## Parent Packet

A grade to services for children with developmental disabilities and chronic medical conditions







#### **Parent Packet**

A guide to services for children with developmental disabilities and chronic medical conditions









#### Vision

We envision a world where everyone has an equal and real opportunity to lead a meaningful life!

## We're here to lend a hand!

Have you just discovered you have a son or daughter with a developmental disability or chronic medical condition?

Don't despair. Don't panic.

All around you are people eager to lend you a helping hand.

There are people from state and federal government agencies. There are people in not-forprofit organizations. Most importantly, there are people – other parents – who have either been in or are still in your shoes.

They've experienced what you're experiencing. They've dealt with the emotions you're dealing with. Reach out to them. They will help you find the positive resources in your life. Lean on them. You'll quickly discover that they will be there when you need them the most.

One of the first things parents of children with developmental disabilities or chronic illness will tell you is that there are five stages you're likely to go through:

- \* Anxiety
- Anguish
- \* Anger
- \* Acceptance
- \* Action

Of these, the last two are critical to the welfare of your child. No matter the age – new-born or adult – there are things to consider immediately.

First, do not make hasty decisions. These are complex issues. Instead, gather as much information as you can. You simply cannot know too much. As a matter of fact, the more you know the better – for you and your child.

Secondly, early treatment is crucial, especially for the young. So, don't delay. Extra or possibly unneeded therapy will not harm a child. The lack of therapy will.

In the process you will learn a whole new language. Don't let it intimidate you. If you don't understand, say so. If you have questions, don't leave them unanswered. This is your child.

Sometimes it may be difficult to find the books, brochures or other materials about your child's disability. Keep searching. The information is there. If you have access to a computer or know someone who does, make ample use of the "information highway". Much of your "need-to-know" material can be found "on-line."

In the end, you'll discover that what you need is available. What you want is attainable. The resources you and your child require are within reach.

What lies ahead may not be easy. You will have to make difficult decisions. That's why the Parent Packet was developed. It's your starting point. It is designed to help you successfully navigate the system. In it you'll find a number of "point-of-entry" referral sections, including: Medical, Health & Human Services; Information & Referral; Parent Support & Assistance; Education Programs; Adult Services; Legal Assistance, and Financial Resources.

Sometimes the hunt for what you and child needs will get confusing. Don't become discouraged. There is light at the end of the tunnel.

The best advice! Take it one day at a time. Accept life as it is. Follow your instincts. You're in the best position to determine your son's or daughter's needs.

Above all else, look for the hope. It exists. And, remember – you are not alone!









#### Mission Statement

The Arkansas Governor's Developmental Disabilities Council supports people with developmental disabilities in achieving independence, productivity, integration and inclusion into the community through advocating and promoting service system that enhance their lives.

The Council believes society gains from full participation of a wide variety of people.

The Council believes in the right of individuals to live, work, play, learn, worship and experience life as they choose.

The Council believes independence entails economic selfsufficiency, equal opportunity, a right to make choices, a right to dignity and respect, the dignity of risk and the opportunity to maximize one's potential and to achieve individual goals.

For Additional Information Contact

#### Arkansas Governor's Developmental Disabilities Council

5800 West 10th Street, Suite 805 Little Rock, Arkansas 72204 (501) 661-2589 (Voice/TDD) + (800) 482-5400, Ext. 2589 + TT/TDD (800) 285-1131 + www.ddcouncil.org



BEFORE YOU START YOUR SEARCH FOR AVAILABLE RESOURCES AND SERVICES, TAKE INTO CONSIDERATION WHAT THE PARENTS OF CHILDREN WITH DISABILITIES RECOMMEND.

Parents who have been there say that locating the information and services their child requires can be confusing and time consuming. To start, it's difficult to figure out where, exactly, to begin. Then, there's knowing the right questions to ask. That's why the Parent Packet was developed. First, we encourage you to work closely with your health care provider while making use of the point-of-entry information and services provided in this packet. Then, check closely the business cards, brochures and other information at the back of the packet. Finally, be certain to include the following key information when calling for information about services - your child's age; your child's diagnosis and/or your main concern, and where you live (city and county). Now, with all that in mind, this is what parents of children with disabilities advise.

#### Be Persistent

It's about not giving up., about asking lots of questions. Why? Because this is your child. You can't quit. Keep calling - keep asking questions (there are no unimportant questions). Ask everyone you talk with for the names and telephone numbers of other people, agencies or organizations you can contact. If recorded voice information seems confusing, stick with it. Staving on the telephone line will often get you connected with a person. And, written requests and/or e-mail sometimes result in better and more timely responses.

#### lake and Keep Notes

It's important to get organized. When you call an agency or organization, write down the date and time of the call, who you talk with and what the conversation is about. You are going to need that information at some point (see pages 2-3) and you'll need to remember the important points. Keep track of:

- The agency's/organization's name;
- \* The name of the person you talk with and their telephone number;
- Important information you receive;
- What you, and they, agree to do, and by what date, and
- Other people, agencies and/or organizations to contact.

#### Educate Yourself

As a parent, you need to educate yourself. You need to learn all you can about your child's disability. To better understand your child's disability, check with your doctors, the local library, other parents or the Internet for articles or other information, and be certain the information you gather is accurate and up-to-date.

#### Learn the Language

Realize you need to possess the "right language" to ask the "right questions." To get the appropriate care and services, you need to know the "buzz" words and acronyms (abbreviations). That's why it's important to listen carefully to the words and abbreviations people with government agencies and not-for-profit organizations throw at you during the course of conversation.

- Ask about any words or abbreviations you don't understand;
- Write the words or abbreviations down. Then write down what the words or abbreviations mean (if necessary, have the person you're talking with spell it all out and give you an exact definition), and
  - Practice using these words and/or abbreviations in conversation.

#### Look to Other Parents

Your greatest resource is other parents of children with a developmental disability. Among the very first things you should do is make connections with other parents. No one can better relate to your situation than the parents of a child in a similar situation disability. Parents recommend that you:

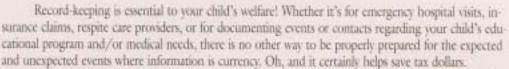
- Find a support group near you;
- Ask your child's health care providers, teachers and other professionals if they can help connect you with other families who have a child with the same diagnosis or similar needs;
  - If you don't find someone at first, keep trying. Connecting with other parents can give you energy.

#### Share What You Learn

Because your child's disability is something you have to deal with on a daily basis, you need to know as much or more about your child's condition than your doctor or the many health care professionals you'll encounter. Equally important, share the knowledge you acquire. Everyone benefits when knowledge is exchanged. It's especially important that you:

- Tell the people you contact how they've helped you;
- Call back if you discover a great resource they don't know about, and
- Pass what you learn on to other parents.

#### Keeping vital records, the essential chore



Like it or not, understand it or not, there are forms you will have to fill out everywhere you go! Having the basic information on hand makes it bearable. It's also a way of noting family history, when developmental landmarks are met, and the next logical areas for change which may help identify delays or detect problems.

#### Personal, Medical & Insurance Information

Below is a list of some of the important information that must be kept. It is not a complete list – that depends entirely on the child's disability. You may also decide to keep this information for other members of your family as well. This includes such personally identifiable information as:

#### Personal

- \* Birth certificates;
- \* Parent or guardian information;
- \* Location of wills and/or trusts;
- + Daily care schedule;
- \* Emergency contacts;

#### Medical

- \* Initial diagnosis:
- \* Health history;
- Physicians and other medical specialists;
- Medication and seizure logs;
- + Daily care schedule:
- \* Immunization records;
- + Office visits;
- \* Hospitalization information;
- Emergency contacts;

#### Insurance

Health and life insurance information:

#### Medical Bills & Insurance Claims

Keep all information needed to fill out claim forms. Keep a supply of blank claim forms, envelopes and stamps. Maintain a file of all insurance company correspondence on every claim. For tax purposes, keep an accurate account of what the insurance company covered and your out-of-pocket expenses.

#### **Evaluations, Reports & Records**

Keep copies or records of all correspondence (written and verbal) with every service provider, medical support specialist and other professionals your child comes in contact with, along with all reports, records and other documents. These may contain important information in those cases where discrepancies arise concerning your child's needs and/or program. Be certain that copies of all medical reports are sent to your child's physician.

#### Getting Organized

How your record-keeping system is organized is your choice. Just be certain it allows quick, easy access to all the information you may need under any given circumstance. Here are a couple of suggestions:

(1) Purchase a three-ring binder with pockets for organizing and holding reports, etc. Insert blank pages and/or forms for recording your own information. Keep all current information in the notebook. Keep older information in a permanent, but portable, filing system.

(2) Purchase a small, portable file and file folders. File information using separate file folders for each category. To prevent record keeping from becoming a chore that keeps you from spending time with the important people in your life, organize early and in a manner best suited your family's individual needs.



THERE IS

NOTHING MORE

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RECORD-KEEPING

SYSTEM.

## PARENT PACE

#### Personal/Medical Information



Personal Information	
Child's Name:	
Birthplace:	
Address:	
	Social Security Number:
	City:
State:Zip: Home Telephone Number: (	
Mother/Legal Guardian:	
	City:
	Work Telephone Number: ()
Emergency Contact(s):	
Family Member:	
Daytime Telephone Numbers: ()	Evening Telephone Numbers: ()
Health History	Insurance Information
Initial Diagnosis:	Primary Insurance Carrier:
Diagnosis Date :	Office Address:
Other Medical Conditions:	Ciry: State: Zip:
	Office Telephone Number:()
Family Physician:	Policy Number: Group Number:
Office Address:	Policyholder:
City: State: Zip:	A CONTRACTOR OF THE PROPERTY O
Office Telephone Number:()	Office Address:
Allergies:	City: State: Zip:
Medications:	Office Telephone Number:( )
	Policy Number: Group Number:
Assistive Devices:	
Eye and/or Hearing Devices:	Control of the Contro
Other Medical Specialist:	
Office Address:	
City: State: Zip:	
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Other Medical Specialist:	
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### Your Point of Entry

OFTEN CONFUSING AND ALWAYS TIME CONSUMING, THE SEARCH FOR THE RIGHT CARE FOR YOUR CHILD BEGINS HERE AND NOW.

#### MEDICAL, HEALTH AND HUMAN SERVICES

Parents of children who have been diagnosed with developmental disabilities can find necessary medical, health and human services at a number of state agencies or private organizations. Among these "first" contacts in state government are the Department of Human Services (DHS) and the Department of Health. Other sources of aid include organizations like the Dennis Developmental Center at Arkansas Children's Hospital, etc.

#### Department of Human Services/Developmental Disabilities Services (Early Intervention)

Telephone - 1-800-643-8258 • 1-501-682-8695

Email - sherrill.archer@mail.state.ar.us

Website - www.state.ar.us/dhs/dds/index.html

Fax - 1-501-682-8687

Mailing Address - Donaghey Plaza North, 7th and Main Streets, P.O. Box 1437, Slot #502, Little Rock, AR 72203-1437

What Information to Ask For – The "First Connections" program which is specific to developmental evaluation and service coordination for infants and toddlers from birth to three years old.

Why You Need This Information - To provide appropriate instruction for required physical therapy and speech-language therapy in a natural environment.

Who You Need to Make Contact With – The Early Intervention Coordinator's name and telephone number at your county DHS office.

#### Department of Human Services/Developmental Disabilities Services

Telephone - 1-501-682-8701

Email - patti.goff@mail.state.ar.us

Website - www.state.ar.us/dhs/dds

Fax - 1-501-682-8890

Mailing Address - Donaghey Plaza North, 7th and Main Streets, P.O. Box 1437, Slot N-502, Little Rock, AR 72203-1437

What Information to Ask For – Available community services; home and community based waivers (Waiver Services); such residential services as intermediate care facilities for persons with mental retardedation (ICFsMR), group homes, human development centers (HDCs), and developmental day treatment clinic services (DDTCS) core services.

Why You Need This Information – To get appropriate individual and family support services for children and adults, including case management; personal care; employment services; supported living; adult development and therapy.

Who You Need to Make Contact With – The DDS Service Coordinator's name and telephone number at your county DHS office.

#### Department of Human Services/Mental Health Services

Telephone - 1-877-227-0007 + 1-501-686-9177

Email - nena.williams@mail.state.ar.us

Website - www.state.ar.us/dhs/dmhs

Fax - 1-501-686-9182

Mailing Address – 4313 West Markham, Little Rock, AR 72205

What Information to Ask For – Services for individuals who are experiencing mental health difficulties, including abnormal behavior and/or emotional problems.

Why You Need This Information – For crisis intervention, inpatient and outpatient services, emergency services, treatment, consultation, hospitalization and case management.

Who You Need to Make Contact With –The local Mental Health Services coordinator's name and telephone number at your County DHS office and/or mental health center.

#### Department of Human Services/ Children's Medical Services

Telephone - 1-800-482-5850, ext. 2277 or 2270 ◆ 1-501-682-2277

Email - nancy.holder@medicaid.state.ar.us

Website - www.state.ar.us/dhs/cms

Fax - 1-501-682-8247

Mailing Address - Donaghey Plaza South, 7th and Main Streets, P.O. Box 1437, Slot S-380, Little Rock, AR 72203-1437

What Information to Ask For – A complete listing of the medical, surgical and rehabilitation treatment for children with disabilities under age 18.

Why You Need This Information—To get appropriate diagnostic services and medical treatment; locate medical specialist and therapy(s) and to receive medication, supplies and medical equipment; follow-up treatment, and information and training.

Who You Need to Make Contact With – The local Children's Medical Services coordinator's name and telephone number at your County DHS office.

#### Department of Health/Child and Adolescent Health

Telephone - 1-800-235-0002 \* 1-501-661-2200

Website - www.healthyarkansas.com

Fax - 1-501-280-4082

Mailing Address – 4815 West Markham, Slot 17, Little Rock, AR 72205-3867

What Information to Ask For – Well-child clinics, Early Periodic Screening Diagnosis and Treatment (EPSDT) screening, the Women, Infants and Children (WIC) program and other health screening services. Why You Need This Information - To get appropriate health services, immunizations, developmental assessments, nutrition assessments and physical examinations.

Who You Need to Make Contact With - The location and telephone number of the nearest county Health Department office.

#### Arkansas Children's Hospital/Dennis Developmental Center

Telephone - 1-501-364-1830

Email - thomastimothyh@.uams.edu

Website - www.archildren.org

Fax - 1-501-364-4867

Mailing Address - 1612 Maryland, Little Rock, AR 72202

What Information to Ask For – Available diagnostic and evaluation services for any child 12 years or younger who is at risk for or is experiencing developmental delays or disabilities in such areas as speech and language, school performance, mental retardation, cognitive development, autism and attention-deficit hyperactivity disorder.

Why You Need This Information – To get appropriate diagnosis and testing to correctly identify and/or verify a developmental delay, disability or other health-related condition.

Who You Need to Make Contact With – The Dennis Developmental Center, the family doctor, the Department of Health, the Department of Human Services and/or other health and learning professionals.

#### INFORMATION AND REFERRAL SERVICES

There's more to meeting the needs of a child with a developmental disability than just taking care of their health and financial needs. Parents need to be educated about how the system works and how they can correctly work within the system to benefit their child. There are a number of agencies and not-for-profit organizations whose primary purpose is to provide the information and/or training needed to allow parents to properly advocate for their child.

#### Arkansas Governor's Developmental Disabilities Council

Telephone - 1-800-482-5400, ext 2589 (V/TDD) 1-501-661-2589

Website - www.ddcouncil.org

Email - wstewart@healthyarkansas.com

Fax - 1-501-661-2399

Mailing Address – 5800 West 10th Street, Suite 805, Little Rock, AR 72204

What Information to Ask For – Available services, including informational and training opportunities designed to better prepare parents to provide for children with disabilities. The Council also acts as a clearing house for information about services available to parents of a child with a disability.

Why You Need This Information - To better understand your child's needs and the services which meet those needs.

Who You Need to Make Contact With - Wilms Stewart, Coordinator

#### Partners for Inclusive Communities

Telephone - 1-800-342-2923 (V/TDD) \* 1-501-682-9900

> Email – swansonmarke@uams.edu Website – www.uams.edu/uap Fax – 1-501-682-9901

Mailing Address – 2001 Pershing Circle, Suite 300, North Little Rock, AR 72114-1841

What Information to Ask For – The availability of training programs, information, technical assistance and other services for children with a disability, their parents and adults with disabilities.

Why You Need This Information – To increase your knowledge about disabilities, services and supports that will improve the quality of life for persons with disabilities.

Who You Need to Make Contact With - Dr. Mark Swanson, Director

#### Disability Rights Center

Telephone – 1-800-482-1174 (V/TTY) ◆ 1-501-296-1775 (V/TTY)

Email - panda@arkdisabilityrights.org

Website - www.arkdisabilityrights.org

Fax - 1-501-296-1779

Mailing Address – 1100 North University, Suite 201, Little Rock, AR 72207

What Information to Ask For – How to access appropriate individual advocacy, systems advocacy and legal services needed to protect your child's human, civil and legal rights.

Why You Need This Information – To get the technical assistance needed to assist you with resolving legal issues you may encounter while accessing services for your child.

Who You Need to Make Contact With - A Core Services Coordinator.

#### Arkansas Autism Society

Telephone - 1-800-831-4827 ◆ 1-501-682-9930

Email - autism@aristotle.net

Website - www.autism.org

Fax - 1-501-682-9901

Mailing Address - 2001 Pershing Circle, Suite 300, North Little Rock, AR 72214-1841

What Information to Ask For – The most up-to-date information and referral services on the cause and treatment of autism spectrum disorders.

Why You Need This Information—To be better acquainted with the families, professionals, educators and providers who concerned with the treatment of autism spectrum disorders.

Who You Need to Make Contact With - Karan Burnette, Board President

#### Arkansas Disability Coalition

Telephone - 1-800-223-1330 (V/TTY) ◆ 1-501-614-7020 (V/TTY)

Email - adc@alltel.net

Fax - 1-501-614-9082

Mailing Address - 1123 South University, Suite 225, Little Rock, AR 72204

What Information to Ask For - Current information on the Individuals with Disabilities Education Act (IDEA); parent training in the development of an appropriate Individualized Education Program (IEP), and advocacy services in dealing with the school system for school age children with a developmental disability.

Why You Need This Information – To get the assistance necessary for working with your school officials while writing an appropriate IEP.

Who You Need to Make Contact With - Wanda Stovall, Director.

#### Arkansas People First

Telephone - 1-888-488-6040 \* 1-479-575-4015

Email - peoplefirstark@yahoo.com

Website - www.rcep6.org/peoplefirst.htm

Fax - 1-870-488-8004

Mailing Address – 104 Arkansas Union, Fayetteville, AR 72703

What Information to Ask For – The action you need to take to become a more effective self-advocate.

Why You Need This Information – To learn how to work with others in an effort to increase your opportunity for independence, productivity, inclusion and integration into the community.

Who You Need to Make Contact With - Julie Petty, State Coordinator

#### ICAN (Increasing Capabilities Access Network)

Telephone - 1-800-828-2799 ◆ 1-501-666-8868 (V/TTY)

Email - sogaskin@arx.state.ar.us

Website - www.arkansas-ICAN.org

Fax - 1-501-666-5319

Mailing Address - 2201 Brookwood, Suite 117, Little Rock, AR 72202

What Information to Ask For - Information on assistive technology device(s) necessary for your child.

Why You Need This Information – To get the appropriate information on locating, funding and training in the use of the assistive technology device(s) your child needs.

Who You Need to Make Contact With - Barbara Gullett, Executive Director

#### Parent Advisory Council Inc.

Telephone - 1-800-482-5850, ext 22277 ◆ 1-501-682-1461

Email - refarley@juno.com

Fax - 1-501-682-8247

Mailing Address - P.O. Box 1437, S-380, Little Rock, AR 72203-1437

What Information You Should Ask For – The indepth information the council can provide to assist you in understanding how to get special health care services for your child.

Why You Need This Information – To learn how to develop and maintain a "collaborative" relationship while working with the state agencies and not-for-profit organizations that provide services for your child.

Who You Need to Make Contact With – Rodney Farley, Parent Activities Coordinator

#### Arkansas Alliance for the Mentally III/NAMI Arkansas

Telephone - 1-800-844-0381, ext 8772 \* 1-501-661-1548

Email - nami--ar@nami.org

Website - www.namiar.org

Fax - 1-501-664-0264

Mailing Address - 712 West Third Street, Suite 200, Little Rock, AR 72205

What Information to Ask For – The location of mental health treatment centers throughout Arkansas and the availability of other support, education and advocacy services in the state.

Why You Need This Information – To take full advantage of mental health services, peer support programs and education courses designed to provide families of individuals with serious brain disorders with information on such topics as mental illness and its treatment, coping skills and advocating for individuals with brain disorders.

Who You Need to Make Contact With - Pauline Charton, Executive Director

#### PARENT SUPPORT AND ASSISTANCE

Organizations like the Arkansas Disabilities Coalition, the Arkansas Autism Society, NAMI of Arkansas and the Parent Advisory Council Inc., offer information, training, direct assistance, referral services and much needed moral support to parents of children with a disability. As advocates for families of children with disabilities, these groups are made up of parents and professionals who believe that it is the family who is best equipped to express and fulfill the needs of the child.

#### Arkansas Disability Coalition

Telephone - 1-800-223-1330 (V/TTY) ◆ 1-501-614-7020 (V/TTY)

Email - ado@alltel.net

Fax - 1-501-614-9082

Mailing Address – 1123 South University, Suite 225, Little Rock, AR 72204

What Information to Ask For – Current information on the Individuals with Disabilities Education Act (IDEA); parent training in the development of an appropriate Individualized Education Program (IEP), and advocacy services in dealing with the school system for school age children with a developmental disability.

Why You Need This Information—To get the assistance necessary for working with your school officials while writing an appropriate IEP.

Who You Need to Make Contact With - Wanda Stovall, Director.

#### Arkansas Autism Society

Telephone - 1-800-831-4827 \* 1-501-682-9930

Email - autism@aristotle.net

Website - www.autism.org

Fax - 1-501-682-9901

Mailing Address - 2001 Pershing Circle, Suite 300, North Little Rock, AR 72214-1841

What Information to Ask For – The most up-to-date information and referral services on the cause and treatment of autism spectrum disorders.

Why You Need This Information - To be better acquainted with the families professionals, educators and providers concerned with the treatment of autism spectrum disorders.

Who You Need to Make Contact With - Karan Burnette, Board President

#### Parent Advisory Council Inc.

Telephone - 1-800-482-5850, ext 22277 \* 1-501-682-1461

Email - refarlev@juno.com

Fax - 1-501-371-3464

Mailing Address - P.O. Box 1437, S-380, Little Rock, AR 72203-1437

What Information to Ask For – The broad range of information the council can provide to assist you in understanding how to get the special health care services your child requires.

Why You Need This Information - To learn how to develop and maintain a "collaborative" relationship while working with the state agencies and not-for-profit organizations that provide services for your child.

Who You Need to Make Contact With - Rodney Farley, Parent Activities Coordinator

#### Arkansas Alliance for the Mentally III/NAMI Arkansas

Telephone - 1-800-844-0381, ext 8772 ◆ 1-501-661-1548

Email - nami-ar@nami.org

Website - www.namiar.org

Fax - 1-501-664-0264

Mailing Address - 712 West Third Street, Suite 200, Little Rock, AR 72205

What Information to Ask For – The location of mental health treatment centers throughout Arkansas and the availability of other support, education and advocacy services in the state.

Why You Need This Information – To take full advantage of mental health services, peer support programs and education courses designed to provide families of individuals with serious brain disorders with information on such topics as mental illness and its treatment, coping skills and advocating for individuals with brain disorders.

Who You Need to Make Contact With - Pauline Charton, Executive Director

#### FINANCIAL RESOURCES

Although often limited and restricted, direct financial assistance is available through a number of avenues. Children and adults with developmental disabilities may qualify for cash subsidies and/or various federal and state programs. Each program has differing application and eligibility requirements.

#### Social Security Administration

Telephone - 1-800-325-70778 (TTY) ◆ 1-501-324-5827

Website - http://www.ssa.gov

Fax - 1-888-475-7000

Mailing Address – Social Security Administration, Federal Building, 700 West Capitol, Room 1433, Little Rock, AR 72201

What Information to Ask For – The Social Security and Supplemental Security Income (SSI) benefits for children with developmental disabilities and SSI for adults (18 and over) with a disability.

Why You Need This Information – To apply for Social Security or Supplemental Security Income benefits; Medicare and Medicaid services for medical and health care.

Who You Need to Make Contact With – The Social Security representative in your local area.

#### Department of Human Services/Division of County Operations

Telephone - 1-800-482-8988 ◆ 1-501-682-8820 (TDD)

Email - ruthie.broughton@mail.state.ar.us

Website - www.state.ar.us/dhs/dco

Fax - 1-501-682-8978

Mailing Address - Donaghey Plaza South, 7th and Main Streets, P.O. Box 1437, Slot # 230, Little Rock, AR 72203-1437

What Information to Ask For – Transitional Employment Assistance (TEA); food stamps; Medicaid eligibility, and other DHS programs that cover financial and medical needs.

Why You Need This Information - To get assistance and information on how to apply for financial and medical assistance.

Who You Need to Make Contact With - Ask for the

location and telephone number of the representative at your county DHS office.

#### **EDUCATION PROGRAMS**

A quality education for children with a developmental disability is critical for all children with developmental disabilities. That's what drives the Special Education Department's Pre-school and K-12 programs. The goal is to provide children with disabilities the kind of "special" instruction that meets each child's individual educational needs.

#### Department of Education/Special Education (Preschool & K-12 Program)

Telephone - 1-501-682-4225

Website - www.arkedu.state.ar.us/directory/accountability\_p1.html

Email - mcrowley@arkedu.k12.ar.us

Fax - 1-501-682-5159

Mailing Address - Special Education Unit, Arkansas Department of Education, Victory Building C, Suite 450, 1401 West Capitol, Little Rock, AR 72201

What Information to Ask For – Services available under the Arkansas Special Education Program, including referral, screening, evaluation, analysis, eligibility and such related services as transportation and other supportive programs needed to assist children ages 3 through 21 with a disability to benefit from special education.

Why You Need This Information – To find out what steps you need to take to assure that the preschool and K-12 special education for their child. Legal rights information includes services offered by such organizations as the Disability Rights Center and Adult Protective Services and include information, referral, shortterm individual case advocacy, and monitoring and investigation programs can benefit your child.

Who You Need to Make Contact With—Dr. Michael Crowley, Administrator for Monitoring and Technical Assistance.

#### University/College Disability Support Services

Telephone - 1-501-569-3162

Email - mpthomtonr@ualr.edu

Website - www.ualr.edu/ Ark-Ahead

Fax - 1-501-569-8240

Mailing Address - Ark-Ahead, P.O. Box 250914-0914, Little Rock, AR 72225

What Information to Ask For—A list of Disability Support Services for state colleges and universities, including available services, required documentation for eligibility and information on how to help the young adult with a disability prepare for college.

Why You Need This Information – Services at the college level differ from those for school-aged children, but a wide range of services are available.

Who You Need to Make Contact With - Melanie Thornton, chairperson, Ark-Ahead.

#### ADULT SERVICES ORGANIZATIONS

Parents of adult sons or daughters with a developmental disability face a number of questions ranging from transitioning from school to work, finding employment opportunities and accessing community services. There are a number of agencies and organizations that deal with a wide range of issues, including vocational training, housing, community-based waivers, assistive technology and devices, supported employment, independent living and such D

residential/community services as group homes, and human development centers.

#### Arkansas Rehabilitation Services

Telephone - 1-800-330-0632 (V/TTY) \* 1-501-296-1616

Email - earoberts@ars.state.ar.us

Website - www.state.ar.us/ars

Fax - 1-501-296-1655 or 1-501-296-1675

Mailing Address –1616 Brookwood Drive, P.O. Box 3781, Little Rock, AR 72203-3781

What Information to Ask For – Services including evaluation, guidance, counseling, referral, vocational training, and transportation required for supported employment services for individuals with a disability.

Why You Need This Information—To make appropriate decisions regarding the employment of an individual with a developmental disability.

Who You Need to Make Contact With - John Wyvill, Commissioner.

#### Increasing Capabilities Access Network (ICAN)

Telephone - 1-800-828-2799 ◆ 1-501-666-8868 (V/TTY)

Email - sogaskin@ars.state.ar.us

Website - www.arkansas-ICAN.org

Fax - 1-501-666-5319

Mailing Address – 2201 Brookwood, Suite 117, Little Rock, AR 72202

What Information to Ask For - Information on assistive technology device(s) necessary for your child.

Why You Need This Information – To get the appropriate information on locating, funding and training in the use of assistive technology device(s) your child may need.

Who You Need to Make Contact With - Barbara Gullett, Executive Director

#### Arkansas Independent Living Council

Telephone - 1-800-772-0607 (V/TDD) • 1-501-372-0607 (V/TDD)

Email - ailc@alltel.net

Website - www.ailc-ar.org

Fax - 1-501-372-0598

Mailing Address - 323 South Louisiana St., Suite 305, Little Rock, AR 72201

What Information to Ask For – Programs and services including independent living skills training, information and referral on technology, housing and transportation and other services, peer support and counseling and technical assistance on a number of topics related to independent living.

Why You Need This Information – To make an "educated" decision on whether or not independent living is an option for your family member with a developmental disability.

Who You Need to Make Contact With - Peggy Vickers, Executive Director

#### Department of Human Services/Developmental Disabilities Services

Telephone - 1-501-682-8701

Email - patti.goff@mail.state.ar.us

Website - www.state.ar.us/dhs/dds/

Fax - 1-501-682-8890

Mailing Address - Donaghey Plaza North, 7th and Main Streets, P.O. Box 1437, Slot N-502, Little Rock, AR 72203-1437

What Information to Ask For - Available community

services; home and community based waivers (Waiver Services); such residential services as intermediate care facilities for the mentally retarded (ICFsMR), group homes, human development centers (HDCs), and developmental day treatment clinic services (DDTCS) core services.

Why You Need This Information – To get appropriate individual and family support services for children and adults, including case management; personal care; employment services; supported living; adult development and therapy.

Who You Need to Make Contact With—The DDS Service Coordinator's name and telephone number at your county DHS office.

#### LIGAL ASSISTANCE

Parents of a child with a developmental disability need to know and understand their rights, including how to access services needed

#### **Disability Rights Center**

Telephone - 1-800-482-1174 (V/TTY) ◆ 1-501-296-1775 (V/TTY)

Email - panda@arkdisabilityrights.org

Website - www.arkdisabilityrights.org

Fax - 1-501-296-1779

Mailing Address – 1100 North University Ave., Suite 201, Little Rock, AR 72207

What Information to Ask For - How to access appropriate individual advocacy, systems advocacy and legal services needed to protect your child's human, civil and legal rights.

Why You Need This Information – To get the technical assistance needed to assist in the resolution of legal issues you may encounter while accessing services for your child.

Who You Need to Make Contact With- A Core Services Advocate

#### Department of Human Services/Division of Aging and Adult Services (Adult Protective Services)

Telephone – 1-800-482-8049 ◆ 1-501-682-2443 (TDD) Website – www.aradultprotection.com

Fax - 1-501-682-6393

Mailing Address - 1417 Donaghey Plaza South, P.O. Box 1437, Slot-540, Little Rock, AR 72203

What Information to Ask For – The signs and symptoms of the abuse of individuals with a developmental disability who are 18 years of age or older that could result in emotional, mental or physical harm.

Why You Need This Information – To prevent the abuse of adult individuals with a developmental disability.

Who You Need to Make Contact With - A representative of the DHS Division of Aging and Adult Services, Adult Protective Services.

#### Center for Arkansas Legal Services

Telephone - 1-501-376-3423 • 1-800-950-5817

Email - zfraizer@arkansaslegalservices.org

Website - www.arkansaslegalservices.org

Fax - 1-501-376-3664

Mailing address - 303 West Capital, Little Rock, AR 72201

What Information to Ask For – The legal resources for gaining the services assured by state legislation, IDEA, 504 and selfadvocacy and helpful information on guardianships and adoptions.

Why You Need This Information – For help with problems in obtaining services.

# PROGRAM

## Every Child Deserves a Medical Home

A Medical Home is not a building, a house or a hospital. It is a way of providing quality health care services in a high-quality and cost-effective manner.

Children, young adults and their families who participate in the Medical Home program get the medical support services they need from a well-trained physician who provides primary care and helps to manage and facilitate essentially all aspects of care. Physicians, families and allied health care professionals work together as partners in a Medical Home to identify and access all the medical and non-medical services needed to help children, young adults and their families achieve their maximum potential.

The Medical Home concept states that the medical care of children, adolescents and young adults should be accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective. The physician should be known to the child, young adult and family and should be able to develop a partnership of mutual responsibility and trust with them.

#### The Family's Role

Ideally, families of children with special care needs should lead the care coordination team. Family involvement is essential to proper care. It is the family who knows the child's or young adult's needs best. For this to happen, parents must have access to complete information about:

- The child's or young adult's condition;
- The coordination of care, and
- Other necessary resources.

At the very least the family should be an active participant in all team decisions. In situations where a parent or family member can't take the lead role, treatment planning can be insufficient and the care coordinator selected by default. When that happens, the result is often the selection of a person is not qualified, prepared or has access to needed support. That's why all children and young adults with a developmental disability or a chronic medical condition and their families need access to a quality medical home as a partner.

#### **Partnership**

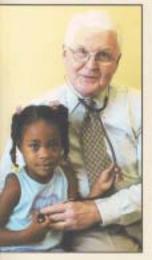
Very positive changes occur when families and professionals work together to support families in their central role as caregivers. This partnership between individuals with special health care needs, their families, and their physician rests on the mutual understanding of the diagnosis and service needs. The partnership should evolve as a strong relationship to help make good treatment and services decisions. The Medical Home should be a resource to help gain access to the multiple services systems that may be needed to implement a chosen care plan.

#### Concept to Reality

Around for nearly a decade, the Medical Home concept was, until recently, little more than a loosely defined term. Now, the Medical Home concept is on its way to becoming a reality in Arkansas. Children's Medical Services, an Arkansas Department of Human Services Agency, in collaboration with the Section of Developmental-Behavioral Pediatrics in the Department of Pediatrics, University of Arkansas for Medical Sciences, received a grant from the federal Maternal and Child Health Bureau called "Medical Homes for Children with Special Health Care Needs in Arkansas." The purpose of the grant is to improve the accessibility and quality of Medical Homes available to Arkansas children. The activities of the grant are focused on educating both physicians and families about the seven major components of the Medical Home concept and the characteristics that bring the concept to life. Defined by the American Academy of Pediatrics, the desirable characteristics of a Medical Home are:

#### What are the benefits of a Medical Home?

- Increased patient and family satisfaction;
- Establishment of a forum for problem solving;
- Improved coordination of care;
- Enhance efficiency individuals and families;
- Efficient use of limited resources;
- Increased professional satisfaction, and
- Increased wellness resulting from comprehensive care



UNDER THE MEDICAL HOME CONCEPT, CARE OF CHILDREN AND ADULTS IS ACCESSIBLE, CONTINUOUS, COMPREHENSIVE, FAMILY-CENTERED. COORDINATED, COMPASSIONATE AND CULTURALLY EFFECTIVE.

#### Accessible

- Care is provided in the child's or youth's community.
- All insurance, including Medicaid, is accepted.
- Changes in insurance are accommodated.
- The practice is accessible by public transportation, where available.
- Families or youth are able to speak directly to the physician when needed.
- The practice is physically accessible and meets Americans with Disabilities Act (ADA) requirements.
- The medical home physician is known to the child or youth and family.
- Mutual responsibility and trust exists between the patient and family and the medical home physician.

#### Family-Centered

- The family is recognized as the principal caregiver and center of strength and support for the child.
- Clear, unbiased, and complete information and options are shared on an ongoing basis with the family.
- Families and youth are supported to play a central role in care coordination.
- Families, youth and physicians share responsibility in decision making.
- The family is recognized as the expert in their child's care, and youth are recognized as the experts in their own care.

#### Continuous

- The same primary pediatric health care professionals are available from infancy through adolescence and young adulthood.
- Assistance with transitions, in the form of developmentally appropriate health assessments and counseling, is available to the child or youth and family.
- The medical home physician participates to the fullest extent allowed in care and discharge planning when the child is hospitalized or care is provided at another facility or by another provider.

#### Comprehensive

- Care is delivered or directed by a well-trained physician who is able to manage and facilitate essentially all aspects of care.
- Ambulatory and inpatient care for ongoing and acute illnesses is ensured, 24 hours a day, 7 days a week, 52 weeks a year.
- Preventive care is provided that includes immunizations, growth and development assessments, appropriate screenings, health care supervision, and patient and parent counseling about health, safety, nutrition, parenting and psychosocial issues.
  - Preventive, primary, and tertiary care needs are addressed.
- The physician advocates for the child, youth, and family in obtaining comprehensive care and shares responsibility for the care that is provided.
- The child's or youth's and family's medical, educational, developmental, psychosocial, and other service needs are identified and addressed.
- Information is made available about private insurance and public resources, including Supplemental Security Income, Medicaid,

the State Children's Health Insurance Program, waivers, early intervention programs, and Title V State Programs for Children with Special Health Care Needs.

 Extra time for an office visit is scheduled for children with special health care needs, when indicated.

#### Coordinated

- A plan of care is developed by the physician, child or youth, and family and is shared with other providers, agencies, and organizations involved with the care of the patient.
- Care among multiple providers is coordinated through the medical home.
- A central record or database containing all pertinent medical information, including hospitalizations and specialty care, is maintained at the practice. The record is accessible, but confidentiality is preserved.
- The medical home physician shares information among the child or youth, family, and consultant and provides specific reason for referral to appropriate pediatric medical subspecialists, surgical specialists, and mental health/developmental professionals.
- Families are linked to family support groups, parent-to-parent groups, and other family resources.
- When a child or youth is referred for a consultation or additional care, the medical home physician assists the child, youth and family in communicating clinical issues.
- The medical home physician evaluates and interprets the consultant's recommendations for the child or youth and family and, in consultation with them and subspecialists, implements recommendations that are indicated and appropriate.
- The plan of care is coordinated with educational and other community organizations to ensure that special health needs of the individual child are addressed.

#### Compassionate

- Concern for the well-being of the child or youth and family is expressed and demonstrated in verbal and nonverbal interactions.
- Efforts are made to understand and empathize with the feelings and perspectives of the family as well as the child or youth.

#### **Culturally Effective**

- The child's or youth's and family's cultural background, including beliefs, rituals, and customs, are recognized, valued, respected, and incorporated into the care plan.
- All efforts are made to ensure that the child or youth and family understand the results of the medical encounter and the care plan, including the provision of (para) professional translators or interpretors, as needed.
- Written materials are provided in the family's primary language. (For a complete policy statement, go to the American Academy of Pediatrics website – www.aap.org/policy/5060016.html).

## Opening the door to Medical Home services

#### LEARN HERE AND NOW HOW THE CONCEPT BENEFITS YOU AND YOUR CHILD.

#### MEDICAL, HEALTH AND HUMAN SERVICES

Contact information on the following organizations can be found on pages 2-3.

Early Intervention Services - The "First Connections" program which is specific to developmental evaluation and service coordination for infants and toddlers from birth to three years old.

**Developmental Disability Services** – To get appropriate individual and family support services for children and adults, including case management; personal care; employment services; supported living, adult development and therapy.

Mental Health Services – Services for individuals who are experiencing mental health difficulties, including abnormal behavior and/ or emotional problems.

Children's Medical Services - To get help locating medical, surgical, and rehabilitative treatment for children with developmental disabilities or chronic illness.

Department of Health - To obtain information on immunizations or Women, Infant and Children Program (WIC).

#### Medical Home Arkansas

Telephone - 1-800-482-5850, ext 22277 or 22270 ◆ 1-501-682-2277

E-mail - gil.buchanan@medicaid.state.ar.us

Website - www.medicalhomear.org

Mailing – Donaghey Plaza South, 7th and Main Streets, Slot S380, Little Rock, AR 72203-1437

What Information to Ask For – To help with information about medical home concept and resource information to obtain needed services.

Why You Need This Information - To obtain most current information about resources, funding, or problem issues related to care for children with chronic illness or disability.

Who You Need to Make Contact With - Personnel answering your call will direct you to the most appropriate person to answer your questions.

#### Arkansas Children's Hospital

Telephone - 1-501-364-1100

E-mail - achinfo@www.archildrens.org

Website - www.archildrens.org

Mailing Address - 800 Marshall Street, Little Rock, AR 72202

What Information to Ask For – Help in locating medical or diagnostic services for a child with chronic illness or developmental disability.\*

Why You Need This Information—To decide if you need help with treatment or diagnosis of you child's chronic illness or disability.

Who You Need to Make Contact With - The hospital operator who will direct you to the most appropriate person to help with the child's needs.

\*Questions concern developmental delays or disabilities in such

areas as speech and language, school performance, mental retardation, cognitive development, autism and attention-deficit hyperactivity disorder should be directed to the Dennis Developmental Center.

Telephone - 1-501-364-1830

Fax - 1-501-364-4867

Mailing Address - 1612 Maryland, Little Rock, AR 72202

#### Children's Medical Services (CMS)

Telephone - 1-800-482-5850, ext 22277 or 22270 ◆ 1-501-682-2277

E-mail - nancy.holder@medicaid.state.ar.us

Website - www.state.ar.us/dhs/cms

Fax - 1-501-682-8247

Mailing Address - Plaza South, 7th and Main Streets, P.O. Box 1437, Slot S380, Little Rock, AR 72203-1437

What Information to Ask For – To get help locating medical, surgical, and rehabilitative treatment for children with developmental disabilities or chronic illness.

Why You Need This Information – To get appropriate diagnostic services and medical treatment; locate medical specialist and therapy; to receive medication, supplies and medical equipment; followup treatment, and information and training.

Who You Need to Make Contact With - The local Children's Medical Services coordinator at your County DHS office.

#### Easter Seals Arkansas

Telephone - 1-501-227-3600

E-mail - mail@ar.caster-seals.org

Website - www.ar.easter-seals.org

Fax - 1-501-227-3601

Mailing Address – 3920 Woodland Heights Rd., Little Rock, AR 72212

What Information to Ask For - Infant monitoring program, outpatient therapy services, preschool, children's rehabilitation center.

Why You Need This Information - For services for newborn children with low birth weight, children/adults needing physical therapy, occupational therapy, and/or speech therapy, preschool age children with and without disabilities, or inpatient services for children.

Who you need to make contact with - Kellie Bell (infant monitoring program & out patient therapies), Sandi Billingsley (preschool services), Priscilla Handley (children's rehabilitation center), or Linda Rogers (general questions).

#### INFORMATION AND REFERRAL SERVICES, PARENT SUPPORT AND ASSISTANCE

Contact information on the following organizations can be found on pages 3 and 4

Arkansas Governor's Developmental Disability Council – The Council acts as a clearing house for information about services available to parents of children with a developmental disabilities.

Parents for Inclusive Communities - To increase your

MEDICAL

HOME PROGRAM

knowledge about disabilities, services and supports that will improve the quality of life for persons with disabilities.

Disabilities Rights Center – How to access appropriate individual advocacy; systems advocacy and legal services needed to protect your child's human, civil, and legal rights.

Arkansas Autism Society – The most up-to-date information and referral services on the cause and treatment of autism spectrum disorders.

Arkansas Disability Coalition – Current information on the Individual with Disabilities Education Act (IDEA); parent training in the development of an appropriate Individualized Education Program (IEP), and advocacy services in dealing with the school system for school age children with developmental disabilities.

ICAN – Information on locating funding and training in the use of assistive technology devices.

Parent Advisory Council – To assist you in how to get special health care services for you child.

Arkansas Alliance for the Mentally III/NAMI Arkansas – To help locate mental health treatment centers and other available support, education, and advocacy services in the state.

#### Camp Aldersgate

Telephone – 1-501-225-1444 E-mail – info@campaldersgate.net Website – www.aldersgate.net

Fax - 1-501-225-2019

Mailing Address – 2000 Aldersgate Road, Little Rock, AR 72205

What Information to Ask For – Which program is appropriate for the child, an application, fee, and the deadline for registration.

Why You Need This Information – To help determine which program is appropriate for the child.

Who You Need to Make Contact With – Bill Faggard or Patrick Gobeen

#### The Center for Effective Parenting

Telephone – 1-501-364-7580 \* 364-6911 Website- www.parenting-ed.org

Fax - 1-501-364-1588

Mailing Address – 1120 Marshall St., Brandon Conference Center, Little Rock, AR 72202

What Information to Ask For - Copies of brochures and other information on how to register for parenting classes or parent education.

Why You Need This Information – The Center for Effective Parenting attempts to positively impact children through a focus on improving parenting skills. The Center focuses its efforts in the areas of service, training, and research, therefore striving to have a significant impact not only on parents and children in Arkansas but also on parents and children across the nation.

Who You Need to Make Contact With - Pam Khaler

#### Access Arkansas

Website - www.accessarkansas.org

What Information to Ask For – A website to link to multiple state agencies concerning child care, education and medical services.

Why You Need This Information – A resource for gaining access to multiple state services that might be needed for children or adults with disabilities or chronic illness.

#### Arkansas People First

Telephone - 1-479-575-4015 or 1-888-488-6040

E-mail - peoplefirstark@yahoo.com

Website - www.rcep6.org/peoplefirst.htm

Fax - 1-870-488-8004

Mailing Address - 104 Arkansas Union, Fayetteville, AR 72703

What Information to Ask For – Information to learn about self-advocacy in multiple areas of disability with a focus on rehabilitation and employment.

Why You Need This Information – Self-advocacy skill can improve self-esteem and potential for independent living.

Who You Need to Make Contact With – Julie Petry, State Coordinator

#### ADVOCACY

#### Arkansas Advocates for Children and Families

(Does not provide direct services)

Telephone - 1-501-371-9678

E-mail - aacf@aradvocates.org

Website - www.aradvocates.org.

Fax - 1-501-371-9681

Mailing Address – 523 S. Louisiana, Suite 700, Little Rock, AR 72201-5707

What Information to Ask For – Information and training to help parents become better advocates for their children in dealing with state legislators, state agencies, and service providers.

Why You Need This Information – Sometimes changes are needed in state law or agencypolicies to better serve children with special health care needs which takes special knowledge of how such change can occur and working with other related organizations and individuals trying to improve opportunities for all children.

Who You Need to Make Contact With – The organizations website for reports, information, and training being offered to parents. Other questions may be directed to Julie Robbins.

#### The Arc of Arkansas

Telephone - 1-501-375-7770

Website - www.arcark.org

Mailing Address – 2004 South Main, North Little Rock, AR 72206

What Information to Ask For – What services are available and information on advocacy, education, support groups, or independent living.

Why You Need This Information - To obtain information for individuals with developmental disabilities.

Who You Need to Make Contact With - Jim Eakin

#### **EDUCATION PROGRAMS**

Department of Education/Special Education/504 Program (preschool and K-12 Program) – To find out what steps you need to take to assure educational services for children with chronic illness or disability. Page 5

Early Intervention Services - The "First Connections" program which is specific to developmental evaluation and service coordination for infants and toddlers from birth to three years old. Page 2

#### **Head Start**

Telephone - 1-501-371-0740/1-866-371-0740

E-mail - ann@arheadstart.org

Website - www.arheadstart.org

Fax - 1-501-370-9109

Mailing Address – 523 S. Louisiana, Suite 301, Little Rock, AR 72201

What Information to Ask For - How to locate Headstart

Early Childhood/Pre-K Programs for your child

Why You Need This Information – To determine eligibility and availability of Pre-Kindegarten or Early Childhood Educational Programs.

Who You Need to Make Contact With – State Headstart personnel will direct you to the nearest local program for possible services.

#### TRANSITION AND ADULT SERVICES

Arkansas Rehabilitation Services - To help people with disabilities seek gainful employment and technical assistance. Page 5

ICAN – Information on locating funding and training in the use of assistive technology devices. Page 4

Arkansas Independent Living Council - To gain information about programs and services leading to independent living. Page 6

Partners for Inclusive Communities – Information, training programs, technical assistance and other services for children with a disability. Page 3

Arkansas Disability Coalition – Current information on the Individual with Disabilities Education Act (IDEA); parent training in the development of an appropriate Individualized Education Program (IEP), and advocacy services in dealing with the school system for school age children with a developmental disability. Page 3

#### University/College Disability Support Services

Telephone - 1-501-569-3162

E-mail - mpthorntonr@ualr.edu

Website - www.ualr.edu/ Ark-Ahead

Fax - 1-501-569-8240

Mailing Address - Ark-Ahcad, P.O. Box 250914-0914, Little Rock, AR 72225

What Information to Ask For – A list of Disability Support Services for state colleges and universities and the services available onand-off campus. Other information should include the required documentation for eligibility and information on how to help the young adults with a disability or chronic illness prepare for college.

Why You Need This Information – Services at the college level differ from those for school-aged children, but a wider range of services are available.

Who You Need to Make Contact With - Melanic Thornton, chairperson, Ark-Ahead.

#### Mainstream

Telephone - 1-501-280-0012-voice ◆ 1-501-280-9262-TDD Outside Pulaski County 1-800-371-9026

E-mail - mainstreamlr@earthlink.net

Website - www.mainstreamilrc.com

Fax - 1-501-280-9267

Mailing Address - 1818 South University Ave., Little Rock, AR 72204

What Information to Ask For – The Center provides the following services: peer support, advocacy, training, and education, information and referral, employment services, ramp program, and SSI/ SSDI benefits planning.

Why You Need This Information – To insure that as a child with disability or chronic medical condition transitions into adulthood, he or she receives the services needed to be an active part of the community, and to insure that the child knows how to advocate for himself/ berself.

Who You Need to Make Contact With—Doris Smith/Julie Tripplett (advocacy issues), Vincent Acklin (employment related services), Jo Ann Harris (ramp program), Karen Swinton (benefits planning), or Eva Warner (program questions).

#### LEGAL ASSISTANCE

Disabilities Rights Center - How to access appropriate individual advocacy; systems advocacy and legal services needed to protect your child's human, civil, and legal rights. Page 6

#### Center for Arkansas Legal Services

Telephone - 1-501-376-3423 • 1-800-950-5817

E mail - zfraizer@arkansaslegalservices.org

Website - www.arkansaslegalservices.org

Fax - 1-501-376-3664

Mailing address - 303 West Capital, Little Rock, AR 72201

What Information to Ask For – The legal resources for gaining the services assured by state legislation, IDEA, 504 and self-advocacy and helpful information on guardianships and adoptions.

Why You Need This Information – For help with problems in obtaining services.

#### FINANCIAL RESOURCES

Contact information on the following agencies is on page 5.

Department of Human Services/Division of County

Operations – Information on obtaining Transitional Employment Assistance (TEA); food stamps; Medicaid eligibility; and other DHS programs that cover financial and medical needs.

Social Security Administration – Information for applying for Social Security or Supplemental Security Income Benefits; Medicare and Medicaid services.

#### DISEASE SPECIFIC

Contact information on the following organizations can be found on pages 3 and 4.

Arkansas Autism Society - Information and referral services on the cause and treatment of Autism Spectrum Disorders.

Arkansas Alliance for the Mentally III/NAMI Arkansas – To help locate mental health treatment centers and other available support, education, and advocacy services in the state.

#### United Cerebral Palsy of Arkansas

Telephone - 1-501-224-6067

E-mail - info@ucpark.org

Website - www.ucpark.org (under construction)

Fax - 1-501-227-5591

Mailing Address – 9720 North Rodney Parham Rd., Little Rock, AR 72227

What Information to Ask For – Funding availability, services provided (local/state-wide), volunteering, and auxiliary membership.

Why You Need This Information - To obtain general information and/or services for a child/adult with Cerebral Palsy.

Who You Need to Make Contact With – Depending on services needed, the following is a listing by departments: Adult Services (501-379-2660/501-228-3805), Medicaid Waiver (501-224-6067), Butterfly Learning Center (501-228-3868), Conductive Education (479-725-1015), NW Region (479-444-0088), NE Region (870-743-2827), Community living arrangements (501-225-0425).

#### **Down Syndrome Families and Friends**

Telephone - 1-501-671-6571

E-mail - contact@dsff.org

Website - www.dsff.org

Mailing Address – PO Box 17541, Little Rock, AR 72222
What Information to Ask For – New Parent Handbook, health care concerns associated with Down Syndrome, a health care

checklist for parent and pediatricians, and list of resources.

Why You Need This Information – To get the special care required for children with Down Syndrome and other medical problems associated with it (cogenital heart defects, developmental delays, etc).

Who You Need to Make Contact With - Various support group members.

#### Learning Disabilities Association of Arkansas

Telephone - 1-501-666-8777

E-mail - ldaa@sbcglobal.net

Website - www.ldzarkansas.org

Fax - 1-501-666-4070

Mailing Address – 7509 Cantrell Rd. # 103C, Little Rock, AR 72207

What Information to Ask For – Information on identification of Learning Disabilities, rights of students and parents and where to look for services.

Why You Need This Information – To assist you in finding help for a child who exhibits symptoms of learning disabilities.

Who You Need to Make Contact With - Dana Jackson or Kristen Joyner

#### NATIONAL ORGANIZATIONS MEDICAL HOME

#### The American Academy of Pediatrics

Telephone – 1-847-434-4000 E-mail – kidsdocs@aap.org

Website - www.aap.org

Fax - 1-847-434-8000

Mailing Address - 141 Northwest Point Blvd., Elk Grove Village, IL 60007-1098

What Information to Ask For – Informational materials on physical, mental, and social health and well-being for children, adolescents and young adults, pediatrician referral service, or advocacy issues. However, the academy is unable to respond to requests from parents regarding the personal medical concerns of their children.

Why You Need This Information – To obtain general information on a variety of children's healthcare topics or to help find a pediatrician in your area. Providers may obtain a Medical Home checklist for healthcare plans, fact sheets, and Medical Home training information.

#### Maternal and Child Health Bureau

Telephone - 1-301-443-2170

E-mail - ctibbs@hrsa.gov

Website - www.mchb.hrsa.gov

Mailing Address - Parklawn Building, Room 18-05, 5600 Fishers Lane, Rockville, MD 20857

What Information to Ask For – Informational materials on a variety of healthcare topics, safety issues, and genetics as well as training information for professionals.

Why You Need This Information - To ensure continued improvements in the health, safety, and well-being of women, children and their families.

#### National Center for Education in Maternal & Child Health

Telephone – 1-703-524-7802 E-mail – info@ncemch.org Website – www.ncemch.org

Fax - 1-703-524-9335

Mailing Address - 2000 15th St. N, Ste. 701, Arlington, VA 22201-2617

Note – The National Center for Education in Maternal and Child Health provides national leadership to the maternal and child health community in three key areas – program development, education, and state-of-the-art knowledge—to improve the health and wellbeing of the nation's children and families.

What Information to Ask For – All pertinent Informational/ educational materials.

Why You Need This Information - To improve the health and well-being of the nation's children and families.

#### The National Center of Medical Home Initiative for Children with Special Health Care Needs

Telephone - 1-847-434-8000

E-mail - medical\_home@aap.org

Website - www.medicalhomeinfo.org

Fax - 1-847-228-7035

Mailing Address - 141 Northwest Pt. Blvd., Elk Grove Village, IL 60007

What Information to Ask For - Information about the Medical Home concept and links to multiple state Medical Home activities.

Why You Need This Information – To ensure that children with special healthcare needs have access to a medical home and obtain support for medical providers and families of children with special healthcare needs.

#### FAMILY SUPPORT AND ASSISTANCE

#### **Bright Futures**

Telephone - 1-703-524-7802

E-mail - brightfutures@ncemch.org

Website - www.brightfutures.org

Fax - 1-703-524-9335

Mailing Address – Georgetown University, NCEMCH, 2000 15th St., North, Ste. 701, Arlington, VA 22201-2617

What Information to Ask For- Informational materials on promoting and improving the health, education, and well-being of children, adolescents and families and to learn how to build a successful professional/parent partnership on behalf of children's health.

#### March of Dimes Birth Defects Foundation

Telephone - 1-888-MODIMES

E-mail - resourcecenter@modimes.org

Website - www.modimes.org

Fax - 1-914-428-8203

Mailing Address - 1275 Mamaroneck Ave., White Plains, NY 10605

What Information to Ask For- Informational material on birth defects and genetic disorders and how they may be prevented, location of local chapters, and national advocacy efforts.

#### National Information Center for Children & Youth with Disabilities (NICHCY)

Telephone - 1-800-695-0285-TDD/voice

E-mail - nichcy@aed.org

Website - www.nichcy.org

Fax - 1-202-884-8441

Mailing Address - PO Box 1492, Washington, DC 20013-1492

What Information to Ask For – To obtain contact information on disability-related issues, local resources, parent groups, and parent training.

#### National Alliance for the Mentally III

Telephone - 1-703-524-7600

E-mail - NAMIOFF@aol.com

Website - www.nami.org

Fax - 1-703-524-9094

Mailing Address – Colonial Place Three, 2107 Wilson Blvd., Ste. 300, Arlington, VA 22201

What Information to Ask For – Informational materials on mental health disorders, self help, support, referrals to local resources, location of local chapters, advocacy efforts, and/or national conferences.

#### Abledata

Telephone - 800-227-0216 \* 1-301-608-8912-TDD

E-mail - abledata@macroint.com

Website - www.abledata.com

Fax - 1-301-608-8958

Mailing Address – 8630 Fenton St., Ste. 930, Silver Spring, MD 20910

What Information to Ask For – The help in needed to obtain a variety of assistive technology and/or rehabilitative equipment (canes, voice out-put programs, etc) from domestic and international sources.

#### Parent Pals

Telephone -714-283-4758

E-mail - superpal@parentpals.com

Website - parentpals.com

What Information to Ask For – Information on a variety of conditions related to children with special healthcare needs, including special education and gifted information, continuing education, support(s), tips, and book resources for parents and professionals. The website contains 300 website links for parents, professionals, and schools.

#### The National Patient Travel Helpline

Telephone - 1-800-296-1217 \* 1-757-318-9174

E-mail - mercymedical@erols.com

Website - www.patient-travel.org

Fax - 1-757-318-9107

Mailing Address - Mercy Medical Airlift, 4620 Haygood Rd., Suite 1, Virgina Beach, VA 23455

What Information to Ask For- Information and help with needed transfers to obtain medical care.

#### **Exceptional Parent**

Telephone - 1-201-489-4111

Website - www.eparent.com

Fax - 1-201-489-0074

Mailing Address - 65 East Edge, NJ 07661

What Information to Ask For- Informational material, support, encouragement, and outreach for parents of children with special health care needs.

#### Magic Foundation

Telephone - 1-708-383-0808

E-mail - mary@magicfoundation.org

Website - www.magicfoundation.org

Fax - 1-708-383-0899

Mailing Address - 1327 N. Harlem Ave., Oak Park, IL 60302

What Information to Ask For – Information covering a variety of children's growth disorders and to provide opportunity to communicate with others with similar related disorders.

#### Grant-A-Wish/The Children's Promise Foundation

Telephone - 1-800-933-5470

E-mail - wish@grant-a-wish.org

Website - www.grant-a-wish.org

Fax - 1-410-744-1984

Mailing Address - PO Box 21243, c/o Brian Morrison, Baltimore, MD 21228

What Information to Ask For – Informational materials and/or supportive services for children 17 and under who are battling life-threatening illnesses.

#### LEGAL ASSISTANCE

#### Amicus for Children, Inc.

E-mail - sheri@amicusforchildren.org

Website - www.amicusforchildren.org

Fax - 1-610-689-8320

Mailing Address – 1023 Old Swede Rd., Douglassville, PA 19518

What Information to Ask For – Information on special education laws, support in finding special services, referrals to community services, program development, information services, and team building.

Why You Need This Information – To obtain information in helping you become an effective advocate for a child with special needs; to help "build bridges" between parents schools, and service providers; to help you obtain services for a special needs child; to help you design and implement parent support and children's programs.

Who You Need to Make Contact With - Sheri Taylor

#### National Association of Protection and Advocacy System

Telephone - 1-202-408-9514 + 1-202-408-9521-TDD

E-mail - NAPAS@earthlink.net

Website - www.protectionandadvocacy.com

Fax - 1-202-408-9520

Mailing Address - 900 2nd St. NE, Ste. 211, Washington, DC 20002

What Information to Ask For – Informational materials, referrals, and local chapters.

Why You Need This Information – To obtain legally based advocacy services and referrals to local resources.

#### ADVOCACY

#### Family Voices

Telephone - 1-888-835-5669

E-mail - kidshealth@familyvoices.org

Website - www.familyvoices.org

Fax - 1-505-872-4780

Mailing Address – 3411 Candelaria NE, Ste. M, Albuquerque, NM 87107

What Information to Ask For – Family Voices is an organization made up of families, friends, caregiver, and professionals who advocate for children with special health care needs. A national, grassroots clearinghouse for information and education concerning the health care of children with special health needs. Family Voices shares the expertise and experiences of families from around the nation with state and national policymakers, the media, health professionals, and other families. Ask for information and educational materials on the health care of children with special health care needs; local chapters, and national conferences.

#### Families USA

Telephone -202-628-3030 E-mail - info@familiesusa.org

Website - www.familiesusa.org

Fax - 202-347-2417

Mailing Address - 1334 G Street NW, Washington, DC 20005

What Information to Ask For – Families USA is a nonprofit organization that works at national and state levels with organizations and individuals assisting them in participating in shaping health care policies through educating the public and policy makers and developing solutions to the problems families face. There are also related sites focusing on managed care and Medicaid. Ask for informational materials on health care, managed care, and Medicaid.

#### DISEASE SPECIFIC

#### Tourette Syndrome Association, Inc.

Telephone - 800-237-0717

E-mail - ts@tsa-usa.org

Website - www.tsa-usa.org

Fax - 719-279-9596

Mailing Address - 42-40 Bell Boulevard, Bayside, NY 11361

What Information to Ask For – Informational materials, referral service, support groups, research information.

Why You Need This Information – To obtain general information, referrals to local resources, location of local chapters, research information, and advocacy efforts.

Who You Need to Make Contact With - Jennifer Cammon

#### The National Children's Cancer Society

Telephone - 314-241-1600

E-mail - pfs@children-cancer.com

Website - www.children-cancer.com

Fax - 314-241-6949

Mailing Address – 1015 Locust, Suite 600, St. Louis, MO 63101

What Information to Ask For – Financial and emotional support services, application for assistance, or advocacy information.

Why You Need This Information – To obtain financial assistance, emotional support, information on advocacy issues and to reduce the risk cancer through education and prevention programs.

#### National Down Syndrome Society

Telephone - 800-221-4602

E-mail - info@ndss.org

Website - www.ndss.org

Fax - 212-979-2873

Mailing Address - 666 Broadway, 8th floor. New York, NY 10012-2317

What Information to Ask For - Educational/advocacy information, networking/matching, referrals, local chapters, and national conference information.

Why You Need This Information – To understand and increase public awareness about Down Syndrome, to obtain referrals to local resources, locations of local chapters, and national conferences.

#### **Autism Society of America**

Telephone - 800-328-8476

E-mail - www.autism-society.org

Fax - 301-657-0869

Mailing Address – 7910 Woodmont Ave., Ste. 300, Bethesda, MD 20814-3067 What Information to Ask For – Informational materials, periodical/newsletter, local chapters, national conferences, advocacy and research information.

Why You Need This Information – To obtain general information, locations of local chapters, support groups, and advocacy efforts.

#### Children and Adults with Attention Deficit Hyperactivity Disorder (CHADD)

Telephone - 800-233-4050

E-mail - national@chadd.org

Website - www.chadd.org

Fax - 301-306-7090

Mailing Address - 8181 Professional Place, Ste. 201, Landover, MD 20785

What Information to Ask For - Information materials, networking/matching, referrals, conferences and help with advocacy issues.

Why You Need This Information – CHADD's local chapters sponsor parent and adult support groups, convene educational meetings, provide a listing of advocates in the area and work with local school systems to provide education to teachers about AD/HD and accommodations for children with AD/HD.

#### American Speech, Language, Hearing Association

Telephone - 800-942-2732-TDD/voice

Website - www.asha.org

Fax - 301-571-0457

Mailing address - 10801 Rockville Pike, Rockville, MD 20852

What Information to Ask For – Informational materials on speech/language and/or hearing disorders, national conferences, research and advocacy information.

Why You Need This Information - To obtain general information, help with advocacy issues, and access the research registry.

#### National Organization for Rare Disorders, Inc. (NORD)

Telephone - 800-999-6673/203-744-0100

E-mail - orphan@rarediseases.org

Website - www.rarediseases.org

Fax -203-746-6481

Mailing Address - 55 Kenosia Ave., PO Box 1968, Danbury, CT 06813-1968

What Information to Ask For – The National Organization for Rare Disorders (NORD) is a federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education advocacy, research, and service.

#### Spina Bifida Association of America

Telephone - 800-621-3141

E-mail - sbaa@sbaa.org

Website - www.sbaa.org

Fax - 202-944-3295

Mailing Address - 4590 MacArthur Blvd. NW, Stc. 250, Washington, DC 20007-4226

What Information to Ask For – Informational materials, referrals, local chapters, national conferences, research information.

Why You Need This Information - To obtain general information, locations of local chapters, and referrals to local resources.





#### Arkansas Governor's Developmental Disabilities Council

Freeway Medical Tower + 5800 West 10th Street + Little Rock, AR 72204 (501) 661-2589 + (800) 482-5400, Ext. 2589 + TT/TDD (800) 285-1131 + Fax (501) 661-2399

#### **Medical Home Arkansas**

Donaghey Plaza South ◆ 7th and Main Streets, S308 ◆ Little Rock, AR 72203 (501) 682-2277 ◆ (800) 482-5850, Ext. 22277 or 22270