would like more information on current practices, please feel free to contact us again.



On the following pages, you will find more information on Spina Bifida from sources the MODDRC regards as respected and trustworthy. All information has been reprinted with permission and is for educational purposes only. For more information regarding your personal situation, please consult your team of medical professionals.



Hydrocephalus and shunts in the person with Spina Bifida

Hydrocephalus means there is a build-up of fluid around the brain. Like a bathtub with the water on and a partially clogged drain, this fluid on the brain can't drain fast enough. This fluid is made by special brain cells to protect the brain and spinal cord. When there is too much fluid, it can be dangerous.

Most of the time, it is easy for doctors to see that there is too much fluid on the brain. There are special fluid-filled pockets, or cavities, called ventricles, that get too big when there is too much liquid. In some cases, it isn't as easy to see. There are cases where there may be a little more fluid than normal, and the person has little or no signs of a problem. In these rare cases, neurosurgeons might treat the problem where other types of doctors would not. Part of the reason why this might happen is because experts disagree on when the best time is to treat the problem.

The most common treatment for hydrocephalus is to insert a tube, called a shunt, to drain excess fluid from the head to another place where the body can remove it naturally. Shunts have valves that regulate both the direction and amount of fluid that is drained. All shunts have three parts: 1) a ventricular catheter to reach the area where there is too much fluid, 2) a valve to control flow (there are many types) and 3) tubing to carry the fluid from one place in the body to another.

Types of shunts

The most common type of shunt is the ventriculo-peritoneal (VP) shunt. This shunt drains fluid from the ventricle to the body's abdomen. Other types that are less common are:

- Ventriculo-atrial (VA) shunts — VA shunts move the fluid to a vein, usually in the neck or under the collarbone;
- Ventriculo-pleural shunts — These shunts move fluid to the chest around the lungs; and
- Ventriculo-gall bladder shunts — These shunts move fluid to the gall bladder.

There are several types of shunt valves. All of them work by controlling the amount of fluid that is drained. Most are made to work automatically when fluid pressure in the head gets too high. Some valves also may have special devices to keep too much fluid from draining.

Experts have not yet learned which type of shunt is best for whom. So neurosurgeons usually pick ones that they think are best. Shunts can be put into one of these places in the head:

- The edge of the soft spot.
- Above and behind the ear.
- The back of the head.

Experts don't know if one place is better than



another. So where to put the shunt also is up to what the surgeon thinks is best.

About 80 percent of people with Spina Bifida have hydrocephalus that needs treatment. Almost all shunts are put in during the first days or weeks after birth. Sometimes the shunt will be inserted at the time of the initial back closure. A child who doesn't need a shunt by the time they are five months old probably will never need one.

Signs of shunt problems

Signs of hydrocephalus (or of shunt malfunction) in infants may include:

- rapid head growth;
- full or tense soft spot (fontanelle);
- unusual irritability;
- repeated vomiting
- crossed eyes;
- an inability to look up;
- periods in which the baby stops breathing called apnea);
- difficulty swallowing;
- a hoarse or weak cry;
- difficulty in keeping the infant awake; and
- any worsening brain function.

A head ultrasound, Computed Tomography (CT) scan or a Magnetic Resonance Imaging (MRI) scan will show this fluid build-up, but a shunt still may not be working right even if it doesn't show up on a CT or MRI scan. New, long-term treatments using small endoscopes may eliminate the need for a shunt. All patients with hydrocephalus should be seen by a neurosurgeon at least every one to two years.

Most people with Spina Bifida and shunted hydrocephalus will need the shunt for life. The most common problem with shunts is that they can get blocked up, break or come apart. About 40 percent of shunts will fail and need changing (or revision) within one year, 60 percent within five years and 80-85 percent within 10 years. About 20 percent of people with Spina Bifida will need more than one shunt revision.

The signs of shunt problems in people with Spina Bifida are different for each person. This can make it hard for families and health care providers to know what's going on. The most common sign of a shunt problem is headache. Vomiting and nausea can happen, too, but not always.

Less common signs of a shunt problem include:

- seizures (either the onset of new seizures or an increase in the frequency of existing seizures);
- a significant change in intellect, school performance or personality;
- back pain at the Spina Bifida closure site;
- worsening arm or leg function (increasing weakness or loss of sensation, worsening coordination or balance and/or worsening orthopedic deformities);
- increasing scoliosis;
- worsening speech or swallowing difficulties; and
- changes in bowel or bladder function.

Shunt malfunction can look like any of the signs of a Chiari malformation or spinal cord tethering. In fact, when brain or spinal cord function gets worse and there is no other clear cause, health care providers should check to see if there are shunt problems.

To see if there is a problem with a shunt, health care providers will study images of the brain (usually a CT scan or, for children under one year, a head ultrasound). MRI scans can show shunt problems, but they usually are not necessary, are more expensive and may require sedation or anesthesia. When ventricles start to get too big, it is a strong sign that the shunt is not working right. It is important to know that some people (between 5 and 15 percent) with Spina Bifida may have very few signs or even no visible change in the size of the ventricles when the shunt is not working correctly.

On the other hand, some people with shunted hydrocephalus can develop the slit (or stiff) ventricle syndrome. For these people, too much fluid drainage leads to very small (or slit)



ventricles. In these cases, experts think that the walls of the ventricles temporarily block the shunt catheter. This leads to a series of temporary shunt malfunctions without any visible increase in the size of the ventricles. Families and health care providers must pay close attention to a person's symptoms, especially if they are similar to those that were present with previous shunt problems.

Infections

Infection is a major problem that can happen with shunt operations. Between 5 and 10 percent of people will have this problem. Shunt infections are higher in babies than in older children and adults. Seventy percent of shunt infections happen within the first two months after a shunt operation. Eighty percent of these infections develop within the first six months. Skin bacteria (*Staphylococcus epidermidis*) are the most common causes of shunt infection. Half of people with shunt infections show signs of a shunt malfunction.

Additional signs of an infection include:

- fever;
- neck stiffness;
- pain;
- tenderness;
- redness;
- drainage from the shunt incisions or tract; and
- abdominal pain.

The diagnosis can be checked by putting a small

needle into the valve or a chamber of the shunt and taking out fluid for study.

Infections are commonly treated with antibiotics and with removal and replacement of the shunt system. There are two ways of doing this. The first is to take out the shunt system and then put in a temporary external drainage tube at the same time that antibiotics are given. When the treatment is done, the tube is taken out and a new shunt is put back in. This almost always stops the infection, but it takes two operations. The second (assuming that the shunt is working) is to keep the infected shunt in until the end of the antibiotic treatment. Then the infected shunt is removed and replaced with a new one. The second way only takes one operation, but it does not get rid of the infection as often as the first.

Making decisions

The opinion of a health care provider is very important when working with someone with Spina Bifida and shunted hydrocephalus. When making decisions, here is some helpful advice to families and health care providers:

- Pay attention to a parent's (and particularly mom's) gut feeling about shunt problems — these feelings are usually right.
- Be aware that shunt problems can cause many symptoms that may not be obviously shunt-related.
- Be on the lookout for shunt problems, and make sure the shunt is working OK before performing other neurosurgical treatments.

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Revised June 2008





Toilet training the child with Spina Bifida

Toilet training is an important part of growing up. In the U.S., kids learn bladder control when they are 2 to 3 years old. By age 5 they fully control their bladder during the day. Bowel training usually happens before bladder training. This is because stooling occurs less often and is more predictable. To toilet train successfully, children must be ready. They must be able to sit, follow directions and stay dry for at least two hours.

Children with Spina Bifida usually have damage to nerves that control the bowel and bladder. These nerves exit the spinal cord between the sacral levels two and three. In some cases, there is “sparing” of these nerves. This may allow children to have some bladder and bowel control. Most people with Spina Bifida need catheterizations and/or drugs for complete bladder and bowel control.

Getting Started

If it is not necessary to start a catheterization or bowel program, families can safely wait to see what toileting abilities their children might develop on their own. For children with Spina Bifida, the age of toilet training is usually delayed, but children should start training before going to school.

Preparing for toilet training starts early. Prevent constipation in infants and young children to preserve bowel tone and function. Later on, regular bowel movements will make it easier for children to learn control. Fruit, fruit juices, water and additives (like fiber supplements) can keep bowel movements regular. Drugs can be used, too. It is helpful to let young children go into the

bathroom. This teaches them that the bathroom is a private matter.

Bowel control happens before urinary control. So it is helpful to begin toilet training by focusing on bowel patterns. Keep a record of bowel movements for about three weeks to see if there is a pattern. Start toilet training by placing children on the toilet 15-20 minutes after eating. Make sure that feet are supported. Then teach them to “grunt” or “bear down.” Praise them for working with the toilet training program. At first, give rewards for cooperation. Then change the reward for having a bowel movement in the toilet. At the end, change the reward again for “accident-free” days. Regular toileting times are the key to this “habit training.”

If habit training does not work, try a “cleanliness program.” This program uses digital stimulation, suppositories or enemas. Doing any program on a schedule increases its success. SBA has publications and names of clinics that can help with choosing and starting a bowel program.

Special Considerations

Some signs may help adults learn children’s potential for bladder control. Those with the best chance for bladder control produce a good urine stream, are dry between urinating and have an urge to void. The chance for bladder control is much lower for those that leak urine constantly, never have a good urine stream or do not have an urge to void. There is no harm in toilet training any child as long as parents remain upbeat and realistic.



Toilet training for the bladder is the same as “normal” training except for intensity and age. Putting children on the toilet first thing in the morning and then every two hours during the day may increase dryness. Also, practicing “pottyng” is helpful. This includes removing clothes, sitting on the seat, getting dressed, flushing and washing hands. Rewards can help with cooperation, voiding in the toilet and having accident-free days.

Clean Intermittent Catheterization (CIC)

If timed toileting does not lead to dryness, CIC and drugs are needed. CIC involves inserting a small plastic tube into the bladder to drain urine. It is usually done every three to four hours. If a

child is not dry between drainings, drugs may help with dryness. CIC and drugs do not lessen a child’s given ability for bladder control. Rather, CIC empties the bladder at intervals while drugs relax the bladder and/or increase the tightness of the sphincter. If using CIC with drugs does not result in dryness, surgery may be needed.

Conclusion

Toilet training has many implications for a child’s development. For children with Spina Bifida, it is important to assess their needs. Then you can start a bowel and bladder control program. It is important to know that no one with Spina Bifida should live with uncontrolled bowel and bladder problems. Good health care and tailored programs can help.

Resources:

“Bowel Continence and Spina Bifida,” S. Leibold, et al., SBA, 1995.

“Toilet Training for Individuals with Autism and Related Disorders,” M. Wheeler, Future Horizons, Inc., 1998.

“Bladder and Bowel Management for the Child with Spinal Cord Dysfunction,” L. Merenda, J. Brown, Journal of Spinal Cord Medicine, SCI Supplement, Vol 27, 2004, p. 16-23.

“Incontinence: Toilet Training a Child with Special Needs,” C. Keeler, Exceptional Parent, October 2000, p. 82-86.

“Incontinence: Toilet Talk,” G. Paley, et al., Exceptional Parent, November 2000, p. 96-102.

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This information does not constitute medical advice for any individual. As specific cases may vary from the general information presented here, SBA advises readers to consult a qualified medical or other professional on an individual basis.

Revised June 2008





Personal Stories

The purpose of this section is to provide you with the perspective of parents, family members and those living with the disability or special health care need. These stories give you insight of what life was like growing up and what life looks like now, as well as some of the joys and challenges that were experienced.

Written personal stories are one way of connecting to others who have similar experiences. Another way of connecting with others is through the Sharing Our Strengths peer support network. This service of the MODDRC provides you with an individualized match specific to what you want. This may include being matched to mentors with a similar disability experience, a mentor located in a similar part of the state or around a specific issue. If you are interested in being matched or in becoming a mentor for someone else, please contact us.



Winning with Attitude

Questions by MODDRC, Answers by Malinda C.

What was it like growing up with spina bifida?

School

At school, the teachers and students were mostly kind and understanding. The most difficult part was ridicule by other students, which did not occur much until about the fourth grade. Surprisingly, the ridicule came from students younger than me. My mother and I talked about this, because it was very hurtful. She told me that, just because children made fun of me, it didn't mean I was a less worthwhile person. They simply didn't understand my differences. She told me to hold my head up and ignore them, which I found to be good advice for life.

I studied hard and made good grades, which made me feel proud. I always felt that I had to prove myself because of my disability. Some of my teachers told my mother that they believed having me in the classroom made my classmates more accepting of differences in people.

Recreation/Hobbies

Naturally, I couldn't participate in sports, but I joined in a variety of other activities and clubs. I don't believe my spina bifida really affected my recreation and hobbies. I took swimming lessons from an early age, and swimming brought me great enjoyment and helped with my physical condition.

Friends

During grade school, high school, and college, my friends mostly treated me as though I had no disability, and included me in all of their activities to the degree that I could participate. It made me realize in hindsight that my attitude toward my disability greatly influenced their attitude.

I had many friends. Together, we did lots of typical activities throughout my school years. A difficult thing for me was when I first did overnights at friends' houses, due to the bladder and bowel issues. My mother was friendly with my grade school friends' parents, and she did a good job of telling them about difficulties I might have. I shared some of my bladder issues with my closest friends. By college, I was relatively open with my close

female friends about those issues. Even though it made me nervous at first sharing such personal information, all of my close friends were always comfortable with it and made me feel comfortable. I still get together with friends from grade school, high school and college.

Family life

I am blessed with wonderful parents who always made me believe I am a wonderful daughter who could accomplish whatever I decided to do in life, and that my disability in no way made me any less of a person. I think parents are the first and foremost people who teach and instill self-worth in their children. At the time, I thought they should give me a break on some things, but in hindsight I know that their expectations for doing the best I could do became my expectations. I am thankful for that, because some of the people I encountered in life saw mostly my disability rather than my ability, and I had to learn to not let that affect me.

I have an older brother and sister, both who treated me just like they treated each other. They never minded being seen in social situations with me, and they were also very protective if anyone made fun of me. They included me in activities with their friends, which really helped me feel good about myself. My sister was a senior in high school when I was a freshman, and that was a huge benefit to me. And my brother and his friends would help me get around when I was little at events. He sometimes even carried me on his shoulders.

I was also blessed with a huge, loving extended family of uncles, aunts, and cousins. I don't ever remember feeling any different than my cousins. I felt like they treated me as though I was "extra special in a good way." I am still very close with the three cousins who are my age, and we still do things together socially.

Employment

My spina bifida was a major factor in my choosing social work as my field of employment, because I wanted to help others with disabilities. When I was seeking employment, I debated whether to mention my disability in my cover letters or interviews. I



choose to do so, because I felt it was an asset. It gave me unique perspectives and showed my persistence. I always brought up the subject, and I assured the prospective employer that it would not negatively impact my work performance. I believe it was important to discuss it, to show that I am comfortable with my disability, and to help them become more comfortable with it.

I entered the social work field, working with consumers with disabilities. I know I have chosen a good profession for myself, and find it to be very rewarding. I believe I bring a unique and helpful perspective, and I can be a very effective advocate for people with disabilities. I may have not been hired for some positions because of my disability, but in general, I have found great employment in a reasonable length time.

I believe having a positive attitude and stressing the positive aspects of experiences I have had (due to my disability) can be a powerful aid in obtaining employment. I also believe volunteer experience brings value, in that it networks a person with a wide variety of acquaintances and resources.

What are some good things about having spina bifida?

I feel I have a rich and rewarding life as a person with spina bifida. I chose to participate in a wide variety of volunteer activities: Spina Bifida-Kansas City Association; Camp MITIOG (a camp for people with spina bifida, ages 6 to 17); the Kansas City Mayor's Committee for People with Disabilities; Transition Camp Committee (provides workshops for students with spina bifida transitioning from high school to college or a job, etc.); Sharing Our Strengths (mentoring others with spina bifida and their families); and SAVE, Inc. (a foundation that provides assistance toward special projects). Being involved in these organizations has allowed me to become friends and mentors with wonderful people who share my same concerns and issues.

I believe having spina bifida has made me a stronger person because I've had additional challenges in life that I've dealt with successfully. These made me believe I could cope with many challenges. Spina bifida has also given me greater empathy and insights for others with disabilities

or differences. It has given me the opportunity to offer hope to others by my example, attitude, and openness, and that is very rewarding. Spina bifida has always helped me to see the good in all people regardless of their abilities, appearances, or social standing.

What are you most proud of?

I am most proud of my career. It has allowed me to assist and advocate for many people with a variety of disabilities. I'm also grateful that my parents taught me to be a good moral person, and proud that I followed that teaching. I believe that having spina bifida helped shape me into the person I am, which makes me proud that I'm living my life with my disability in a positive rather than a negative way.

What is the hardest part of having spina bifida?

The hardest part of having spina bifida is dealing with the medical and physical challenges, particularly the bladder and bowel issues.

What would you want a parent of a child with spina bifida to know?

First and foremost, you have a wonderful child, who happens to have a disability. You will travel together on an incredible journey through life, with many ups and downs. You have the opportunity to become very close with your child as you learn to face difficult challenges together, reap the rewards, and become stronger through it.

Parents are the most important influence in a child's life. They affect a child's attitude about self-worth, positive or negative outlook on life, and how he/she deals with the physical, social, and intellectual challenges of spina bifida. As your child progresses, teach him/her about spina bifida as best you can. Always answer questions truthfully. Help your child be as self-sufficient as possible, and to take responsibility for his/her health, medications, talking with doctors at appointments, exercise, eating properly, and completing educational responsibilities.





Family Support, Advocacy and Services

The purpose of this section is to provide you with a listing of organizations specifically designed to meet the support needs of individuals with developmental disabilities or special health care needs and their families. This listing includes parent organizations, support groups or other advocacy organizations.



Support for Families

Sharing Our Strengths (SOS) Peer Support Network

215 W. Pershing Rd, 6th floor
 Kansas City, MO 64108
 Toll free: 800-444-0821
 Web: <http://www.sharingourstrengths.com>

SOS is a statewide support network of parents, family members, individuals with developmental disabilities or special health needs, and professionals who are matched with peer mentors to share experiences, offer emotional support and to network with others. You can request an individual parent to parent or peer support match with another parent or individual who has experienced similar circumstances.

<p>Spina Bifida Association of America 4590 MacArthur Blvd. NW, Suite 250 Washington, DC 20007285 Phone: 202-944-3285 Toll free: 800-621-3141 Web: www.spinabifidaassociation.org Email: sbaa@sbaa.org</p>	<p>Spina Bifida Kansas City Mark Newkirk, President PO Box 5462 Kansas City, MO 64131 Phone: 816-277-9087 Web: www.sbkc.org Email: info@sbkc.org</p>
<p>Spina Bifida of Greater St. Louis Mark Abbott, President 8050 Watson Rd., Suite 115 St. Louis, MO 63119 Phone: 314-843-2244 Toll free: 800-784-0983 Web: www.sbstl.com</p>	<p>Disabled Sports USA 451 Hungerford Dr., Suite 100 Rockville, MD 20850 Phone: 301-217-0960 Web: www.dsusa.org Email: dsusa@dsusa.org</p>
<p>National Dissemination Center for Children with Disabilities (NICHCY) U.S. Department of Education Office of Special Education Programs PO Box 1492 Washington, DC 20013-1492 Toll free: 800-695-0285 Web: www.nichcy.org Email: nichcy@aed.org</p>	<p>March of Dimes Foundation 1275 Mamaroneck Ave. White Plains, NY 10605 Phone: 914-997-4488 Toll free: 888-663-4637 Web: www.marchofdimes.com Email: askus@marchofdimes.com</p>





Missouri Service Systems

The purpose of this section is to provide you with a listing of agencies focused on areas such as educational, medical care or social services to individuals with developmental disabilities or special health care needs. This includes listings such as state or local agencies, hospitals, clinics or education systems.



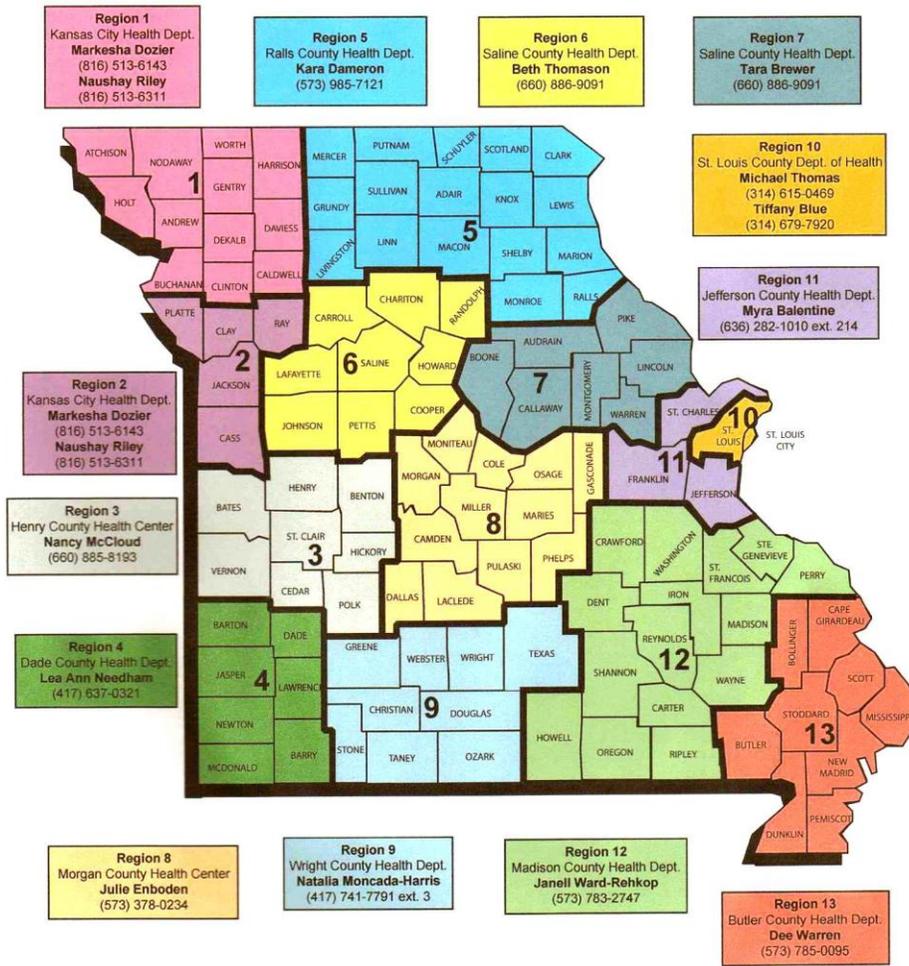
Missouri Service System Contacts

Children with Special Health Care Needs (CSHCN) Program

Missouri resident children (age 0-21) with Spina Bifida who also meet financial guidelines may be eligible for the Missouri Children and Youth with Special Health Care Needs (CYSHCN) Program. This program covers outpatient tests and evaluations, and possibly inpatient care, surgery, physical therapy, occupational therapy, speech and language therapy, prescriptions, equipment and supplies.

If you feel that you or a member of your family may qualify for a Special Health Care Need Program, please use the map below and call the regional office that serves the county in which you reside or call: 1-800-451-0669.

**Missouri Department of Health and Senior Services
Bureau of Special Health Care Needs
Children and Youth with Special Health Care Needs (CYSHCN) Program
Service Coordinator Contact Information**



7/22/10



Missouri Service System Contacts, continued

Regional Offices, Division of Developmental Disabilities

Missouri Department of Mental Health

Toll free: 800-207-9329

Email: ddmail@dmh.mo.gov

Web: www.dmh.mo.gov/dd

The Division of Developmental Disabilities improves the lives of persons with disabilities through programs and services to enable those persons to live independently and productively. If you would like more information, please call (573) 751-4054, or toll free 800-207-9329.

You must apply through one of 11 regional offices to gain access to many state services, including funding through HCBS (Home and Community-Based) waiver programs. To find the regional office for your area, use the toll free number listed above or visit: <http://www.missouri.networkofcare.org> and click on Developmental Disabilities.

Division of Developmental Disabilities
REGIONAL OFFICES AND HABILITATION CENTERS

