Contact Us:

To learn more, or to support DSAM, please contact our office at 901.547.7588 or e-mail us at admin@dsamemphis.org.

Down Syndrome Association of Memphis and the Mid-South
2893 S. Mendenhall Road, Suite 3
Memphis, TN 38115 www.dsamemphis.org

Special thanks to:
Church of the Holy Communion for providing space for our New Parent Brunches

New Parents Guide
For Parents of Babies with Down Syndrome

Sponsored by the Down Syndrome Association of Memphis and the Mid-South

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Letter to New Parents

Congratulations! You have just become the parent of a remarkable little person. Like all newborns, your baby loves and needs you. In addition to the care that all newborn babies require, this little one has some special needs that may seem overwhelming to you right now. First and foremost, remember that your baby is a baby first.

If you are like most people, you have little idea of what Down syndrome means. We would like to introduce you to the Down Syndrome Association of Memphis and the Mid-South (DSAM), an organization founded by parents of children with Down syndrome. DSAM supports and empowers individuals with Down syndrome and their families. Our organization provides this folder, which was written and assembled by parents of children with Down syndrome in order to consolidate vital information that you will need. We recommend that you start by reading the “Health Issues: What Should I do First?” section. Read and use the other information whenever you are ready.

Along with this packet, we would like to give you a complimentary book with current & comprehensive information about Down syndrome. If you have not received a copy, please contact our office at

901.547.7588
admin@dsamemphis.org

As the parent of a child with Down syndrome, we know you have many questions and lots of different emotions right now. Remember – you are not alone. There is a group of parents available to give you support and information.

Again, congratulations on your new baby! We look forward to meeting all of you.

Sincerely yours,

Down Syndrome Association of Memphis and the Mid-South

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National Down Syndrome Society

Education. Research. Advocacy. The National Down Syndrome Society, a not-for-profit organization, was established in 1979 to benefit people with Down syndrome through education, research and advocacy. Since that time, the NDSS has grown into one of the largest non-governmental supporters of Down syndrome-specific research in the United States. Today, the NDSS continues its commitment to enhancing the quality of life and realizing the potential of all people with Down syndrome.

National Down Syndrome Society
8 E. 41st Street, 8th floor
New York, NY 10017
800.221.4602
www.ndss.org
What is Down Syndrome?

Down syndrome is the most commonly occurring genetic condition. Individuals with Down syndrome have an extra copy of the number 21 chromosome present in all or some of their cells. The medical term for Down syndrome is Trisomy 21. This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome. It is estimated that one in every 691 live births will result in a child with Down syndrome, representing approximately 6,000 births per year in the United States. There are approximately 400,000 individuals with Down syndrome in the United States today.

There is a wide variation in the abilities, physical development and behavior of individuals with Down syndrome. When describing your child, you should say he/she has Down syndrome. Your baby is a baby first and foremost. The fact that your baby has Down syndrome is of secondary importance. This is called “People First” or “People Centered” language.

With appropriate education, therapy, support, opportunity and love, individuals with Down syndrome can and will lead fulfilling and productive lives.

Health Issues

What Should I do First?

Children with Down syndrome are often at increased risk for certain health problems. Congenital heart defects, increased susceptibility to infection, respiratory problems and obstructed digestive tracts occur with greater frequency among children with Down syndrome. Fortunately, advances in medicine have rendered most of these health problems treatable. As with all children, you must take an active role in ensuring the best health care for your child. Some steps we recommend you take soon after birth include:

1. Talk to your pediatrician about their experience with children with Down syndrome. The Down Syndrome Association of Memphis and the Mid-South (DSAM) does not endorse any health care provider. DSAM can help you in contacting other parents, so you can ask questions about how they selected a pediatrician for their child. You may also ask pediatricians for recommendations of colleagues who have experience treating children with Down syndrome.
2. Obtain an echocardiogram. It is important that all children born with Down syndrome, even those who have no symptoms of heart disease, have an echocardiogram in the first 2 or 3 months of life. Symptoms may present themselves as heart failure, difficulty breathing or failure to thrive. The symptoms may not be apparent at first. Most hospitals have the capability to perform an echocardiogram. It is often convenient to take care of this before leaving the hospital.

3. Ensure that the diagnosis of Down syndrome is confirmed via chromosomal karyotyping. A genetic counselor can help explain the results.

4. Have your pediatrician check for gastrointestinal blockage. Some signs of gastrointestinal blockage include vomiting or absence of stools. Again, the symptoms may not present themselves for a period of time.

5. If your child has any feeding difficulties, consult a feeding specialist. Ask for a consult with a feeding specialist. Most children with Down syndrome have success with breastfeeding.

6. Obtain a hearing test before leaving the hospital. Some children with Down syndrome experience hearing loss. With new testing procedures, this can be detected easily in newborns.

For health care guidelines, visit our website at www.dsamemphis.org. Please note: This non-exclusive list is not meant to replace the care and advice of a qualified physician.
The concept of early intervention is simple. If a child with a developmental delay such as Down syndrome receives proper help and supports early on in life, problems in the future may be minimized.

**What is the cost?**
At this time, Early Intervention services should be provided at no cost.

**Is there an age limit to receive Early Intervention services?**
The age limit to receive Early Intervention services is newborn to three years.

**What kinds of things will my child do in Early Intervention?**
After eligibility is determined (most children with Down syndrome qualify), an Individualized Family Services Plan (IFSP) will be developed. It is written with help from the parents and professionals (therapists, educators, medical professionals). Your child may participate in a variety of activities planned by licensed therapists, teachers, other medical professionals and most importantly, your family. The setting for these activities may include individual or group therapies, scheduled home visits or other activities in your home, day-care, hospital or clinic. You will be able to work out a plan that is appropriate for your child and your family. Your child’s records will be kept confidential.

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**Myth: Parents will not find community support in raising their child with Down syndrome.**
**Truth:** In almost every community of the United States there are parent support groups and other community organizations directly involved in providing services to families of individuals with Down syndrome.

**Myth: People with Down syndrome are always happy.**
**Truth:** People with Down syndrome have feelings just like everyone else in the population. They respond to positive expressions of friendship and they are hurt and upset by inconsiderate behavior.

**Myth: Children with Down syndrome must be placed in segregated special education programs.**
**Truth:** Children with Down syndrome have been included in regular academic classrooms in schools across the country. In some instances they are integrated into specific courses, while in other situations students are fully included in the regular classroom for all subjects. The degree of mainstreaming, now called inclusion, is based on the IEP of the individual; but the trend is for full inclusion in the social and educational life of the community.

**Myth: Adults with Down syndrome are unable to form close interpersonal relationships leading to marriage.**
**Truth:** People with Down syndrome date, socialize form ongoing relationships and get married. They lead full and independent lives.
Early Intervention typically includes but is not limited to the following services:

**Physical Therapy**
Pediatric Physical Therapy (PT) concentrates on the development of gross motor (large muscles) skills such as crawling, sitting, walking, balance, and mobility. Children with Down syndrome may have low muscle tone and need physical therapy to condition muscles, build strength and improve movement.

**Occupational Therapy**
Pediatric Occupational Therapy (OT) focuses on the development of fine motor (small muscles) and self-help skills. The goal of OT is to help make learning possible by helping children to develop the underlying skills that will lead to independence in personal, social, academic or vocational activities. This includes difficulties a child may encounter with ADL’s (Activities of Daily Living) such as dressing, grooming, and feeding.

**Speech Language Therapy**
Speech Language Therapy (SLT) addresses the child’s communicative needs. This includes verbal and non-verbal communication. Often speech therapy incorporates non-verbal techniques such as sign language. SLT is designed to help with speech disorders often referred to as articulation or phonological disorders - problems with the way sounds are made or how sounds are sequenced to form words; oral motor problems resulting in difficulty producing speech sounds, and delays in feeding skills.

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**Myths & Truths**

**Myth: Down syndrome is a rare genetic disorder.**
**Truth:** Down syndrome is the most commonly occurring genetic condition. One in every 691 live births is a child with Down syndrome, representing approximately 6,000 births per year in the United States alone. Today, Down syndrome affects more than 400,000 people in the United States.

**Myth: Children with Down syndrome are born to older parents.**
**Truth:** Eighty percent of children born with Down syndrome are born to women younger than 35-years-old. However, the incidence of births of children with Down syndrome increases with the age of the mother.

**Myth: People with Down syndrome have severe cognitive delays.**
**Truth:** Most people with Down syndrome have IQs that fall in the mild to moderate range of cognitive delays. Children with Down syndrome are eager to learn and educators and researchers are still discovering the full educational potential of people with Down syndrome.

**Myth: People with Down syndrome are institutionalized.**
**Truth:** Today people with Down syndrome grow up at home with their families and are active participants in the educational, vocational, social, and recreational activities of the community. They are integrated into the general education system, take part in sports, camping, music, art programs, socialize with people with and without disabilities, and as adults obtain employment and are able to live in independent housing arrangements.
Can a baby with Down syndrome learn how to nurse and be strong enough to nurse successfully? It may take a little longer for the baby to learn how to suck well, or for an experienced nursing mother to learn the particular “trick,” but with a little patience, and lots of love, it can be done!

A child born with Down syndrome may be a little sleepier and have a poor sucking reflex, while others may have respiratory problems and more serious difficulties. If your baby is weak at birth, they may experience some difficulty in learning to suck and swallow, so you will need to be calm and patient while he/she learns.

Babies with Down syndrome may be placid and sometimes have low muscle tone and generalized weakness at birth. Therefore, the mother will have to learn to be a clock watcher, picking the baby up frequently and offering the breast, rather than waiting for him to cry to be fed. The baby should be encouraged to nurse about every two hours during the day and several times during the night. Sometimes mothers have trouble getting the baby’s tongue down from the roof of their mouth. If this happens, insert the tip of your finger between the roof of the baby’s mouth and the tongue in an upside down position, then turn the finger over, to condition the sucking reflex.

This procedure can be repeated four or five times before each nursing, starting with the finger at the front of the baby’s mouth and pushing it slowly into the baby’s mouth so the baby will think he is drawing in.

Stay in close contact with your doctor so that he/she can continue to evaluate your baby’s progress. Let your doctor’s advice and your baby’s needs be your guide. Many babies with Down syndrome are slow, leisurely nursers, so long feedings are to be anticipated.
**Special Kids and Families, Inc.**

Special Kids and Families is a family-centered Early Intervention program that serves children with developmental disabilities from birth to age three. SKF serves the needs of families and children through family training, a preschool program, therapies, transition, and advocacy training.

**SRVS Special Kids and Families, Inc.**

4738 Walnut Grove Road
Memphis, TN 38117
901.312.9915

**The Harwood Center, Inc.**

The Harwood Center is an early intervention program which provides services to children with developmental disabilities from birth to age three, and offers support to their families. Some of its programs include school for children with developmental delays, home-based services, speech/language therapy, and behavioral services.

**SRVS Special Kids and Families, Inc.**

4738 Walnut Grove Road
Memphis, TN 38117
901.312.9915

**The Harwood Center, Inc.**

711 Jefferson Avenue
Memphis, TN 38105
901.448.6580
www.harwoodcenter.org

The First Connections Program is authorized and funded through Part C of the Individuals with Disabilities Education Act. The Department of Human Services (DHS) is the Lead Agency for the Program. The Division of Developmental Disabilities Services (DDS) is the division within DHS, which has administrative responsibility for implementation of the program.

Family help and information line: 1-800-643-8258

**The Harwood Center, Inc.**

711 Jefferson Avenue
Memphis, TN 38105
901.448.6580

**Steudlein Learning Center** is a non-profit, developmental disabilities service center. Our mission is to work with children who have been diagnosed with developmental disabilities. We serve children from birth to five years old. Our focus is for each child to increase developmental skill level and education in order to transition into the general curriculum of preschool, daycare or school. We believe that it is necessary to provide a strong curriculum for children; one that will address each child’s needs and at the same time, is developmentally appropriate with engaging, hands on, multisensory activities. Our services include evaluation/assessment, early intervention, and special instruction in a structured classroom environment, as well as, physical, occupational and speech/language therapy. It is our goal to teach children and help them reach a level of skill that will enable them to be successful as they reach kindergarten and school.

**Steudlein Learning Center**

207 Balfour Road
West Memphis, AR 72301
(870) 733-9950
Insurance and Medicaid

You can apply for Disabled Child Living at Home through the Division of Medicaid even if you have insurance and are employed. Medicaid may pay medical bills incurred on behalf of your child. Disabled Child Living at Home is NOT based on your income level; it is based on your child’s disability. Medicaid will pay for a variety of items and services that may not be included in your insurance plan, including co-pays, prescriptions, deductible, and limits on therapeutic services, etc. Medicaid will likely cover what your insurance doesn’t cover. Medicaid will even provide diapers if your child needs them after age three. It is worth the time and investment to fill out the paperwork.

MR/DD Medicaid Waiver

If you qualify for Medicaid for Disabled Child Living at Home, you are eligible to apply for the MR/DD Medicaid Waiver program. This program provides an approved number of hours of attendant care or respite care free of charge in your home to allow you to work and take care of your family’s other needs. MR/DD Waiver can also provide Community Care, which would provide free care for your child at a Medicaid-approved facility.

Mississippi Division of Medicaid
Senatobia Regional Office
(Counties served: DeSoto, Panola, and Tate)
2776 Highway 51 South
Senatobia, MS 38668-9403
Phone: 662.562.0147
Fax: 662.562.7897
www.medicaid.ms.gov

Resources in Arkansas

First Connections, Arkansas Infant and Toddler Program
The First Connections Program is a statewide system of services to assist infants, toddlers, and their families. Children grow, learn, and develop at different rates and in different ways. Just as children are all individuals, families also have different abilities and needs. The First Connections Program works with families on an individualized basis to assist in locating and coordination services and assistance to enhance not only the child’s abilities but those of the family to assist their child.

Le Bonheur Early Intervention and Development (LEAD)

Designated as an Early Intervention Resource Agency by Tennessee’s Department of Education, Le Bonheur Early Intervention and Development (LEAD) specializes in providing exceptional care to children age birth to three years. LEAD receives referrals from Tennessee Early Intervention System. More than 500 children and their families receive early intervention from LEAD each year.

Le Bonheur Children’s Medical Center
51 N Dunlap St #100
Memphis, TN 38105
901.287.4900
www.lebonheur.org

The Department of Intellectual and Developmental Disabilities (DIDD)

DIDD is the state agency responsible for providing services and supports to Tennesseans with intellectual disabilities. DIDD provides services directly or through contracts with community providers in a variety of settings. These settings include community based living.

The TN Family Support Program, under DIDD, is funded by state dollars and designed to assist individuals with disabilities and their families to remain together in their homes and communities. Family support is not a substitute for more comprehensive services provided under other programs, including the Medicaid HCBS Waiver, TennCare, Medicare, or private insurance. SRVS currently has the Family Support contract for Shelby County.

DIDD
West Tennessee Coordinator:
Susan Kurts-Acred
West Tennessee Regional Office
11437 Milton Wilson Road
Arlington, TN 38002
Phone: 901.745.7348
Fax: 901.745.7723
Email: Susan.Kurts-Acred@tn.gov
ABLE TN

Able TN is a savings program designed to help people with disabilities put aside money to pay for qualified expenses. These accounts provide the opportunity to save and invest with tax-free earnings to help participants maintain independence and quality of life with little to no impact on federal benefits. To learn more about ABLE TN, visit [http://www.abletn.gov/](http://www.abletn.gov/)

ECF Choices

Employment and Community First (ECF) Choices is a new TN Care program for individuals with intellectual and other developmental disabilities. This program is designed to provide needed supports for both children and adults in their own home or in the community. These are called Home and Community Based Services or HCBS. If your child has TennCare, contact your Managed Care Organization (MCO) to learn more. You can find this information on your child’s TennCare card. If your child does not have TennCare, contact your regional office for the Department of Intellectual and Developmental Disabilities (DIDD) at 1.866.372.5709.

Support and Training for Exceptional Parents (STEP)

STEP is a statewide family-to-family program in Tennessee that provides trainings and information on special education for parents and caregivers, free of charge. The purpose of STEP is to support families by providing free information, advocacy training, and support services to parents of children eligible to receive special education services under the Individuals with Disabilities Education Act (IDEA) who reside in Tennessee. STEP services are available to any parent or family member of a special education student or a student who may need special help in school (birth through age 22).

STEP
2157 Madison Ave., Suite 204
Memphis, TN 38104
Phone: 901-726-4334
1-800-280-STEP | toll free
1-800-975-2919 | en español
[www.tnstep.org](http://www.tnstep.org)

The ARC of Tennessee
151 Athens Way #100
Nashville, TN 37228
Phone: 615-248-5878
Toll Free: 800-835-7077
Fax: 615-248-5879

Resources in Mississippi

First Steps

The State of Mississippi provides early intervention services called First Steps, for qualified children from birth to three years of age at no cost to parents.

These services include evaluation/assessment, special instruction, speech therapy, occupational therapy, and/or physical therapy. The Early Intervention office will conduct an evaluation and assessment to identify your baby’s strengths and to develop a plan for services. Early Intervention is a system designed to enhance families’ abilities to help babies grow, develop, and learn. A Service Coordinator will help your family identify and use resources that will empower you to be a better advocate for your baby.

Your child can receive early intervention services in your home, day care, or other community setting. A team will work with your family to help decide what services your family will receive and where the services take place.

First Steps is administered through your local county health department. Contact your local health department or the Mississippi Department of Health Early Intervention program. Information, including a referral form, is available on their website.

Mississippi Department of Health, Early Intervention Program
Phone: 800.451.3903
Fax: 601.576.7540
[www.msdh.state.ms.us/ MSDHsite/_static/41,0,74.html](http://www.msdh.state.ms.us/ MSDHsite/_static/41,0,74.html)