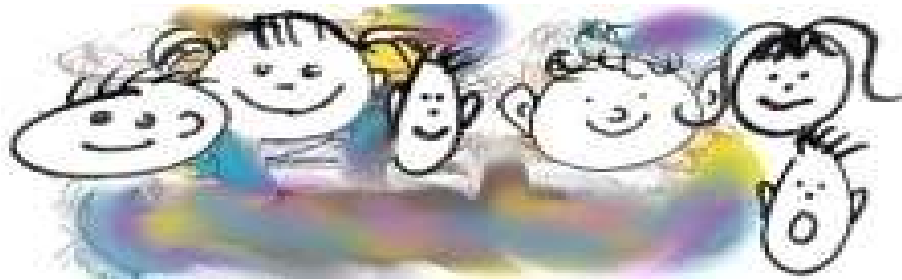


The Arc of Kentucky

“Over fifty years of Advocacy and Partnership”

KEEPSAKE



**A Family to Family Resource Guide
to Services & Opportunities
for Kentuckians with
Special Health Care Needs
and Their Families**



*From: Our Family
To: Your Family*

The Arc of Kentucky Family to Family Guide to Services and Opportunities for Kentuckians with Special Health Care Needs and Their Families is intended to serve as a resource for accessing services and to use in conjunction with The Arc of Kentucky's guide for future planning, Visions. It is funded by the Center for Medicare and Medicaid Services Real Choices Systems Change Grant- Family to Family Health Information & Education Initiative. The Guide is a modified version of The Point – Arc of Northern Kentucky's Family to Family Life Needs.

Agencies are listed in alphabetical order in each topic area. Each description of services was provided and essentially written by each of the provider agencies - *keep that in mind when reading the descriptions*. The Arc of Kentucky implies no guarantee of quality or entrance.

Spend an evening reading through the booklet. It has no plot, no compelling characters; however deciding whether your son or daughter will be eligible for a service, or how long the waiting list is or if the option you prefer is available - can provide more than enough suspense.

It will also serve as a guide to learning the "system." It becomes immediately apparent that the Cabinet for Health and Families is the major source for services. Although there are other agencies providing services and offering programs, the Mental Health/Mental Retardation Regional Board – Comprehensive Care Centers (most have different names) are one of the key local providers.

How many parents of children with disabilities would include their Area Agency on Aging and Independent Living in their "to call list?" When people mention national trends, this is one of them. How many of *us* really want to go to a nursing home? How many of *us* want to stay in our own home and have some help in remaining independent? Some people who are aging are living with family and those folks will need some help too. The same types of services people in the disabilities community are advocating for; and the same kinds of obstacles are encountered. Together, individuals who are aging, those with disabilities and their families can make a dynamic alliance of advocates.

Consumers and families must decide which resources they will pursue. Many services have long, long waiting lists but that should not prevent individuals or their families from registering. Any call to a service provider should conclude with the questions, "Is there another resource you would recommend? What is their phone number and is there a contact person?"

It is an unfortunate, yet frustrating truth, the moment a resource directory is published some part of it becomes outdated. For that reason, individual names of contact people and service/program fees are kept to a minimum.

The directory *does* contain primary resources but *does not* contain all resources available. Many families are familiar with these resources and have additional information about useful services. It would be appreciated if this knowledge were shared so the list can be continually updated.

The Family to Family Guide is available in print. It is on The Arc of Kentucky's web site and is linked to each provider who has a web site and email address. Please contact us by phone, mail or email. We would enjoy hearing from you!

THE ARC OF KENTUCKY
Over 50 years of Advocacy and Partnership
706 Main Street, Suite A, Frankfort, KY 40601
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Email: arcofky@aol.com Web site: www.arcofky.org

A BRIEF DISCUSSION ABOUT DISABILITY LANGUAGE...

For decades, the language used to describe disabilities has been the topic of heated discussion and disagreement. Those who prefer other words such as handicap, special needs, impairment or challenged dispute the term disability.

In the early 1900's, the term idiot, imbecile, moron and feeble-minded were legitimate, medical diagnostic terms. Today, they are used as insults or "put-downs" without awareness of their original meaning and use. Mental retardation replaced the diagnostic label of feeble-minded. Now it has entered the everyday vocabulary as *retard* and is used with the intent to insult. Replacements such as *intellectual*, *cognitive* or *developmental disability* will inevitably become derogatory terms; then, they will be replaced, and so on and so on. Only when society changes its negative attitudes toward disabilities and those who live with the labels will the ability to stigmatize be eradicated.

Meanwhile, everyone struggles to find the appropriate language.

Few people realize that programs or services funded by taxpayers and donors are bound by service descriptions of who will be served. For example, the term *developmental disability** is used by the general population as a broad description of people who grow up with a disability. However, it has specific criterion defined by the federal government. People asking for services funded for developmental disabilities will need to fit that criterion. Federal and State regulations or other funding sources use language that can be offensive to some. For example, Kentucky's Department for Mental Health/*Mental Retardation Services* has a vast array of resources – individuals served must fit this diagnosis.

The language used in this guide is the description provided by each individual service provider for his or her resource, service or program. In some incidents, people first language* has been substituted.

*U.S. Code Definition of "Developmental Disability": (A) In general, the term "developmental disability" means a severe, chronic disability of an individual that 1. is attributable to a mental or physical impairment or combination of mental and physical impairments; 2. is manifested before the individual attains age twenty-two; 3. is likely to continue indefinitely; 4. results in substantial functional limitations in three or more of the following areas of major life activity: self care and/or receptive and expressive language and/or learning and/or mobility and/or self-direction and/or capacity for independent living and/or economic self-efficiency AND 5. reflects the individual's need for a combination and sequence of special, interdisciplinary or generic services, individualized supports or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

Developmental Disability in Infants and Young Children: An individual from birth to age nine, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting three or more of the described in the above one through five of subparagraph (A) if the individual, without services and supports, has a high probability of meeting those criteria later in life.
42 USC Sec. 15002 – Definitions

Check out more on definitions:

http://manuals.chfs.ky.gov/dpbs_manuals/dpp/docs/A%20Manual%20of%20Collaboration.doc

*"People first language" is a means of emphasizing the individual identity of the person rather than the disability - not identifying the individual as a disability, i.e. the program serves "individuals with disabilities" rather than "the disabled".

Topics

Although some topics are categorized by age,
other topics have resources for all ages.

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Many thanks to those people who shared their information, helped compile the data,
reviewed and contributed suggestions with the sole intent of helping individuals and
families to find services.

Compiled and Edited by: Judy DeSalvo, Patty Dempsey, Linda Wainscott,
Linda Thomas, Ann Smits
September, 2007

SECTION 1

THE ARC OF KENTUCKY AND OTHER SOURCES FOR SUPPORT AND INFORMATION

THE ARC OF KENTUCKY – LOCAL ARCS & OTHER SOURCES OF SUPPORT & INFORMATION

“Give a man a fish; he’ll eat for a day. Teach a man to fish, he’ll eat for a lifetime” – That is what the Arc of Kentucky is all about.”

Anonymous Donor to The Arc of Kentucky

As you are reading, notice the number of organizations that have been started by “a small group of parents”. Many of these parents started when the future for their son or daughter was very, very bleak. Ask an older parent about the “old days” – not only the negative attitudes about their children but the negative attitudes extended to them, the parents. How many thousands of parents sold raffle tickets, manned festival booths, volunteered in the kitchen, and on and on to support their child’s private school – started by their ARC? How many parents of children receiving special education services today realize the vision of the ARC of Pennsylvania who in 1971 brought a successful civil rights suit against the Commonwealth of Pennsylvania in a battle to have their children attend public school? Winning that suit set in motion the passage of The Mandatory Education Act for Handicapped Children, the foundation for IDEA. Life keeps moving, this is the twenty-first century, and the advocacy is passed to the younger generation. What will their small, passionate, committed group bring to fruition?

THE ARC OF KENTUCKY
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Frankfort, KY 40601
Toll Free: (800) 281-1272
Fax: (502) 875-5226
Email: arcofky@aol.com
Web site: www.arcofky.org



Celebrating its 52nd birthday, The Arc of Kentucky is a part of a national grassroots movement whose majority of members are parents of children with intellectual and developmental disabilities. Starting at a time when institutional care was the only option for parents, the network of local, state and national Arcs, through advocacy, have changed and continue to change the nature of services from institutional to community options.

Its vision is for people with intellectual and developmental disabilities to be contributing members of schools, work places, churches, synagogues, neighborhoods and the community. The Arc values services and supports that enhance the quality of life through interdependence, friendships, choices, and respect for individuals with intellectual and developmental disabilities.

The Arc of Kentucky has consistently developed advocacy-training programs. These training programs are open to individuals who have a disability and/or family members. Under the grants, expenses, often including respite, are included. Current initiatives are:

Advocates in Action – Self-Determination/Leadership Training. An innovative training program designed to train individuals with disabilities, family members, siblings of family members with disabilities and professionals working with people with disabilities.

Participants will hear the most up-to-date information on the most crucial issues facing individuals with disabilities and their families. There are two statewide events; the first scheduled for the fall and the second in January. Participants must agree to attend both sessions.

Family to Family Health Information and Education Initiative of Kentucky.

One of ten agencies in the U.S., The Arc of Kentucky was awarded a Family to Family Health Information & Education grant in 2004. Through this project families have been provided training and information on special health care needs. It also provides a central information center and:

- Provides education and training opportunities for families with children who have special health care needs;
- Collaborates with existing Family to Family Health Care & Education Centers;
- Promotes the philosophy of individual and family-directed supports;
- Connects families of children with special health care needs with other families who have similar needs and experiences.
- Gives families the opportunity to share information and support;
- Links families with local, state and national resources for families, including conferences, workshops, support groups, councils, agencies, web sites, books, newsletters, etc.; and
- Provides guidance for those who would like to become support families and parents.

The vision of The Arc's Family to Family Initiative is to enhance the ability of all Kentuckians to make responsible health care choices through education, training, mentoring, resources, and networking opportunities.

Aging Caregiver Project – Through funding from the Cabinet for Health and Family Services, Department for Aging and Independent Living, The “Kentucky Resource Market” One Stop Shop for Aging Caregivers, The Arc provides training regionally for individuals with disabilities, parents, family members, siblings, friends and service providers. The training series included “An Overview of Available Services and Supports – Planning Future Supports and Services for a Loved One with an Intellectual or Developmental Disability” and Estate Planning Workshops – Creating a Safe and Secure Future for a Loved One with an Intellectual or Developmental Disability.”

They have produced several handbooks – Kentucky General Assembly – Quick Resource Guide for Legislative Advocates and Hot Tips for Legislative Advocates. In addition to its newsletter, The Arc of Kentucky publishes Hot Stuff, an accounting of disability news of the day laced with advocacy opinion. Contact the Arc for your copies or get it on line. Ask to be added to the Arc's *email news group* for up to date information about current issues in legislation, funding and advocacy. The Arc of Kentucky in collaboration with other state organizations presents workshops and develops training manuals on the most current issues facing Kentuckians with intellectual and developmental disabilities.

LOCAL ARCS

“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.”

Margaret Mead, U.S. Anthropologist - 1901-1978

Throughout the state and country, local Arcs differ widely in their functions and services. However, they all have the same vision of a positive future for individuals with intellectual and developmental disabilities and their families; a future of communities with services and supports that will promote lives of value for Kentuckians with intellectual and developmental disabilities. Some Arcs are thirty-five, fifty years old; some are just organizing. Some have staff in offices; some have volunteers who work out of their home. Contact your local Arc for membership and bring your talents and skills to the advocacy.

Some Arcs were not able to send in their material for this issue of the Family to Family Guide but their information will be added as received.

Frankfort Habilitation in Frankfort
3755 US 127 South
Frankfort, KY 40601
Phone: (502) 227-9529

Greater Metro Louisville Arc
3713 Fallen Timber Drive
Louisville, KY 40241
Phone: (502) 339-8690
Email: gail619@bellsouth.net

Newly formed, it meets the first Tuesday of the month at 7:00 P.M. at the Bon Air Regional Library in Louisville. This grassroots organization includes people with disabilities, family members, service providers, and caring community people from Louisville and its surrounding counties. They have joined together to advocate for the full rights and participation of people with intellectual and/or developmental disabilities in the community.

Their vision: the full participation of children and adults with intellectual and/or developmental disabilities in a community that is welcoming, encouraging and supportive.

The Greater Metro Louisville Arc is in the Seven Counties Mental Health/Mental Retardation Region.

Hugh E. Sandefur Center in Henderson
1449 Corporate Court
Henderson, KY 42420
Phone: (270) 827-2401

P.L.A.N.S. – The Arc of Christian County in Hopkinsville
“Persons Learning about Needs and Services” of children and adults with disabilities
P.O. Box 1257
Hopkinsville, KY 42241-1257
Phone: (270) 886-5481 or (270) 885-7959
Email: cjthorpe828@bellsouth.net

PLANS meets the second Monday of each month at 6:00 p.m. at the Doctor’s Pavilion at Jennie Stuart Medical Center (lower level), in Hopkinsville. Membership dues are \$15.00 per person which also makes the individual a member of The Arc of Kentucky.

It was started in 1990 with a small number of parents and grandparents raising children with disabilities from ages - infancy to high school age, through a project of The Arc of Kentucky. They have grown to over forty on the mailing list and have learned about needs and services in their community.

PLANS is in the Pennyroyal Mental Health/Mental Retardation Region.

The Arc of Barren County in Glasgow
Mailing Address: P.O. Box 205
Office Location: 123 East Washington Street
Glasgow, KY 42142-0205
Phone: (270) 659-0802

Founded in 1998 by a small group of parents, it meets on the second Thursday of the month. The Arc of Barren County advocates for the rights of citizens with intellectual and other disabilities: *to participate* in and be included in all phases of community life; *to make choices* about and take control over their own lives to as large extent as possible – including where and with whom they will live and work in the community; *by initiating and supporting* local, state and national *prevention* efforts to reduce the incidence and limit the consequences of disabilities through research, advocacy, education and family support; *by providing leadership, pursuing equality and justice* and developing human and financial *resources* to reach the above goals.

It sees its mission as: Advocating for legislation that promotes and funds services and supports in the community that enhance the quality of life and hold to our vision: educating federal, state, and local elected officials, agency personnel, policymakers, service providers, and the general public, including local chapter

members, individuals with intellectual and other disabilities and their families about the services and supports that hold to the vision; supporting and creating the opportunity for individuals with intellectual and other disabilities and their families to use their unique gifts, talents, and competencies to speak, on their own behalf, to achieve a positive future.

The Arc of Barren County is a part of the Lifeskills Mental Health/Mental Retardation Region.

The Arc of Breckinridge County
3161 Haysville Road
Brandenburg, KY 40108
Phone: (270) 422-3778

The Arc meets on the third Thursday of the month; call for more information.

The Arc of Carroll County in Carrollton
616 Seminary Street
Carroll, KY 41008
Email: alissaraelyn@hotmail.com

The Arc of Hardin County
ARHHC
P.O. Box 2012
225 College Street
Elizabethtown, KY 42702-2013
Phone: (270) 737-1140 or (270) 234-0149
Fax: (270) 234-9115
Email: arhhc@windstream.net

Officially organized on April 3, 1955 by the Elizabethtown League of Women Voters, ARHHC's purpose is to: advocate for individuals with disabilities; provide programs and activities for individuals with disabilities when feasible; and to offer a support network for individuals with disabilities and their families/caregivers. ARHHC opened the first school in Hardin County for children with mental retardation in 1959 and provided housing for Communicare's Opportunity Workshops from 1969 to 2003. It has monthly board and general meetings the first Tuesday of each month. Call for more information.

Its advocacy involvement includes: conducting monthly business meetings; working with state and national organizations such as the Arc; communicating with elected officials on issues and concerns regarding individuals with disabilities; offering informational workshops on topics such as estate planning, wills and trusts, and guardianship.

Its programs include: Project L.E.A.R.N, a twelve month program which provides an opportunity to maintain existing skills and acquire new skills in a safe, nurturing environment for adults with severe disabilities. It is also an opportunity for respite for parents/caregivers. They operate a Summer Recreation and Retention Program. It provides an opportunity for school-age children with disabilities to maintain and reinforce learned skills as well as provide an opportunity for recreational activities. In addition, several social and recreational opportunities for individuals and their families are offered throughout the year, i.e. Halloween Dance, Christmas Dinner and a Valentine Dance.

The ARHHC provides a support network by coordinating with other agencies and programs who serve individuals with intellectual /developmental disabilities, coordinating with the school systems regarding post high school opportunities when appropriate and offering the opportunity for parent networking.

The ARHHC is a part of the Communicare Mental Health/Mental Retardation Region.

The Arc of the Mountains in Harlan
P.O. Box 663
Cumberland, KY 40823

The Arc of Lake Cumberland in Somerset

Contact: Marsha Vanhook

Phone: (606) 875-9890

Email: marshavanhook@hotmail.com

Web site: www.TheArcofLC.com

Organized since 1987, The Arc of Lake Cumberland is in the process of reorganizing to reach a broader area in the region. It meets the fourth Thursday of each month at 11:30 a.m. at Bob Evans Restaurant.

The Arc of Lake Cumberland is in the Adanta Mental Health/Mental Retardation Region.

The Arc of Logan County in Russellville

443 Hopkinsville Road

Russellville, KY 42276

Phone: (270) 726-8770

This group meets on the third Monday of the month, 5:00 p.m. at Life Skills Workshop on Sheldon Lane.

The Arc of Madison County

P.O. Box 1863

Richmond, KY 40475

Phone: (859) 622-2314

Email: michelle.gerken@eku.edu

They meet on the third Wednesday of the month at 1:30 p.m. at Richmond Parks and Recreation Department at Eastern Kentucky University.

The Arc of Madison County is in the Bluegrass Mental Health/Mental Retardation Region.

The Arc of Meade County in Brandenburg

1310 Brandenburg Road

Brandenburg, KY 40108

Meets every second month on the third Tuesday at 7:00 p.m. at MARC Industries, 1895 Brandenburg Road in Brandenburg.

The Arc of Owensboro, Inc.

731 Jackson Street, Zip: 42302

P.O. Box 1833, Zip 42302

Owensboro, KY

Phone: (270) 685-2976

Email: oppcbtr@bellsouth.net

Founded in 1956, by a group of parents who wanted to create new opportunities for their sons and daughters with a disability. It started by providing school services and has evolved into vocational rehabilitation/ employment services. The group has been, and is involved in getting laws passed that would help ensure their children's lives could be as fulfilling and independent as possible. The Arc of Owensboro, in conjunction with The Arc of Kentucky and The Arc of the U.S. has been instrumental in getting people moved from institutions to community services as well as public school services available for children with disabilities. Membership dues are \$15.00.

The Arc of Owensboro operates Opportunity Center Workshop, Inc. Its mission is to provide vocational evaluation/assessments, training support, work services and job placement services to individuals who are physically/mentally disabled and/or vocationally disadvantaged, thereby increasing their vocational and social independence as well as their ability to earn income and to provide support, referral and advocacy services to and for clients/consumers, their families and/or other interested persons.

Eligibility Requirements: Must be sixteen years of age and older; provide own transportation (city bus, GRITS, car, etc.); have third party sponsorship as appropriate or private pay; be recommended by Inter-Disciplinary Team consensus that placement meets the basic safety health and welfare needs of the individual; be willing to abide by the attendance policy and other client/consumer policies of the Arc.; show evidence of benefiting from work oriented, rehabilitation and training. Call the Arc of Owensboro for more information.

The Arc of Owensboro is in the River Valley Behavioral Health Region

The Arc of Tamarlane Industries in Beaver Dam

**846 South Main Street
Beaver Dam, KY 42320
Phone: (270) 274-4534**

The Point Arc of Northern Kentucky

**104 West Pike Street
Covington, KY. 41011
Phone: (859) 491-9195
Fax: (859) 491-0763
Email: thepoint@thepointarc.org
Web site: www.thepointarc.org**

Its mission is to provide opportunities to people with intellectual/developmental disabilities to reach their highest potential educationally, residentially, socially and vocationally. Its goal is: to empower individuals to become productive and included members of their families and their communities, while promoting self-determination so that each person is equipped to make informed decisions regarding the quality of their lives: and to protect and advocate for each individual to be treated with dignity and respect, while teaching personal responsibility.

The Point offers the following programs:

The Activities Program is designed to offer opportunities to adult men and women who have intellectual/developmental disabilities, through supervised community activities, to develop and grow socially. The program offers a wide array of social, educational and recreational opportunities. Volunteers are recruited, screened and trained to act as hosts/hostesses for each activity. Membership fee is twenty-five dollars annually.

Eligibility Requirements: Men and women, age eighteen and older who have intellectual/developmental disabilities.

Employment Services: Comprehensive job training and placement services for individuals wanting to work in integrated community settings. All services are customized to the needs of the individual to achieve successful community employment. The scope of services include: vocational assessment/goal-setting, instruction on workplace skills & issues, paid on the job training, job coaching, resume' development, interviewing skills, job search, job development services, placement and on-site training, long term follow up, staff accessibility, transportation assistance and support coordination with other agencies. Pre-vocational training classes are offered to develop fine motor, communication, social and artistic skills.

Training Companies: For individuals with little or no work experience, The Point offers the opportunity to gain work experience within agency sponsored-training companies. Individuals can build employment skills in safe, supportive environments.

Opened in 1982, *The Point Deli and Catering* provides the opportunity to gain work experience in a restaurant serving the general public. Trainees learn food preparation, dishwashing and customer service.

Operating since 1996, *The Point Laundry* is a commercial laundry company, which employs people with and without disabilities. It also serves as an employment-training site. Hotels contract with The Point Laundry to process over 3.4 million pounds of laundry each year. It operates seven days a week. In 2003, it expanded thereby increasing its capacity to process laundry and tripling its employee-trainee base.

The Point Commercial Cleaning Company contracts with businesses to clean offices and provides training opportunities.

Eligibility Requirements: High school students and adults with intellectual and developmental disabilities. Referrals to The Point are made by individuals, local agencies, schools and Vocational Rehabilitation.

Group Homes: The Point has committed its resources to finding “a key of their own” for individuals with intellectual/developmental disabilities. The Point currently operates eight residences. For those individuals who do not need the structure of a group home, The Point offers a boarding house option in which residents have their own personal living areas as well as sharing common areas of the home. Staff supports this arrangement with help in paying bills, shopping and other tasks. Families have willed their homes to The Point with the request that their son or daughter continue living in the family home. The Point has provided staff in these homes and found additional residents whose personality, shared interest and skills compliment each other.

Eligibility Requirements: Adults, age eighteen and over with intellectual/developmental disabilities.

Outreach: Special Education Advocacy - The goal is to assist children with disabilities to receive the educational services needed to increase their competency, independence and employability by working with their care-giving families and educators to develop working partnerships through mediation, negotiation and implementation of their rights under IDEA, Section 504 and the American Disabilities Act (ADA); and, to mentor the care-giving family in their rights and responsibilities in participating in their child's special education plan and outcomes.

Advocate/mentors will talk with caregivers over the phone regarding their concerns and issues regarding special education, review records and discuss them with caregivers, and, with a signed release for information, contact with the district administration may occur. The advocate/mentor can attend the school ARC meetings with the parent/caregiver. The advocate/mentor does not replace the parent or assume educational decision making responsibility. There is no fee for service.

Eligibility Requirements: Children with developmental disabilities residing in Boone, Campbell and Kenton Counties, ages three to twenty-one.

Through the Outreach program, parent workshops are given on a regular basis at The Point and to other community groups.

The Point Arc of Northern Kentucky is in the North Key Mental Health/Mental Retardation Region.

The Arc of Hazard (Pending)

The Arc of Shelby County (Pending)

THE ARC OF THE UNITED STATES

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Fax: (301) 565-3842 or (301) 565-5342
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Web site: www.thearc.org

Public Policy:
The Disability Policy Collaboration
1660 L. Street, NW, Suite 701
Washington, D.C. 20036
Phone: (202) 783-2229
Fax: (202) 783-8250
General Information Email: gaoinfo@thearc.org

Mission Statement: The Arc of the United States advocates for the rights and full participation of all children and adults with intellectual and developmental disabilities. With a network of members and affiliated chapters, they improve systems of supports and services; connect families, inspire communities and influence public policy.

Founded more than fifty years ago by a small group of parents and other concerned individuals, when little was known about the condition of mental retardation or its causes, The Arc today is the world's largest grassroots organization of and for people with intellectual and developmental disabilities. It has over 140,000 members affiliated through more than 850 state and local chapters across the nation.

The Arc produces Monday Morning in Washington which is available on line each Monday. It details the issues that impact people with disabilities. In addition to its advocacy, The Arc has developed numerous Fact Sheets, CDs and other media about issues surrounding the needs and lives of people – infant to senior citizens with intellectual and developmental disabilities.

ADDITIONAL SOURCES OF SUPPORT & INFORMATION

I have three children with special needs. You can guess that there is never a dull moment at our house. Another special needs parent told me about the Family to Family Project and I attended. The most important part of it was learning about the resources that are out there – nobody tells you about them. We have gone through a lot of difficulties but now my life is leveling out. I've started college, majoring in Early Childhood Education. I want to work with the regular education teachers to hopefully teach them more about children with disabilities.

Shannon Collins, Wheelwright

ANGELMAN SYNDROME FOUNDATION
3015 East New York Street, Suite A2265
Aurora, IL 60504
Phone: (630) 978-4245
Toll Free: (800) IF-ANGEL (432-6435)
Email: info@angelman.org
Web site: www.angelman.org

Its mission is to advance the awareness and treatment of Angelman Syndrome through education and information, research, and support for individuals with Angelman Syndrome, their families, and other concerned parties

The Angelman Syndrome Foundation is a national organization of families, caregivers and professionals who care about those with Angelman Syndrome. It is a member organization of the International Angelman Syndrome Organization (IASO).

ASPERGER SYNDROME
MAAP Services for Autism and Asperger Syndrome
P.O. Box 524
Crown Point, IN 46308
Phone: (219) 662-1311
Email: chart@netnitco.net
Web site: www.maapservices.org

MAAP Services for Autism and Asperger Spectrum is a nonprofit organization dedicated to providing information and advice to families of More advanced individuals with Autism, Asperger's syndrome, and Pervasive developmental disorder (PDD). Through its quarterly newsletter, *The MAAP*, the organization provides the opportunity for parents and professionals to network with others in similar circumstances and to learn about more advanced individuals within the autism spectrum.

AUTISM SOCIETY OF AMERICA (ASA)

7910 Woodmont Avenue, Suite 300

Bethesda, Maryland 20814-3067

Phone: (301) 657-0881

Toll Free: (800) 328-8476

Web Page: <http://www.autism-society.org/site/PageServer>

The Autism Society of America was founded in 1965. Over the last 40 years, the Society has grown from a handful of parents, into the leading source of information, research, and reference on autism. ASA is the oldest and largest grassroots organization within the autism community. Today, more than 120,000 members and supporters are connected through a working network of nearly 200 chapters nationwide. ASA membership continues to grow as more and more parents and professionals unite to form a collective voice representing the autism community.

ASA is dedicated to increasing public awareness about autism and the day-to-day issues faced by individuals with autism, their families and the professionals with whom they interact. The Society and its chapters share a common mission of providing information and education, supporting research and advocating for programs and services for the autism community.

Chapters are places that the ASA mission of creating a world where persons within the autism spectrum disorder are fully included, participating members of their communities, is implemented. Chapters enhance community awareness, provide education for professionals and parents, and maintain supportive, informative networks comprised of parents, professionals, and community leaders. Contact ASA for the location of your Chapter.

Autism Society of Kentuckiana is a chapter of the ASA whose mission is to provide families and individuals affected by autism and related disabilities with support, information and advocacy.

Contact them: **Phone: Laurie at (502) 222-4706, Email lauriespezzano@insightbb.com**

Web site: www.ask-lou.org/contactus

Autism Society of the Bluegrass is a resource and support group for families and professionals in the Central Kentucky area who are involved with autism. A chapter of the ASA and a non-profit organization, it provides education as well as scholarships for our members to obtain continuing autism-related education. ASBG meets on the last Monday of each month at 6:30 – 8:30 p.m. St. Michael's Episcopal Church, 2025 Bellefonte Drive, Lexington, KY. Free, experienced childcare is provided.

Autism Society of Western Kentucky, 230 Second Street, Henderson, KY 42420.

Phone: (270) 826-0510. The organization has a Web site filled with information and links including a chat room for moms. It offers a support group, trainings, conferences, and a Resource library.

Autism Spectrum Disorders Network (ASDN) in Northern Kentucky – meets at the Rising Star Studios, 701 Philadelphia Street, Covington, 41011. Phone: (859) 640-9242

Web site: www.risingstarstudios.org Autism Spectrum Disorders Network is a non-profit organization that provides the following: support group meetings, information & referrals, education for families and professionals, Autism awareness in the community and collaboration with Rising Star Studios to provide social activities. Monthly meetings are conducted on the first Saturday of the month at Rising Star Studios on the second floor. Time is 9:00 a.m. to 11:00 a.m. Call for a description of the program to be offered.

BIRTH DEFECTS FOUNDATION

March of Dimes Birth Defects Foundation

1275 Mamaroneck Avenue

White Plains, NY 10605

Phone: (914) 428-7100

Web site: www.marchofdimes.com

The mission is to improve the health of babies by preventing birth defects, premature birth and infant mortality. They carry out this mission through research, community services, education and advocacy to save babies' lives. March of Dimes researchers, volunteers, educators, outreach workers and advocates work together to give all babies a fighting chance against the threats to their health; prematurity, birth defects and low birth weight.

BRAIN INJURY ASSOCIATION OF KENTUCKY (BIAK)

7410 New LaGrange Road, Suite 100

Louisville, KY 40222

Phone: (502) 493-0609

Toll Free: (800) 592-1117

Web site: <http://www.biak.us/about>

The mission is to serve those with a brain injury through advocacy, education, prevention, service and support.

BIAK links survivors of brain injury and their families to support from others with similar experience; provides them with education and information about living and coping with brain injury; assists them in locating resources for financial assistance; and seeks to connect people with sources of emotional support.

CHILDREN AND ADULTS WITH ATTENTION DEFICIT /HYPERACTIVITY DISORDER (CHADD)

8181 Professional Place, Suite 150

Landover, MD 20785

Toll Free: (800) 233-4050

Fax: (301) 306-7070

Web site: www.chadd.org

Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD), is a national non-profit, tax-exempt organization providing education, advocacy and support for individuals with AD/HD. In addition to their informative Web site, CHADD also publishes a variety of printed materials to keep members and professionals current on research advances, medications and treatments affecting individuals with AD/HD. These materials include *Attention!* magazine, the *CHADD Information and Resource Guide to AD/HD*, News From CHADD, a free electronically mailed current events newsletter, as well as other publications of specific interest to educators, professionals and parents.

CHADD does not endorse, recommend, or make representations with respect to the research, services, medication, treatments or products on the Web site.

CLEARINGHOUSE ON DISABILITY INFORMATION

Office of Special Education and Rehabilitative Services (OSERS)

Communications and Customer Service Team (CCST), United States Department of Education

550 12th Street, S.W., Room 5133

Washington, DC 20202-2550

Phone: (202) 245-7307

Phone: (202) 205-5637 TTD

Fax: (202) 245-7636

OSERS Web site: <http://www.ed.gov/about/offices/list/osers>

The Clearinghouse provides information to people with disabilities or anyone requesting information, by doing research and providing documents in response to inquiries. Information provided includes areas of federal funding for disability-related programs. Clearinghouse staff is trained to refer requests to other sources of disability related information, if necessary.

This office is in the Office of Special Education and Rehabilitative Services (OSERS) which is divided into three areas: the Office of Special Education Programs and Rehabilitation Services Administration, the National Institute on Disability, and the National Institute on Disability and the Rehabilitation Research.

Information provided may be useful to individuals with disabilities, their families, schools and universities; teacher's and/or school administrators and organizations that have persons with disabilities as clients. There is no fee.

COMMISSION FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

**982 Eastern Parkway,
Louisville, KY 40217
Phone: (502) 595-4459
Toll Free: (800) 232-1160
Fax: (502) 595-4673
Web site: <http://chfs.ky.gov/ccshcn>**

The Commission for Children with Special Health Care Needs (CCSHCN) is a statewide healthcare program that provides treatment, including clinic services, office visits, tests, and medications, physical, occupational and speech therapy, audiology services, durable medical equipment, and more for Kentucky children with certain medical disabilities from birth to age 21. The Commission staff includes a parent liaison who can help families find resources.

**CONSUMER INFORMATION CENTER
Pueblo, Colorado 81009**

Write for free publications on developmental disabilities, plus a wide variety of other topics are available.

EPILEPSY FOUNDATION OF AMERICA

**4351 Garden City Drive
Landover, MD 20785
Toll Free: (800) 332-1000
Email: postmaster@efa.org
Web site: www.efa.org**

The Epilepsy Foundation is the national voluntary agency solely dedicated to the welfare of the 3 million people with epilepsy in the U.S. and their families. The organization works to ensure that people with seizures are able to participate in all life experiences; and to prevent, control and cure epilepsy through research, education, advocacy and services. In addition to programs conducted at the national level, epilepsy clients throughout the United States are served by local Epilepsy Foundation offices in nearly one hundred communities.

EPILEPSY FOUNDATION OF KENTUCKIANA

**501 East Broadway, Ste. 380
Louisville, KY 40202
(502) 584-8817
(866) 275-1078
Email: dmgrath@efky.org
Web site: www.efky.org**

The Epilepsy Foundation of Kentuckiana offers numerous programs and services designed to educate, advocate and support people with epilepsy and their families throughout Kentucky and Southern Indiana.

**THE ERIC CLEARINGHOUSE ON DISABILITIES AND GIFTED EDUCATION (ERIC EC)
THE COUNCIL FOR EXCEPTIONAL CHILDREN**

**1110 North Glebe Road
Arlington VA 22201-5704
Toll Free: (800) 328-0272
E-mail: erice@cec.sped.org
Web site: <http://ericec.org>**

Council for Exceptional Children and ERIC Clearinghouse on Disabilities and Gifted Education are organizations for professionals in the field. Visit their web site for a wealth of resources for information about disabilities including a site listing famous people who have a disability.

FAMILY VOICES

3411 Candelaria N.E., Suite M

Albuquerque, NM 87107

Phone: (505) 872-4774

Toll Free: (888) 835-5669

Fax: (502) 872-4780

E-mail: kidshealth@familyvoices.org

Web site: www.familyvoices.org

Family Voices, a national grassroots network of families and friends, advocates for health care services that are family-centered, community-based, comprehensive, coordinated and culturally competent for all children and youth with special health care needs; promotes the inclusion of all families as decision-makers at all levels of health care, and supports essential partnerships between families and professionals.

Family Voices believes that children and youth with special health needs face common problems caused by fundamental inadequacies in our health care system. Family Voices does not support any specific health care reform plan. Instead, the role of Family Voices is to advocate for the inclusion of a set of basic principles in every health care reform proposal. Those principles, which have been found effective in thousands of communities throughout the United States are: every child deserves quality primary and specialty health care that is affordable and within geographic reach, families are the core of this nation's health system, their children's most important health providers and caregivers, quality health care is family-centered, community-based, coordinated, and culturally competent, family-centered health benefits and services are flexible, and guided by what children and youth need, strong family-professional partnerships improve decision-making, enhance outcomes, and assure quality, and families practice cost-effectiveness and expect the same from our health systems and services.

Family Voices is a national grassroots organization that provides information and education about ways to ensure and improve family-centered health care for children and youth with disabilities and chronic conditions. The Family Voices network shares information, experiences, and expertise with other families, professional partners, youth leaders, and policymakers. They help bring the family perspective to policy discussions and decisions through their work with other organizations, health agencies and systems, and research projects across the nations.

HEATH RESOURCE CENTER

The George Washington University

2134 G Street, N.W.

Washington, D.C. 20052-0001

Phone: (202) 973-0904

Fax: (202) 994-3365

Email: AskHEATH@gwu.edu

Web site: <http://www.heath.gwu.edu/node/4>

The HEATH Resource Center is an online clearinghouse on postsecondary education for individuals with disabilities. It serves as an information exchange about educational support services, policies, procedures, adaptations and opportunities at American campuses, career technical schools and other postsecondary training entities.

INTERDISCIPLINARY HUMAN DEVELOPMENT INSTITUTE (IHDI or HDI)

University of Kentucky

126 Mineral Industries Building

Lexington, KY 40506-0051

Phone: (859) 257-1714 Voice/TTY

Fax: (859) 323-1901

Email: ihdi-www@lsv.uky.edu
Web site: <http://www.ihdi.uky.edu/default.asp>

Read the *DIRECTORY OF DIRECTORIES* section for a wide selection of resource information:

<http://www.ihdi.uky.edu/kydrm/>

The Interdisciplinary Human Development Institute, a University Center for Excellence in Developmental Disabilities Education, Research and Service, focuses its efforts on improving lifelong opportunities and services for individuals with disabilities, their families and the community.

The Institute provides a strong foundation for more than 30 research, training and service projects, addressing a wide range of topics and issues in areas such as early childhood, education, transition and community living and personnel preparation.

JUVENILE DIABETES RESEARCH FOUNDATION

Email: mkondratick@jdrf.org
Web site: www.jdrf.org/

Founded in 1970 by the parents of children with juvenile diabetes, it has provided more than one billion dollars to diabetes research worldwide. Its mission is constant: to find a cure for diabetes and its complications through the support of research. By registering on their web site, you will get legislative alerts and a newsletter.

KENTUCKY PARTNERSHIP FOR FAMILIES AND CHILDREN, INC. (KPFC)

207 Holmes Street, First Floor
Frankfort, KY 40601
Phone: (502) 875-1320
Toll Free: (800) 369-0533
Fax: (502) 875-1399
Email: kpfc@kypartnership.net
Web site: www.kypartnership.net

Kentucky Partnership for Families and Children (KPFC) has a thirty-one member board that consists of caregivers of children with emotional, behavioral and mental health challenges and agency affiliated professionals. Parent support group delegates act in an advisory capacity to KPFC's board of directors. These delegates are invited to attend "train the trainer" conferences twice a year at little or no cost, to their support group.

A fifteen member Youth Council acts in an advisory capacity to KPFC's board. The Youth Council is comprised of youth and young adults between the ages of fourteen and twenty-four with an emotional, behavioral, and/or mental health challenge. This Council has developed a presentation that includes skits and a question/answer panel.

A private, nonprofit organization, donations are tax-deductible. *KPFC provides scholarships for parents to attend conferences and workshops across the state.* It is supported by grants from the Substance Abuse and Mental Health Services Administration and the Kentucky Department of Mental Health and Mental Retardation as well as private and agency donations.

For information about specific disabilities, support groups and contact people in your area, call the toll free parent phone number.

KENTUCKY SPECIAL PARENT INVOLVEMENT NETWORK (KY SPIN)

**10301-B Deering Rd.
Louisville, KY 40272
Phone: (502) 937-6894
Fax: (502) 937-6464
Toll Free: (800) 525-7746
E-mail: spininc@kvspin.com
Web site: <http://www.kvspin.com/>**

KY SPIN is a statewide federally funded nonprofit organization that provides training, information and support to parents and families of children of all ages with all types of disabilities. Educators, doctors, therapists and other professionals also use SPIN resources. All staff of SPIN have family members with disabilities.

KENTUCKY YOUTH ADVOCATES (KYA)

**11001 Bluegrass Parkway, Ste. 100
Jeffersontown, KY 40299
Phone: (502) 895-8167
Toll Free: (888) 825-5592
E::mail: info@kyyouth.org
Web site: <http://www.kyyouth.org>**

Kentucky Youth Advocates is a non-profit children's advocacy organization that work on behalf of Kentucky's children with the state legislature, community and media to promote positive changes and policies that impact children. KYA provides research, timely publications on issues and collaborates with a variety of groups to craft policies that positively affect Kentucky's children, especially those who are poor and otherwise disadvantaged.

LAST PASSAGES

Web site: <http://www.albany.edu/aging/lastpassages/>

The purpose of the Last Passages project is to share information and promising practices to enhance end of life care for persons with developmental disabilities.

LEARNING DISABILITIES ASSOCIATION OF AMERICA (LDA)

**4156 Library Road
Pittsburgh, PA 15234
Phone: (412) 341-1515
Web site: <http://www.ldaamerica.org/>**

Since 1963, LDA has provided *support to people with learning disabilities*, their parents, teachers and other professionals. At the national, state and local levels, LDA provides *cutting edge information* on learning disabilities, *practical solutions*, and a *comprehensive network of resources*. These services make the Learning Disabilities Association of America the leading resource for information on learning disabilities.

LDA believes that every person with learning disabilities can be successful at school, at work, in relationships, and in the community -- given the right opportunities.

LEARNING DISABILITIES ASSOCIATION OF KENTUCKY

**2210 Goldsmith Lane, #118
Louisville, KY 40218
(502) 473-1256
Toll Free: (877) 587-1256
E:mail: LDAofKY@yahoo.com
Web site: www.ldaofky.org**

Learning Disabilities Association of Kentucky is a non-profit organization of individuals with learning differences and attention difficulties, their parents, educators, and other service providers. The goals of

LDA is to educate the public on learning disabilities, attention deficit disorder, dyslexia, etc; support parents of the individuals with learning differences through information sharing and support; make available to professionals information that will assist them as service providers; provide direct services that will assist those who learn differently become more productive, independent and self-motivated contributors to society.

NATIONAL ALLIANCE ON MENTAL ILLNESS

**Colonial Place Three
2107 Wilson Boulevard, Suite 300
Arlington, VA 22201-3042
Phone: (703) 524-7600
Fax: (703) 524-9094
Member Services – Toll Free: (888) 999-NAMI (6264)
Information Helpline – Toll Free: (800) 950-NAMI (6264)
Web Site: <http://www.nami.org/>**

NAMI (the National Alliance on Mental Illness) is the nation's largest grassroots mental health organization dedicated to improving the lives of persons living with serious mental illness and their families. Founded in 1979, NAMI has become the nation's voice on mental illness. A national organization with organizations in every state and in over 1100 local communities across the country who join together to meet the NAMI mission through advocacy, research, support, and education.

The NAMI mission is dedicated to the eradication of mental illnesses and to the improvement of the quality of life of all whose lives are affected by these diseases.

NATIONAL ALLIANCE ON MENTAL ILLNESS OF KENTUCKY

**10510 LaGrange Road
Louisville, KY 40223-1277
Phone: (502) 245-5284
Fax: (502) 245-6390**

NATIONAL DISSEMINATION CENTER FOR CHILDREN & YOUTH WITH DISABILITIES

(NICHCY)

**P.O. Box 1492
Washington, DC 20036-1492
Phone: (202) 884-8200 - Voice/TTY
Toll Free: (800) 695-0285
Fax: (202) 884-8441
Email: nichcy@aed.org
Web site: www.nichcy.org**

NICHCY serves the nation as a central source of information on: disabilities in infants, toddlers, children, and youth; IDEA, which is the law authorizing special education; No Child Left Behind (as it relates to children with disabilities), and research-based information on effective educational practices. Explore the web site. Visit: <http://www.nichcy.org/kids/index.htm> *designed for kids with disabilities*. Communicate in English or Spanish. Visit their Kentucky resource page: <http://www.nichcy.org/stateshe/ky.htm>

NATIONAL DOWN SYNDROME CONGRESS

**1370 Center Drive, Ste. 102
Atlanta, GA 30338
Toll Free: (800) 232-6372
E:mail: info@ndscenter.org
Web site: www.acds.org**

National Advocacy organization for Down Syndrome and to provide leadership in all areas of concern related to persons with Down Syndrome.

NATIONAL DOWN SYNDROME SOCIETY

666 Broadway
New York, NY 10012-2317
Toll Free: 9800) 221-4602
E:mail: info@ndss.org
Web site: www.ndss.org

Provides information and referral services to parents, professionals and others about Down Syndrome; referrals to local parent support groups.

Club NDSS, a Web site for people with Down Syndrome and other developmental disabilities.
<http://www.clubndss.org>

NATIONAL FRAGILE X SYNDROME FOUNDATION

P.O. Box 190488
San Francisco, CA 94119
Toll Free: (800) 688-8765
Fax: (925) 938-9315
Web site: www.FragileX.org

Organized since 1984, the mission of the National Fragile X Foundation is to unite the Fragile X community to enrich lives through educational and emotional support, promote public and professional awareness, and advance research toward improved treatments and a cure for Fragile X.

NATIONAL REHABILITATION INFORMATION CENTER

National Institute on Disability and Rehabilitation Research (NIDRR)
8455 Colesville Road. Suite 935
Silver Spring, MD 20910-3319
Phone: (301) 588-9284 Voice
Phone: (301) 495-5626 TTY
Toll Free: (800) 346-7824
Fax: (301) 587- 1967
Email: naric@capaccess.org
Web site: <http://www.naric.com/aboutus.cfm>

The National Institute on Disability and Rehabilitation Research is one of three components of the Office of Special Education and Rehabilitative Services (OSERS) at the U.S. Department of Education. NIDRR operates in concert with the Rehabilitation Services Administration (RSA) and the Office of Special Education Programs (OSEP).

It is the mission of NIDRR to generate, disseminate and promote new knowledge to improve the options available to people with disabilities. The ultimate goal is to allow these individuals to perform their regular activities in the community and to bolster society's ability to provide full opportunities and appropriate supports for its disabled citizens. Toward this end, NIDRR conducts comprehensive and coordinated programs of research and related activities to maximize the full inclusion, social integration, employment and independent living of individuals of all ages with disabilities. NIDRR's focus includes research in areas such as employment; health and function; technology for access and function; independent living and community integration; and other associated disability research areas.

NOAH - THE NATIONAL ORGANIZATION FOR ALBINISM AND HYPOPIGMENTATION

PO Box 959
East Hampstead NH 03826-0959
Phone: (603) 887-2310
Toll Free: (800) 473-2310
Fax: (800) 648-2310
E-mail: webmaster@albinism.org

Web site: www.albinism.org

The objectives of The National Organization for Albinism and Hypopigmentation are to provide information and support regarding albinism and related conditions, to promote public and professional education about these conditions, encourage research and funding that will lead to improved diagnosis and management of albinism, and to provide networking for those with special interests related to albinism such as minority groups and Hermansky-Pudlak. NOAH provides information and support for its members by sponsoring workshops and conferences on Albinism, publishing the Newsletter NOAH News twice annually, publishing information bulletins on topics specific to living with Albinism, providing a network of local chapters and contact people, and providing a web site that has information about Albinism and bulletin boards where people can share experiences.

**OPPORTUNITIES FOR FAMILY LEADERSHIP
DEPARTMENT FOR MENTAL HEALTH AND MENTAL RETARDATION SERVICES**

100 Fair Oaks Lane, 4th Floor

Frankfort KY 40621-0001

Phone: (502) 564-4527

Toll Free Parent Resource Line: (800) 374-9146

Fax: (502) 564-5478

Email: SusanA.Smith@ky.gov

Web site: <http://mhmr.ky.gov/mhsas/OFL.asp>

The Department for Mental Health and Mental Retardation Services within the Cabinet for Health and Family Services values the participation of families throughout the system of care. The goal is to ensure that the family voice is included in every stage of planning, implementation and evaluation of services for the special populations served. Whether it is brain injuries, mental illness, emotional disabilities or intellectual disabilities, the Department for Mental Health and Mental Retardation Services strives to ensure that every family member has the opportunity to offer his or her leadership in the system of care.

Opportunities for Family Leadership provide technical assistance and support to family members and providers. The family perspective is the driving force behind all consultation activities. The OFL resource directory provides information on local parent support groups, state and national organizations, websites, legislation, family resource centers and much more. The directory includes resources for all the special populations served by the Department for Mental Health and Mental Retardation Services. The Resource Directory is available at no charge and is also on their website.

Opportunities for Family Leadership offer a resource line for parents and caregivers. The resource line connects families with the OFL program, which is a first step for accessing education, resources and support. Call the toll free number for the Parent Resource Line.

OFL offers small grants to help support family/caregiver support groups. The grants can be utilized for the development of a support group or resource library or for ongoing support of the group. The grants may also be used to provide training for parents and professionals within the community. Funds from the grants can be used to offer training to parents on stress reduction or can assist a local community in bringing in a specialist in a particular disability. The support group decides on the topic and needs. The grants will only be awarded to family/caregiver support groups. Request for grant proposals are disseminated.

OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES (OSERS)

United States Department of Education

400 Maryland Avenue S.W.

Washington, DC 20202

Phone: (202) 245-7468 or (202) 205-5637 TDD

Fax: (202) 245-7636

Web site: www.ed.gov/about/offices/list/osers

OSERS is committed to improving results and outcomes for people with disabilities of all ages. In supporting President Bush's No Child Left Behind Agenda and the New Freedom Initiative, OSERS provides a wide array of support to parents and individuals, school districts and states in three main areas: special education, vocational rehabilitation and research.

PRADER WILLI-SYNDROME ASSOCIATION

5700 Midnight Pass Rd., Ste. 6
Sarasota, FL 34242
Toll Free: (800) 926-4797

Web site: www.pwsausa.org

The Prader-Willi Syndrome Association was formed in 1975 to provide a vehicle of communication for parents, professionals and other interested citizens.

THE PUZZLE OF AUTISM NATIONAL EDUCATION ASSOCIATION

Student Achievement
1201 16th Street, N.W.
Washington DC 20036-3290

Phone: (202) 822-7373

E-mail: gapsinfo@nea.org

Web site: www.nea.org/specialed/images/autismpuzzle.pdf

Many educators face the inherent challenges of educating students with Autism Spectrum Disorder (ASD) despite having had little experience with or training about ASD. Teachers need resources and information to assist them in working successfully with all of their students, including those with Autism Spectrum Disorder. *The information contained in this guide, available for free download, will benefit all education personnel who work with students with ASD.* A student with ASD presents a unique combination of strengths and challenges that influences their academic achievement and social integration. This guide is not an all-encompassing guide for the education of students with ASD; rather, it should be considered a brief summary of these students' strengths and deficits, the challenges these deficits create in the classroom, and strategies that education personnel can use to facilitate positive educational and social experiences for students with Autism Spectrum Disorder. This guide will provide educators with a general understanding of ASD, explain the characteristics exhibited by students with ASD, suggest evidence-based effective strategies for students with ASD, and identify resources for additional information on ASD.

RETT SYNDROME RESEARCH FOUNDATION (RSRF)

4600 Devitt Drive
Cincinnati, OH 45246
Phone: (513) 874-3020
Fax: (513) 874-2520

Web site: www.rsrf.org

Founded in 1999 by a small but passionate group of parents who were concerned about the absence of research on Rett Syndrome, the RSRF's vision was created. Its vision is a cure for Rett Syndrome. The mission is to fund, promote and accelerate biomedical research for the treatment and cure of Rett Syndrome. No one is more motivated to find treatments and a cure for Rett than parents whose children are suffering. With prominent researchers around the world now focusing on the disorder, leading scientists serving as Foundation advisors, and a strongly committed Board of Trustees and staff, RSRF is confident that its vision will be realized.

RUBENSTEIN-TAYBI SYNDROME **www. Rubinstein-taybi.org**

Site offers information on organizations, new parents, people, articles and more.

SIBLING SUPPORT PROJECT**6512 Third Avenue NW, #213****Seattle, WA 98117****Phone: (206) 297-6368****Fax: (509) 752-6789****Email: donmeyer@siblingsupport.org****Web Site: <http://www.siblingsupport.org>**

The Sibling Support Project is the only national effort dedicated to the interests of over six million brothers and sisters of people with special health, mental health, and developmental needs.

Based in Seattle since 1990, they have trained service providers in all 50 states, England, Ireland, New Zealand, and Japan on how to implement their award-winning Sibshop program for young brothers and sisters, resulting in over 200 replications in eight countries. They have also presented to over 400 audiences of parents and service providers in every state. They have also published curricula and children's books that assist agencies in starting Sibshops and let young sibs know that they are not alone with their unique joys and concerns.

SPINA BIFIDA ASSOCIATION OF AMERICA (SBA)**4590 MacArthur Boulevard, NW, Suite 250****Washington, DC 20007****Phone: (202) 944-3285****Toll Free: (800) 621-3141****Web site: www.sbaa.org**

The Spina Bifida Association (SBA) serves adults and children who live with the challenges of Spina Bifida. Since 1973, SBA has been the only national voluntary health agency solely dedicated to enhancing the lives of those with Spina Bifida and those whose lives are touched by this challenging birth defect. Its tools are education, advocacy, research, and service. Through its network of chapters SBA has a presence in more than 125 communities nationwide and touches thousands of people each year. Lives are changed by the programs SBA has created, the services the organization provides, and the accomplishments of its advocacy efforts.

SPINA BIFIDIA ASSOCIATION OF KENTUCKY**Kosair Charities Centre****982 Eastern Parkway****Louisville, KY 40217****Phone: (502) 637-7363****Toll Free: (866) 340-7225****Fax: (502) 637-1010****Web site: www.sbak.org**

The Spina Bifidia Association of Kentucky is a non-profit organization formed in 1982 to promote the prevention of spina bifida and enhance the lives of all affected.

TASH**1025 Vermont Avenue, Floor 7****Washington, DC 20005****Phone: (202) 263-5600****Fax: (202) 637-0138****Web site: <http://www.tash.org/index.html>**

TASH is an international membership association leading the way to inclusive communities through research, education and advocacy. TASH members are people with disabilities, family members, fellow citizens, advocates and professionals working together to create change and build capacity so that all people no matter their perceived level of disability are included in all aspects of society.

TASH has numerous chapters and thousands of members from thirty-four different countries and territories. Since inception over thirty years ago, TASH has gained international acclaim for their

uncompromising stand against separatism, stigmatization, abuse and neglect. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life.

NEW! TASH KENTUCKY CHAPTER

***6408 Watch Hill Road
Louisville, KY 40228-1354
Phone: (502) 239-4805
Fax: (502) 564-0848
Email: Leslie.Lederer@ky.gov***

TOURETTE SYNDROME ASSOCIATION

**42-40 Bell Blvd.
Bayside, N.Y. 11361
Phone: (718) 224-2999
Fax: (718) 279-9596
Web site: www.tsa-usa.org**

UNITED CEREBRAL PALSY ASSOCIATION

**1660 L Street, N.W., Suite 700
Washington, D.C. 20036
www.ucpa.org**

Their website offers information on research, advocacy, resources and discussion groups.

UNITED PARTNERS IN KENTUCKY –(UPinKY)

UP in KY consists of members committed to work together and share information and expertise in order to enhance and improve the quality of life of persons with disabilities and their families. This group works on behalf of children, youth and young adults with disabilities and their families so they can make informed decisions.

WebSite: www.up-in-ky.com

VIPS (Visually Impaired Preschool Services)

**1906 Goldsmith Lane
Louisville, KY 40218
Phone: (502) 636-3207
Fax: (502) 636-0024
Toll free: 1-888-636-8477
Email: info@vips.org
Web site: www.vips.org**

Contact them for their newsletter.

SECTION 2

**DIRECTORY
OF
DIRECTORIES**

DIRECTORY OF DIRECTORIES

“When my son was little I felt like I was the only parent who ever had to muddle through the system and it seemed like there should be a book so that every parent of a newly diagnosed special needs child didn't have to reinvent the wheel.”

Michelle Armstrong, Hebron

THE ARC OF KENTUCKY
706 East Main Street, Suite A
Frankfort, KY 40601
Phone: (502) 875-5225
Toll Free: (800) 281-1272
Fax: (502) 875-5226
Email: arcofky@aol.com
Web site: www.arcofky.org



The Arc of Kentucky has produced several handbooks – Kentucky General Assembly – Quick Resource Guide for Legislative Advocates and Hot Tips for Legislative Advocates. The Arc of Kentucky publishes Hot Stuff, an accounting of disability news of the month laced with advocacy opinion. Contact the Arc for your copies on line or in print. The Family to Family Resource Guide to Services and Opportunities for Kentuckians with Special Health Care Needs and Their Families and Visions, an outline for planning for the future are two new publications.

**FAMILY RESOURCE CENTER
CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER**
3333 Burnet Avenue
Cincinnati, OH 45229
Phone: (513) 636-7606
Email: specialneeds@cchmc.org
Web site: <http://www.cincinnatichildrens.org/svc/alpha/c/special-needs/resources/default.htm>

The Special Needs Resource Directory is designed to help you when faced with the constant challenge of finding information, resources and services. Created by the Center for Infants and Children with Special Needs, the Special Needs Resource Directory is designed to be a comprehensive reference for parents, caregivers and health care providers. You can quickly find local, regional and national web site links to get information on specific disabilities, identify strategies to help you advocate for your child and develop community connections for ongoing support. The Special Needs Resource Directory is a valuable tool in the coordination of medical and psychosocial care for children with specialized chronic health care needs. The Special Needs Resource Directory brings families and caregivers together with the information they need to build a medical home with integrated, family-centered supports.

INTERDISCIPLINARY HUMAN DEVELOPMENT INSTITUTE (IHDI or HDI)
University of Kentucky
126 Mineral Industries Building
Lexington, KY 40506-0051
Phone: (859) 257-1714
Fax: (859) 323-1901
Email: ihdi-www@lsv.uky.edu
Web site: <http://www.ihdi.uky.edu/default.asp>

Some examples:

Web site: www.transitiononestop.org

This web site has information regarding the many different transitions occurring in our lives from First Steps to adult. The booklet, Step by Step addresses transition to preschool. It is printed and on the web page.

Web site: http://www.ihdi.uky.edu/pubs/inclusive_education.htm

Inclusive Education deal with educating children with disabilities as part of the regular school curriculum.

Web site: www.ihdi.uky.edu/kvdrm

Resource Manual developed for people with disabilities, their families and service providers in Kentucky. It is printed and can be viewed on line.

Web site: www.ihdi.uky.edu/ktcp/

A booklet, Get a Life! Planning for the Transition from High School to Adult Life is available for free download from the website. This book includes information on what you NEED to know, what is NICE to know, where to get more information, a glossary of terms, “definitions” of acronyms and references. It is also available in print.

The Interdisciplinary Human Development Institute, a University Center for Excellence in Developmental Disabilities Education, Research and Service, focuses its efforts on improving lifelong opportunities and services for individuals with disabilities, their families and the community.

KENTUCKY ASSISTIVE TECHNOLOGY SERVICES (KATS)

KATS Network Coordinating Center - Charles McDowell Center

8412 Westport Road, Louisville, KY 40242

Phone: (502) 429-4484

Toll Free: (800) 327-KATS (5287)

TDD: (502) 429-7116

Fax: (502) 429-7114

Email: katsnet@iglou.com

Web site: <http://www.katsnet.org>

The KATS Network publishes a booklet entitled, The Buck Starts Here...A Guide to Assistive Technology Funding in Kentucky. The booklet is exactly what its title implies. It is a step by step guide to searching for funding to get assistive technology with tips on local, state and national sources of funding.

KENTUCKY COMMISSION ON DEAF AND HARD OF HEARING (KCDHH)

632 Versailles Road

Frankfort, KY 40601

Phone: (502) 573-2504

Toll Free: (800) 372-2907

Web site: <http://www.kcdhh.ky.gov/>

The Commission provides legislative advocacy on behalf of people who are deaf or hard of hearing. It also offers information and referral, advocacy and interpreter referral services. It also produces publications, maintains a resource library and manages a telecommunications access program for eligible Kentuckians.

THE KENTUCKY RESOURCE MARKET

Statewide - Toll Free: (877) 293-7447

Regional Pilot Project – Aging and Disability Resource Center in Northern Kentucky

21 Spiral Drive, Florence, KY, Phone: (859) 283-1885.

The one-stop shop is for aging and disability information, programs and services. A state-funded program provided through the Kentucky Department for Aging and Independent Living and the Department for Mental Health and Mental Retardation in partnership with regional Area Agencies on Aging and The Arc of Kentucky. The Kentucky Resource Market provides:

Information by phone about available local and statewide programs and services

Printed materials

Referrals to community resources to meet individual needs

Follow-up with clients and service providers to ensure prompt response and ongoing support.

PROTECTION AND ADVOCACY (P & A)
100 Fair Oaks Lane, 3rd Floor
Frankfort, KY 40601
Phone: (502) 564-2967
Toll free: (800) 372-2988
Fax: (502) 564-0848
E-mail: <http://www.kypa.net/contact/question.html>
Web site: www.kypa.net

Protection and Advocacy has numerous booklets and pamphlets which are available free by calling their office. A few titles are: Guardianship, How to Negotiate in Arc Meeting, Assistive Technology, Partners, Tips on IEPs, Kentucky Department of Education Formal Complaint, Kentucky Department of Education Mediation Book, Functional Behavior Assessment, 504 – The Other Service Option Parents and Students Need to Understand, Overview and Comparison of Individuals with Disabilities (Improvement) Education Act (IDEA), Section 504 and Americans with Disabilities Act (ADA), Tips on Transition and the Office of Civil Rights (OCR).

OFFICE OF VOCATIONAL REHABILITATION (VR)
209 St. Clair Street
Frankfort, KY 40601
Phone: (502) 564-4440 (Voice/TTY)
Toll Free: (800) 372-7172 (Voice/TTY)
Email: wfd.voc rehab@ky.gov
Web site: <http://ovr.ky.gov/>

Go on line to read two publications:

Transition: [Beyond High School](#) – A Transition Guide Book

Resource Manual: [The Rest of My Life: For Youth with Disabilities in Foster Care](#) was written for the child in foster care but can be used by any young person with disabilities who is looking at life after high school.

OPPORTUNITIES FOR FAMILY LEADERSHIP (OFL)
DEPARTMENT FOR MENTAL HEALTH AND MENTAL RETARDATION SERVICES
100 Fair Oaks Lane, 4th Floor
Frankfort KY 40621-0001
Phone: (502) 564-4527
Fax: (502) 564-5478
Toll Free Parent Resource Line: (800) 374-9146
Email: SusanA.Smith@ky.gov
Web site: <http://mhmr.ky.gov/mhsas/OFL.asp>

[Opportunities for Family Leadership](#) offers a resource line for parents and caregivers. The resource line connects families with the OFL program, which is a first step for accessing education, resources and support. Call the toll free number for the Parent Resource Line. Also, OFL Resource Directory in print contains names and contact information for Kentucky Family Liaisons in communities around the state as well as names and contacts of local, state and national organizations. *See the Support & Information section of this guide for additional resources to local support groups.*

PARENT RESOURCE CENTERS (PRCs)

Throughout Kentucky, some local school districts provide information and support to parents of exceptional children through locally funded and staffed Parent Resource Centers (PRCs). Contact your local Parent Resource Center for additional information on a wide range of special education related topics and support. Parent Resource Centers and the Kentucky Department of Education offer a Parent/Professional Conference, usually in the early part of the calendar year. *See the EARLY CHILDHOOD/SCHOOL AGE SERVICES section of this guide for locations.*

SECTION 3

**EARLY CHILDHOOD/
SCHOOL AGE
SERVICES**

EARLY CHILDHOOD/SCHOOL-AGED SERVICES

Christopher was our first child; his brother was born eleven months later. We saw that Christopher's development was slower than his brother. After a year of frustrating failure attempting toilet training, I talked to the pediatrician and she referred us to Weisskopf Center in Louisville. There we were told he had autism. I began my research at the public library; Christopher started therapy. I talked to the professionals involved with him and began to meet other parents. I attended the Family to Family meetings and now I am going to college majoring in Human Services. There have been big changes in my life and in the direction of my life!

Tonia Coffey, Edmonton

CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER

3333 Burnet Avenue

Cincinnati, OH 45229

Phone (main hospital): (513) 636-4200

Dentistry Department: (513) 636-4641

Physical and Occupational Therapy Department: (513) 636-4651

Speech Pathology Department: (513) 636-4341

Home Health Department: (513) 636-4663

Web site: <http://www.cincinnatichildrens.org/svc/topics/special-needs.htm>

Cincinnati Children's Hospital Medical Center's goal is to provide accessible, family-centered, continuous, comprehensive, coordinated, compassionate, culturally effective medical care for children with specialized health care needs. Centers for Developmental Disabilities and Special Needs include:

- * Aaron Perlman Center for Children
- * Attention Deficit Hyperactivity Disorder
- * Center for Infants and Children with Special Needs
- * Cerebral Palsy Clinic
- * Cincinnati Center for Developmental Disorders Board of Trustees
- * Developmental Assessment for Infants / Toddlers
- * Developmental and Behavioral Pediatrics
- * Kelly O'Leary Center for Autism Spectrum Disorders
- * Myelomeningocele Clinic
- * Parent Infant Nurturing Group (PING)
- * Project SEARCH
- * Rubinstein-Taybi Syndrome Program
- * Tourette Syndrome Clinic

EARLY PERIODIC SCREENING, DIAGNOSTIC, AND TREATMENT SERVICES (EPSDT)

Children's Health Services Branch - Dept. of Medicaid Services

275 East Main Street

Frankfort, KY 40601

Toll Free: (800) 635-2570

Fax: (800) 648-6056

Web site: <http://chfs.ky.gov/dms/epsdt.htm>

Eligibility Requirements: Children birth to age twenty-one who are eligible for Medicaid. This is not a Waiver program. EPSDT has two different programs: Screenings and Special Services. Children who are eligible for Kentucky Children's Health Insurance Program (KCHIP) may receive EPSDT screenings but are not eligible for Special Services.

The EPSDT *Screening* program provides routine physicals or well-child check ups for Medicaid eligible children at specified ages. It is considered *preventive care*.

EPSDT *Special Services* program allows coverage for items or services that are medically necessary and are not covered somewhere else in Medicaid. It is considered *treatment*.

To apply for EPSDT coverage, contact a service provider (doctor, home health agency, dentist, and equipment providers); ask the billing department if the Department of Medicaid Services approves that provider. The provider has applications – fill them out and return to the provider. For more information you can also contact your local health department.

EPSDT Screenings (check-ups) are available from your doctor or local health department and can include:

- Review of your child’s medical history and a physical exam
- Check of your child’s growth and development
- Check of your child’s vision and hearing
- Screening of your child for mental health and substance abuse problems
- Check of whether your child is eating healthy foods and information about good nutrition
- Giving you any health education information you may need
- Giving your child shots (immunizations)
- Referring your child for lab tests if needed
- Referring your child to a dentist around age 2 if needed

EPSDT Special Services, which are medically necessary but aren’t covered by the standard Kentucky Medicaid Program can include:

- Inpatient hospital care and psychiatric services
- Outpatient hospital services and rural health clinic services
- Physicians’ services
- Private duty nursing services and home health services
- Physical therapy, occupational therapy, or speech and language therapy
- Dental services, including surgery
- Services of other licensed medical practitioners
- Laboratory and x-ray services
- Family planning services and supplies
- Prescription drugs and eyeglasses
- Case management

All EPSDT special services require prior authorization from the provider.

FIRST STEPS POINT OF ENTRY (POE)

Toll Free: (800) 442-0087

Web site for First Steps: <http://chfs.ky.gov/dph/firstSteps/>

Eligibility Requirements: Children, birth to age 3, who have a developmental delay or a medical condition known to cause a developmental delay and their families are eligible.

Developmental delay means: based on evaluation, the child is not developing typically in one of five skill areas: cognition (the ability to know and understand), communication, physical, social and emotional, or self-help.

Automatic entry occurs when there is a diagnosis of a physical or mental condition which has a high probability of resulting in developmental delay, such as Down Syndrome.

First Steps is a Kentucky’s Early Intervention System (KEIS). Services are provided statewide and coordinated by the lead agency, the Cabinet for Health and Family Services in response to Public Law 99-457 (IDEA Part C). Services may be provided in the home, a center-based program or in clinical settings depending on the needs of the child and family and the availability of services in a given area.

Services provided are: evaluation/assessment, service coordination, certain non-routine health services, assistive technology, nutrition services, physical and occupational therapy, speech/communication services, vision and hearing services, developmental intervention. Early Intervention (EI) services are provided through multiple agencies and may involve multiple disciplines. Based on the child’s needs, services are

identified in the Individual Family Service Plan (IFSP).

Anyone, including a family member, who is concerned about an infant or toddler's development, may make a referral to First Steps by calling the statewide toll-free number listed above.

Referral will then be made to a team at the district Point of Entry Staff office who will initially assist a child and family in accessing needed services. Services are available to any child and family who meet developmental eligibility criteria, *regardless of income. A family's participation in First Steps services is always optional.*

Typically, there is significant improvement in development and learning in those children who participate in early intervention. A child with a delay or condition that is likely to cause delay should not go through the critical developmental years without help. Services and supports benefit families by reducing stress. Early intervention services often decrease the need for later costly special education programs by remediating problems early in the child's life.

POINT OF ENTRY CONTACTS (POE)

Contacts:

District and Counties

First Steps
1502 Westen Avenue, Suite 1
Bowling Green, KY 42104
Phone: (270) 746-9941
Toll Free: (800) 643-6233
Fax: (270) 746-0729

Barren River District: Allen, Barren, Butler, Edmondson
Hart, Logan, Metcalfe, Monroe, Simpson, Warren

First Steps
104 South Front Avenue
Prestonsburg, KY 41653
Phone: (606) 886-8572
Toll Free: (800) 230-6011
Fax: (606) 886-4434

Big Sandy District: Floyd, Johnson, Magoffin, Martin, Pike

First Steps
3161 Custer Drive, Suite 4
Lexington, KY 40517
Phone: (859) 271-9448
Toll Free: (800) 454-2764
Fax: (859) 272-6893

Bluegrass District: Anderson, Bourbon, Boyle, Clark, Estill,
Fayette, Franklin, Garrard, Harrison, Jessamine, Lincoln,
Madison, Mercer, Nicholas, Powell, Scott, Woodford

First Steps
731 Kenton Station Road
Maysville, KY 41056
Phone: (606) 759-5510
Toll Free: (800) 335-4249
Fax: (606) 759-5922

Buffalo Trace District: Bracken, Fleming, Lewis, Mason
Robertson

First Steps
American Greeting Road
P.O. Box 568
Corbin, KY 40702
Phone: (606) 523-0229
Toll Free: (800) 509-9559
Fax: (606) 528-9623

Cumberland Valley District: Bell, Clay, Harlan, Jackson,
Knox, Laurel, Rockcastle, Whitley

First Steps
5850 U.S. 60
Summit Plaza Box 11
Ashland, KY 41102
Phone: (606) 929-9155
Toll Free: (800) 650-1329
Fax: (606) 929-9833

First Steps
39 Cedar Creek Drive
P.O. Box 290
Owingsville, KY 40360
Phone: (606) 674-3204
Toll Free: (800) 942-4358
Fax: (606) 674-8390

First Steps
1600 Breckinridge Street
Owensboro, KY 42303
Phone: (270) 686-5982
Toll Free: (888) 686-1414
Fax: (270) 926-8677

First Steps
3717 Taylorsville Road
Phone: (502) 459-0225
Toll Free: (800) 442-0087
Fax: (502) 452-9079

First Steps
115 Rockwood Lane
Hazard, KY 41701
Phone: (606) 439-1325
Toll Free: (800) 328-1767
Fax: (606) 436-2467

Adanta/First Steps
259 Parkers Mill Road
Somerset, KY 42501
Toll Free: (800) 378-2821
Fax: (606) 676-0537

First Steps
108 New Glendale Road
P. O. Box 2609
Elizabethtown, KY 42701
Phone: (270) 737-5921
Toll Free: (800) 678-1879
Fax: (270) 765-7274

First Steps
2014 Eastern Avenue
Covington, KY 41014
Phone: (859) 815-1095
Toll Free: (888) 300-8866
Fax: (859) 815-1094

FIVCO District: Boyd, Carter, Elliott, Greenup,
Lawrence

Gateway District: Bath, Menifee, Montgomery, Morgan
Rowan

Green River District: Daviess, Hancock, Henderson
McLean, Ohio, Union, Webster

Kentuckiana: Bullitt, Henry, Jefferson, Oldham, Shelby,
Shelby, Spencer, Trimble

Kentucky River District: Breathitt, Knott, Lee, Leslie,
Letcher, Owsley, Perry, Wolfe

Lake Cumberland District: Adair, Casey, Clinton,
Cumberland, Green, McCreary, Pulaski, Russell,

Lincoln Trail District: Breckinridge, Grayson,
Hardin, Larue, Marion, Meade, Nelson, Washington

Northern Kentucky District: Boone, Campbell,
Carroll, Gallatin, Grant, Kenton, Owen, Pendleton

First Steps
735 North Drive
Hopkinsville, KY 42240
Phone: (270) 886-5186
Toll Free: (800) 609-0047
Fax: (270) 886-0393

Pennyrile District: Caldwell, Christian, Crittenden
Hopkins, Lyon, Muhlenberg, Todd, Trigg

First Steps
425 Broadway, Suite 203
Paducah, KY 42001
Phone: (270) 442-5831 or (270) 442-6223
Toll Free: (800) 648-6599
Fax: (270) 442-3268

Purchase District: Ballard, Carlisle, Calloway,
Fulton, Graves, Hickman, Livingston, Marshall,
McCracken

HEALTH ACCESS NURTURING DEVELOPMENT SERVICES (HANDS)

275 East Main Street
Frankfort, KY 40621
Phone: (502) 564-3756
Web site: <http://chfs.ky.gov/dph/ach/ecd/hands.htm>

Eligibility Requirements: First-time moms and/or dads residing in Kentucky

The Health Access Nurturing Development Services (HANDS) program is a voluntary home visitation program for new and expectant parents. Families begin by meeting with a HANDS Parent Visitor who will discuss any questions or concerns about pregnancy or a baby's first year. Based on the discussion, all families will receive information and learn about resources available in the community for new parents. Some families will receive further support through home visitation. Services can begin during pregnancy or anytime before a child is three months old. For more information, contact the local health department.

IMPACT

100 Fair Oaks Lane 4E-D
Frankfort, KY 40601
Phone: (502) 564-4456
Phone: (502) 564-5777 TTY
Fax: (502) 564-9010
Web site: <http://mhmr.ky.gov/mhsas/KY%20Impact.asp>

Eligibility Requirements: a Medicaid recipient under the age of 18 if he/she meets the following criteria:

- Must have a diagnosis of a psychiatric disorder. Diagnosis of chemical dependency, mental retardation or other brain disorder may be present, but cannot be the primary diagnosis.
- Must be severely limited in at least two of the following areas:
 - Self-care:** Providing for and protecting oneself in an age-appropriate manner.
 - Interpersonal relationships:** Building and keeping good relationships with adults and other children.
 - Family life:** Living in a non-abusive or non-negligent family environment.
 - Self-direction:** Using age-appropriate self-control and judgment.
 - Education:** Learning social and intellectual skills from teachers and other adults and remaining involved at school.
 - Risk:** Must have been disabled for at least one year or judged by a qualified mental health professional to be at high risk to continue the disabilities for one year or more without intervention.
 - Service coordination:** Must require service coordination and service planning from two or more agencies at the same time.
- ***Because far more children have severe emotional disabilities than IMPACT can serve, the following children receive priority:***

1. Children who are currently living outside their homes.
2. Children with a history of placements in a hospital or treatment facility.

IMPACT coordinates services between Kentucky's child serving systems: Social Services, Family Resources, Juvenile Justice, Medicaid and a parent representative. Since no two children are alike, the services coordinated by IMPACT are different for each child. Services also differ from community to community, depending on the resources available in each area.

In addition to the services offered by IMPACT's partner agencies, services coordinated by regional IMPACT teams may include the following:

School Support: Providing individual and group therapy in the school, while at the same time helping teachers, counselors and peers understand children with emotional disabilities.

In-Home Services: Helping families develop skills in their home to cope with everyday life.

Respite: Giving families a few hours to meet some of their personal needs while their child is being cared for by a trained professional.

Therapeutic Foster Care: Meeting children's therapeutic needs through trained foster parents.

IMPACT PLUS

100 Fair Oaks Lane 4W-D

Frankfort, KY 40601

Phone: (502) 564-4797

Phone: (502) 564-5777 TTY

Fax: (502) 564-4826

Web site: <http://www.mhmr.ky.gov/mhsas/IMPACT%20Plus.asp?sub5/sub68>

Eligibility Requirements: a Medicaid recipient under the age of 21 if he/she meets the following criteria:

- In the custody or under the supervision of the state; or at risk of being in the custody of the state,
- Are at risk of institutionalization.
- Have been diagnosed with a severe emotional disorder (DSM Axis I) other than dementia or substance abuse; must be able to document a severe behavioral health problem related to the diagnosis during the past six months.
- Have been determined by a behavioral health professional to be at risk of continuing for six months.
- Require a coordinated and intensive plan of medically necessary community-based behavioral health service; services are reasonably expected to improve the child's condition or prevent further regression, so that the child is discharged to a less intense service or program in a six-month time frame.
- One of the following must also be true:
 1. A less intensive service will not meet the child's needs
 2. An appropriate and less intensive service is not available or accessible
 3. An appropriate and less intensive service is available and accessible, but a severe concurrent diagnosis complicates the treatment of the primary diagnosis.

IMPACT Plus is a collaborative effort of the Departments for Medicaid Services, Community Based Services and Mental Health and Mental Retardation Services. This program is designed to help provide community-based services for Kentucky's Medicaid/KCHIP eligible children with complex treatment needs. Parent involvement is the cornerstone of the IMPACT Plus Program. The goal is for parents and caregivers to be able to understand both their child's needs and the systems involved,

A BRIEF DESCRIPTION OF IMPACT PLUS SERVICES:

After School or Summer Program Service. A structured program of rehabilitative and therapeutic activities that focuses on the development of appropriate behaviors and social skills and includes individual and group therapy, behavior management and social skills training, independent living skills training and scheduled activities to promote parent or caregiver involvement.

Behavioral Health Evaluation. A face-to-face evaluation that answers specific clinical questions not usually addressed in a routine clinical interview, psychosocial assessment or behavioral

checklist. This evaluation should result in a diagnosis with specific treatment recommendations.

Collateral Services. This service should be focused on the goals and objectives found in the recipient's collaborative service plan or as part of a service planning process.

Crisis Stabilization Service. A therapeutic environment that has an organized, intensive program that provides for the comprehensive assessment, diagnosis and treatment of complex behavioral health needs.

Day Treatment Service. An organized, behavioral health program of treatment and rehabilitative services that also include educational services linked through an agreement with the local education authority. This service should include individual and group therapy, behavior management and social skills training, independent living skills training, scheduled activities to promote parent or caregiver involvement and to empower the family to meet the eligible recipient's needs and services designed to link with community resources before discharge.

Group Therapy. Provided face-to-face in a group setting NOT to exceed eight individuals. The treatment and interventions should be focused on the goals and objectives found in the collaborative service plan.

Individual Therapy. Provided face to face with a recipient, the treatment and interventions should be focused on the goals and objectives found in the collaborative service plan.

Intensive Out-Patient Behavioral Health Service. A structured behavioral health program of individual and group therapy activities provided at least three times a week for a minimum of two hours daily under the supervision of a behavioral health professional or under clinical supervision.

Parent-to-Parent Service. A service provided face-to-face to an eligible recipient's parent, guardian or caregiver. This service shall assist in advocating on behalf of the recipient, provide information regarding the nature, purpose and benefits of all IMPACT Plus services, provide therapeutic intervention and support, assist in understanding how to implement a behavior management plan at home, and provide overall support and education to a parent or guardian to ensure the parent or guardian is well equipped to support the recipient once services are transitioned and discharge from IMPACT Plus occurs. This service can be provided by a parent of a child who has a behavioral health disorder. The parent providing this service must be supervised by a behavioral health professional or behavioral health professional under clinical supervision.

Partial Hospitalization Service. A therapeutic environment with an organized, intensive program that provides for comprehensive assessment, diagnosis and treatment of complex behavioral health needs. It should be offered less than 24 hours daily, five to seven days per week. It can be provided by a hospital or community mental health center with daily oversight by a psychiatrist.

Targeted Case Management. Assistance in accessing needed medical, social, educational and other support services.

Therapeutic Child Support Service (TCS): Assistance in understanding, treating, identifying or coping with the recipient's behavioral health disorder. This service can take on many roles and functions, such as monitoring a recipient's progress toward transition, assisting with the development of skills, training in behavior management skills, providing in-home support, training a parent or guardian, and mentoring of the recipient.

Therapeutic Group Residential Service: A therapeutic environment in a group residential facility with 24-hour direct supervision that includes individual and group therapy, behavior management and social skills training, scheduled activities to promote family involvement, independent living skills training, after-school and summer programming, and services designed to explore and link with community resources before discharge and to assist the recipient and family with transition to community-based services. An eligible recipient may access the therapeutic group residential service only when being discharged from a psychiatric hospital or crisis stabilization service.

Treatment Foster Care Service. A therapeutic environment that includes twenty-four hour supervision and treatment in a family home by a therapeutic foster parent. A therapeutic foster parent must be employed by or contracted and supervised by a licensed child-placing agency and must have completed the required training to be a therapeutic foster parent. An eligible recipient may access the therapeutic foster care service only when being discharged from a psychiatric hospital or crisis stabilization service.

KENTUCKY AUTISM TRAINING CENTER

911 South Brook Street

Louisville KY 40203

Phone: (502) 852-4631

Toll Free: (800) 334-8635

Fax: (502) 852-7148

E-mail: KATC@louisville.edu

Web site: www.KYAUTISM.com

Kentucky Autism Training Center (KATC) places emphasis on providing information and training on intervention strategies that are supported by research as being effective with individuals with autism spectrum disorders. As new needs are identified, the KATC will strive to meet those needs through collaboration and partnerships. In addition, the Center places emphasis on building performance-based program evaluation efforts at all levels of operation.

While the Kentucky Autism Training Center (KATC) does not provide direct clinical assessment or intervention services, all activities are designed to have a direct impact on the individual. In addition, KATC staff members work with other agencies to assist them in conducting assessments and providing direct intervention services to individuals.

KENTUCKY COMMISSION ON DEAF AND HARD OF HEARING (KCDHH)

632 Versailles Road

Frankfort, KY 40601

Phone: (502) 573-2504

Toll Free: (800) 372-2907

Web site: <http://www.kcdhh.ky.gov/>

The Commission provides legislative advocacy on behalf of people who are deaf or hard of hearing. It also offers information and referral, advocacy and interpreter referral services. It also produces publications, maintains a resource library and manages a telecommunications access program for eligible Kentuckians.

KENTUCKY CHILDREN'S HOSPITAL - UK HEALTH CARE

800 Rose Street

Lexington, KY 40536-0293

Phone: (859) 327-5000

Web site: <http://www.ukhealthcare.uky.edu/services/index.htm>

Developmental and Behavioral Pediatrics Clinic Location:

Second Floor, Wing D

740 South Limestone Street

University of Kentucky

Lexington, KY 40536

Patient Appointments – Tuesday, Thursday & Friday – 8:00 a.m. until 4:30 p.m.

Phone: (859) 323-0211

Fax: (859) 257-7706

In addition to an extensive range of pediatric service areas, Kentucky Children's Hospital offers Developmental and Behavioral Pediatrics. Growing up is one of the hardest jobs we will ever have. And it

is even harder if your brain isn't developing at the same speed as your friends and classmates - or, if your brain just works a little differently.

If you or your doctor suspects your child has a behavioral or developmental problem, the hospital has a team of child psychiatrists, psychologists and nurse practitioners who can be brought in to diagnose and treat the problem with state of the art techniques and testing. The team conducts a weekly clinic to assess children with delays in cognitive, motor and language development. Every child is thoroughly evaluated before a comprehensive treatment plan is developed. Treatment can involve medication, psychotherapy, family therapy and/or direction for educational treatments within the child's school.

Some of the behavioral and psychological problems treated are: Neurodevelopmental disorders, Autistic spectrum disorders, Behavioral and school difficulties, Enuresis and encopresis, Attention Deficit/Hyperactivity Disorder (ADHD), Feeding disorders, Learning disabilities, Tourette syndrome, Obsessive-compulsive disorder, Emotional problems associated with a medical condition.

KOSAIR CHILDREN'S HOSPITAL – NORTON HEALTH CARE

231 East Chestnut Street

Louisville, KY 40202

Phone: (502) 629-6000

Information or Appointments: (502) 629-7700

Web site: www.nortonhealthcare.co/specialties/pediatric/facilities/index.aspx

Kosair Children's Hospital is Kentucky's only free-standing, full service tertiary care facility dedicated exclusively to kids. It serves as the primary pediatric teaching facility for the nearby University of Louisville School of Medicine. Most clinics are located in the outpatient area of the hospital and referrals are available. Several clinics, such as cardiology, also offer outreach services and are regularly scheduled throughout the state.

Designed to be child friendly, Kosair Children's Hospital has red wagons for patient transportation and play rooms on most floors. From an extensive video and book library to day beds for parents in most rooms, the goal is to make children and their families feel comfortable.

Pediatric clinics include: Allergy, Bone Marrow Transplantation, Cystic Fibrosis, Dental, Dermatology, Ear, Nose and Throat, Genito-Urinary, Gynecological, Hematology/Oncology, Neurology, Orthopedic, Preventive Cardiology, Sleep Medicine and Surgical.

WEISSKOPF CHILD EVALUATION CENTER (WCEC)

571- South Floyd Street, Suite 100

Louisville, KY 40202

Phone: (502) 852-5331

Fax: (502) 852-7679

The Weisskopf Child Evaluation Center (WCEC) in the Department of Pediatrics at the University of Louisville is a unique tertiary center that provides center-based and outreach diagnostic evaluations and treatment to infants and children with, or at risk for, developmental disabilities, congenital anomalies, genetic disorders, autism, organic behavior disorders (ADHD) and learning disabilities as well as genetic counseling to adults.

State of the art treatment programs serve children and adolescents with autism and infants and children with feeding disorders. Comprehensive care of children with inborn errors of metabolism is provided through medical and dietary management and enzyme infusion.

SYSTEMATIC TREATMENT OF AUTISM AND RELATED DISORDERS (STAR)

Weisskopf Child Evaluation Center (WCEC)

University of Louisville

571 South Floyd Street

Louisville, KY 40202

Phone: (502) 852-3797

Fax: (502) 852-7679

Email: starhelp@louisville.edu

Web site: <http://www.starautism.louisville.edu/index.htm>

STAR is an intervention program specifically for children with autism spectrum disorders (ASDs) and their families. A program within the Weisskopf Child Evaluation Center, a division of the University of Louisville, School of Medicine, Department of Pediatrics. The primary goals of STAR are to: empower families by sharing knowledge and enhancing skills; provide a range of clinical services based on best practices; conduct individualized treatment evaluations using a collaborative approach to intervention planning called COMPASS; and to conduct research.

The philosophy is: Success results from collaborative planning and implementation of individualized therapeutic plans that meet the specific needs of individuals with autism and related disorders. This approach emphasizes engagement and learning that can be carried over to home, community, educational or other settings

SHRINERS HOSPITALS FOR CHILDREN – LEXINGTON

1900 Richmond Road

Lexington, KY 40502

Phone: (859) 266-2101

Toll Free: (800) 668-4634

Web site: <http://www.shriners.com/Hospitals/Lexington/>

An interdisciplinary approach is used in patient care programs to ensure comprehensive care for each patient. The staff includes orthopedists and pediatricians, as well as other medical specialists.

The Lexington hospital is equipped and staffed to provide care for virtually all pediatric, orthopedic problems, except acute trauma. Included are: Cerebral Palsy, Clubfoot and other foot disorders, Hand and Upper Extremity disorders, Hip disorders, Leg length discrepancies, Limb Deficiencies and amputations, Metabolic bone disease, Osteogenesis Imperfecta (OI), Scoliosis and other spinal deformities, Juvenile Rheumatoid Arthritis (JRA) and other rheumatic disorders, Walking disorders, Orthopedic conditions associated with: Neuromuscular disorders, Spina Bifida/Myelodysplasia and Congenital and Developmental Disorders. Although the hospital does not provide acute care for injuries, those children who have experienced orthopaedic trauma and help dealing with long term results of such injuries are treated.

EDUCATION

"My son, Darrell, was the first student with multiple handicaps who ever attended our local high school. He was fully included in all his classes. He was much happier than when he spent part of his day in a self contained classroom. Everyone noticed the change. Even administrators who did not initially agree with his attending the high school and being fully included with nondisabled peers commented on how successful he was in his new environment. Darrell thrived on the interactions with his peers. He made life long friends. He continues to be a part of his local community, where he is known by many."

Denise Keene, Sadieville

All children living in the United States who have disabilities, age three to twenty-one, have the *right to a free, appropriate, public education (FAPE)*. Some children with disabilities *will qualify* for special education services provided under several different laws – Individuals with Disabilities Education (Improvement) Act (IDEA), Section 504 of the Rehabilitation Act and/or the Americans with Disabilities Act (ADA).

IDEA FOR KIDS

"Congress finds the following: Disability is a natural part of the human experience and in no way diminishes the right of the individuals to participate in or contribute to society." IDEA

With the passage of IDEA, Congress made its intent clear...”Improving educational results for children with disabilities is an essential element of our national policy of ensuring:

- Equality of opportunity
- Full participation
- Independent living
- Economic self-sufficiency”

“.....and to ensure that such children benefit from such efforts and that special education can become a *service for such children rather than a place where such children are sent.....*”

Right – legal right. Special education laws are civil rights laws. There have been many efforts to open public education to children with disabilities. Landmark decisions: Section 504 of the Rehabilitation Act of 1973, the Pennsylvania Assn. for Retarded Children Vs the Commonwealth of Pennsylvania, in 1971 for discrimination in not educating children with disabilities and the Americans with Disabilities Act in 1990 are just a few.

What does **Free Appropriate Public Education – FAPE** mean? Taking it word by word:

Free – at no cost (still pay the same fees typical children pay when attending school)

Appropriate – “*Like many statutory definitions, this one tends toward the cryptic rather than the comprehensive.*” Supreme Court in Hendrick Hudson Central School District Vs Amy Rowley

FAPE emphasizes: specifically designed instruction and related services designed to meet the child’s unique needs & prepare him/her for further education, employment and independent living.

The Admissions & Release Committee (ARC) often referred to as the IEP team has the job of developing F *Appropriate* P E. - FAPE

Members of the ARC include: parents (or person legally responsible for making educational decisions) regular education teacher, special education teacher, someone from the school district, i.e. principal, who is qualified to provide or supervise the provision of specially designed instruction, knows the general curriculum and resources of the district and others who may be therapists, consultants, etc.

ARC members are “equal” in the decision making process. “Separation” occurs if the parent and school disagree.

Public - At public expense, under public supervision & direction, meets standards of State Educational agency, has appropriate elementary, secondary school education and conforms to the Individual Education Program (IEP).

Education - Having high expectations, ensuring access to general education in the regular classroom to the maxim extent possible, strengthen role & responsibilities of parents, coordinate with improvements in education, provide appropriate special education & related services, aids and supports in regular classroom whenever. appropriate, support high quality professional development and the development and use of technology.

Under IDEA: The child, age 3 through 8, may be found eligible if s/he experiences developmental delays in one or more areas of physical, cognitive, communication, social or emotional, adaptive development. By age nine, the child must be determined eligible for one of the thirteen categories of disabilities named in IDEA. They are: autism, specific learning disability, speech or language impairments, emotional disturbance, traumatic brain injury, visual impairment, hearing impairment, deafness, mental retardation,

deaf- blindness, multiple disabilities, orthopedic impairment and other health impairments which meets *specific criteria developed by each state.*

AND

The ARC determines eligibility and then identifies or confirms the “adverse effect” defined as “Progress of the child is impeded by the disability to the extent that the educational performance is significantly & consistently below the level of similar age peers”.

Following a *prescribed process*, the ARC develops an Individual Education Program (IEP).

Simply stated, “Ideally, the IEP is a system for spelling out where the child is, where he should be going, how he will get there, how long it will take, and how to tell when he has arrived.” Bierly, 1978

Under 504: There is an existence of an identified physical or mental condition which substantially limits major life activities which include: walking, seeing, hearing, speaking, breathing, *learning*, working and caring for oneself. Under 504, “appropriate” means an education comparable to the education provided to those students who are not disabled. It is generally provided in the regular classroom.

Both emphasize “least restrictive environment” meaning children with disabilities are to be educated to the maximum extent with children who do not have disabilities.

PARENT RESOURCE CENTERS (PRCs)

Throughout Kentucky, some local school districts provide information and support to parents of “exceptional children” through locally funded and staffed Parent Resource Centers (PRCs). Contact your local Parent Resource Center for additional information on a wide range of special education related topics and support.

Berea Regional Technology Center & Parent Resource Center

116 Jane Street
Berea, KY 40403
Phone: (859) 986-1929

Fayette County Special Education Parent Resource Center

302 Annex Building
701 East Main Street
Lexington, KY 40502
Phone: (859) 381-4229

Franklin County Parent Resource Center

Bondurant M.S., Bondurant Drive
Frankfort, KY 40601
Phone: (502) 875-8440

Hopkins County Parent Resource Center

110 Sugg Street
Madisonville, KY 42431
Phone: (270) 825-1981

Jefferson County Parent Resource Center

P.O. Box 34020
Van Hoose Education Center 4th
Louisville, KY 40232-4020
Phone: (502) 485-3562 or (502) 485-3346

Jessamine County Parent Resource Center

West Jessamine High School
2101 Wilmore Road
Nicholasville, KY 40356
Phone: (859) 887-2421 Ext. 128

Kentucky School for the Blind Parent Resource Center

1867 Frankfort Avenue
Louisville, KY 40206
Phone: (502) 897-1583 Ext. 273

Kentucky School for the Deaf Parent Resource Center

P.O. Box 27, S. Second Street
Danville, KY 40423
Phone: (859) 239-7017 Ext. 2200

Kentucky Valley Educational Cooperative Parent Resource Center

325 Broadway Street
Hazard, KY 41701
Phone: (606) 439-2311 Ext. 24

Magoffin County Parent Resource Center

P.O. Box 109, Gardner Trail
Salyersville, KY 41465
Phone: (606) 349-4200

McCracken County Parent Resource Center
435 Berger Road
Paducah, KY 42003
Phone: (270) 538-4000

Simpson County Parent Resource Center
P.O. Box 467
Franklin, KY 42701
Phone: (270) 586-2008

Upper Cumberland Cooperative Parent Resource Center
116 North 4th Street
Williamsburg, KY 40769
Phone: (606) 549-7001, Ext. 2911 or 2907

If your area does not have a Parent Resource Center, contact Exceptional Children's Services, 500 Mero Street, 8th Floor CPT, Frankfort, Kentucky 40601. Phone: (502) 564-4970.

KENTUCKY EARLY CHILDHOOD TRANSITION PROJECT
Interdisciplinary Human Development Institute (HDI)
University of Kentucky, Lexington, KY 40506-0051
Phone: (859) 257-1267
Web site: <http://www.transitiononestop.org>

Kentucky Early Childhood Transition Project was jointly funded by the Kentucky Department of Education and the Cabinet for Health and Family Services through federal funds under IDEA, Preschool and Infant/Toddler. The "[Step by Step, A Family Guide for Transition into Preschool](#)" is available on line and in print. Spanish and Braille editions are also available.

TRANSITION STARTING AT AGE FOURTEEN AND WRITTEN IN THE INDIVIDUAL EDUCATION PROGRAM (IEP) BY AGE SIXTEEN

"We want our son to have the opportunity to try different jobs so he and we have confidence that he will enjoy his vocation. The ideal would be to use these last few years of school to build his future – putting in place all of the pieces, so he has a life with full participation in the community, doing things that he has chosen - built around his likes and strengths."

Gail Lowe, Louisville

What does IDEA say?

U.S. Department of Education – Office of Special Education and Rehabilitation Services (OSEP)
<http://idea.ed.gov/explore/view/p/%2Croot%2Cdynamic%2CTopicalBrief%2C17%2C>

The purposes of IDEA include ensuring that all children with disabilities have available to them a free appropriate public education (FAPE) that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment and independent living. [34 CFR 300.1(a)] [20 U.S.C. 1400(d) (1) (A)]

The term "transition services" means a coordinated set of activities for a child with a disability that:

- *Are designed to be within a results-oriented process focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to postsecondary education, vocational education, integrated employment (including supported employment); continuing and adult education, adult services, independent living or community participation.*
- *Are based on the individual child's needs, taking into account the child's strengths, preferences and interests: and*

- *Includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, if appropriate, acquisition of daily living skills and functional vocational evaluation.*

Throughout Kentucky there are Education Cooperatives to assist with Transition planning.

Originally, Education Cooperatives were formed by district superintendents to cooperate in their efforts to provide special education services to children in their districts. Today, they have increased their cooperative efforts to provide assistance and expertise for the benefit of their *member school districts*. Contact the Transition Consultant. The list follows. *Go to the web site <http://www.kde.state.ky.us/KDE/> Use "Search" to find Educational Cooperatives – Click on the individual Educational Cooperative for more information about them.*

Big East Educational Cooperative

904 West Rose Road, Ashland 41102
Phone: (606) 928-0205
Fax: (606) 928-3785

Caveland Educational Support Center

1790 Normal Drive, Bowling Green 42101
Phone: (270) 745-3535
Fax: (270) 745-6892

Central Kentucky Special Education Cooperative

University of Kentucky, 43 Dickey Hall
Lexington 40506-0017
Phone: (859) 257-4314
Fax: (859) 323-1166

Green River Regional Educational Cooperative

1906 College Heights Blvd., #21031
Western Kentucky University
Bowling Green 42101-1031
Phone: (270) 745-2451
Fax: (270) 745-5199

Jefferson County Exceptional Child Education Services

P.O. Box 3402, Louisville 40232-4020
Phone: (502) 485-8500
Fax: (502) 485-3776

Kentucky Educational Development Corporation

904 West Rose Road, Ashland 41102-7104
Phone: (606) 928-0205
Fax: (606) 928-3785

Kentucky Valley Educational Cooperative

Hazard Community College
1 Community College Drive, Hazard 41701
Phone: (606) 439-1119
Fax: (606) 439-1322

Northern Kentucky Cooperative for Educational Services

5516 East Alexandria Pike, Cold Springs 41076
Phone: (859) 442-8600
Fax: (859) 442-7015

Ohio Valley Educational Cooperative

P.O. Box 1249, Shelbyville 40066
Phone: (502) 647-3533
Fax: (502) 647-3581

River Region Cooperative

1300 Booth Avenue, Owensboro 42301
Phone: (270) 686-3923
Fax: (270) 686-3017

Southeast/South Central Educational Cooperative

417 Bert Combs Bldg., Richmond 40475
Phone: (859) 622-2581
Fax: (859) 622-6526

Upper Cumberland Special Education Cooperative

116 N. Fourth Street, Williamsburg 40769
Phone: (606) 549-7001, Ext. 2907
Fax: (606) 539-9094

West Kentucky Special Education Cooperative

Murray State University, 420 Wells Hall
Murray 42071-3340
Phone: (270) 809-3962
Fax: (270) 809-2485

Wilderness Trail Educational Cooperative

707 North Second Street, Richmond 40475
Phone: (859) 624-4580
Fax: (859) 624-4529

TRANSITION PLANS

HUMAN DEVELOPMENT INSTITUTE, UNIVERSITY OF KENTUCKY (HDI)

Coldstream Research Campus
1517 Bull Lea Road, #110

Lexington KY 40511
Phone: (859) 519-7375
Fax: (859) 257-4459
E-mail: B.Harrison@uky.edu
Web site: www.ihdi.uky.edu/ktcp/

Successful transition from high school to community for Kentucky youth has been a focus of the Human Development Institute (HDI) at the University of Kentucky since the early 1980s. From model demonstrations, to systems change, and to state improvement grants, the HDI has partnered with colleagues across the state to improve post-school outcomes for Kentucky youth. The current Kentucky Transition Signal project is funded through the Kentucky Department of Education (KDE) Division of Exceptional Children (DECS) State Improvement Grant. Transition Signal project's mission is to facilitate the KDE/DECS goals of decreasing the drop rate for students with disabilities, increasing the rate of graduation with a standard diploma, assuring that post-school goals are addressed with student Individual Education Programs (IEP), and increasing the percentage of students with Individual Education Programs (IEP) who are working and/or continuing their education one year after high school exit.

A booklet "Get A Life! Planning for the Transition from High School to Adult Life" is available for free download at the website. This book includes information on what you NEED to know, what is NICE to know, where to get more information, a glossary of terms, "definitions" of acronyms and references.

FOR MORE INFORMATION, see the LEGAL/ADAVOCACY Section. Find out more:

The Kentucky Department of Education, Exceptional Children Services web site:
<http://www.education.ky.gov/KDE/Instructional+Resource/Student+and+Family+Support/Exceptional+Student/default.htm>

Kentucky Administrative Regulations for Special Education Services under IDEA.
Web site: <http://www.lrc.state.ky.us/kar/title707.htm>

U. S. Department of Education – Office for Special Education and Rehabilitation Services (OSERS)
Web site: <http://www.ed.gov/policy/speced/guid/idea/idea2004.html>

The Wrightslaw site is probably the most recognized legal/advocacy web site for parents of children with disabilities. Web site: <http://www.wrightslaw.com/>

The National Assn. of Special Education Teachers (NASSET). Some sites cannot be visited unless you are a member. It gives an overview of landmark legislation related to special education.

Web site: <http://www.naset.org/landmarkcases.0.html>

Human Development Institute, University of Kentucky (IHDI or HDI). Inclusive Education materials deal with educating children with disabilities as part of the regular school curriculum

Web site: http://www.ihdi.uky.edu/pubs/inclusive_education.htm

SECTION 4

EDUCATION AFTER HIGH SCHOOL/ HABILITATION/ VOCATIONAL

EDUCATION AFTER HIGH SCHOOL/ HABILITATION/ VOCATIONAL PROGRAMS

***“God helps those who help themselves. But, the System helps those who know the system!”
The name of the person who said this first is unknown; those who say it now are legion in number.***

When students leave school, they may enter the work world or choose to continue their education. Some may marry and work at home. The typical graduate is not guaranteed a job. The same is true for the person leaving special education. The laws that mandate education for the individual with a disability no longer apply. There is no “legal right” to employment, continued education or habilitation. The Americans with Disabilities Act (ADA) gives people the “right” to opportunity with reasonable accommodation.

There are agencies located within the community, which assist people with disabilities in obtaining employment, education or habilitation. Keep in mind; many of these agencies have long waiting lists.

Typically, because of funding sources, there is no fee for daily programming; however, some agencies do charge fees for specific services. It is wise to check with each agency and discuss their criteria for entrance and fee scales, if any, program goals and activities as well as any other information you may need.

There are several different kinds of adult day programs. Programs are designed to serve people who have different levels of skill and independence. The following is a broad description of the different types of adult employment-habilitation programs. There are differences in how each agency provides these services.

The purpose of Adult Day Care or Adult Health Care is to continue training in basic skills, i.e., grooming, hygiene, communication, socialization, and community instruction. It does not have a focus of work. People served are adults who require more intensive training and greater supervision in these skill areas.

Adult Day Training (formerly Work Activity or Sheltered Employment) is to provide training in work habits and skills. Work is subcontracted from industries. Job crews may be formed to go to the industrial site to perform the work. There may also be continued instruction in functional academics and community life skills.

With Supported Employment or Job Coach Programs, the agency obtains a potential job, places the person on the job and provides training until the new employee can successfully perform the job independently; Follow-up may be provided and varies with each agency.

EDUCATION

ALL COLLEGES AND UNIVERSITIES are required to be accessible. Contact the Services Coordinator at the College/University who works with students with disabilities to discuss the accommodations and modifications you may require. Vocational Rehabilitation can be very helpful in helping make that connection.

Section 504 of the Rehabilitation Act and the Americans with Disabilities Act (ADA) define disability. A condition that substantially limits a major life activity (such as walking, talking, learning, hearing, and/or seeing) and is covered under the 504/ADA makes a student eligible for services.

In order to be protected under Section 504 and ADA the students with disabilities must make the disability known to the Disabled Student Support Services and provide current and comprehensive documentation concerning the nature and extent of the disability. Students with disabilities may make known their disability and seek verification for it at any point in their academic career. Once the disability is verified, Disabled Student Support Services will work with the instructor and the student to determine reasonable accommodations. Accommodations necessary for ensuring complete access and full participation in the

education process do not require the instructor to adjust evaluations of academic performance nor absolve the student from personal responsibility for class attendance, assignments and all other course material.

Some examples of accommodations are: texts in alternative format, American Sign Language (ASL) interpretation, assistive listening devices, note takers, tape recording lectures, extended time on written evaluations, written evaluations in a distraction-reduced area, voice-activated software, screen-reading software, ergonomic furniture, preferential seating and relaxation of class attendance policy for medical conditions. Note - college students do not have an Individual Education Program (IEP).

GED OPPORTUNITIES

Tests of General Educational Development - the GED test is a national examination developed by the GED Testing Service of the American Council on Education.

KENTUCKY ADULT EDUCATION

Phone: (502) 573-5114 Voice/TTY

Toll Free: (800) 928-7323 Voice/TTY

Fax: (502) 573-5436

Web site: www.kyvae.org/learner/gettingstarted/local_center KYAE.asp

Visit this web site for Centers located throughout *Kentucky*

Disabilities Services: The Commonwealth of Kentucky provides, upon request, reasonable accommodations including auxiliary aids and services necessary to afford an individual with a disability an equal opportunity to participate in all services, programs and activities. To request materials in an alternative format, each agency web site provides information for contacting the person or persons responsible for providing the service within the agency. Persons with hearing and speech impairments can contact each agency by using the Kentucky Relay Service, a toll-free telecommunication device for the deaf (TDD). For voice to TDD, call 1-800-648-6057. For TDD to voice, call 1-800-648-6056.

Services can include: Adult basic reading, GED and Test Preparation, Corrections Education, English as a Second language, Family Literacy, Kentucky Employability Certificate, Workplace Education/Assessment Service. All services are free.

EMPLOYMENT ASSISTANCE

OFFICE OF VOCATIONAL REHABILITATION (VR) *

209 St. Clair Street

Frankfort, KY 40601

Phone: (502) 564-4440 (Voice/TTY)

Toll Free: (800) 372-7172 (Voice/TTY)

Email: wfd.vocrehab@ky.gov

Web site: <http://ovr.ky.gov>

*Vocational Rehabilitation has undergone numerous name changes, i.e. *Bureau* for Vocational Rehabilitation (BVR), *Department* for Vocational Rehabilitation (DVR), and *Office* for Vocational Rehabilitation (OVR). For the purpose of this directory, it is shortened to Vocational Rehabilitation. (VR).

Eligibility Requirements: Individual must have a physical or mental impairment that results in a substantial impediment to employment; must require vocational rehabilitation services and if you meet the criteria will be determined eligible unless there is clear and convincing evidence that you cannot benefit from vocational rehabilitation services. If you receive Social Security disability benefits (i.e. SSI or SSDI) you are considered to be an individual with a significant disability and are presumed to be eligible for services.

Vocational Rehabilitation (VR) provides services to individuals with physical or mental disabilities to enable them to enter or return to employment. Services include:

Vocational Assessment- consumers will be assisted in determining their eligibility for services, their vocational aptitudes and interests in order to determine a vocational objective consistent with their vocational capabilities, potential and the job market.

Counseling and Guidance- consumers will be assisted in analyzing, understanding and using their assets (capabilities and aptitudes) in order to overcome barriers to employment.

Vocational Training and Related Services- consumers can receive assistance with post-secondary education, on-the-job training, adjustment training, GED training necessary to develop specific overall skills.

Rehabilitation Technology- services may include property modification, assistive listening devices, vehicle modification, etc. It is the systematic application of technology, engineering and scientific principles to meet the needs and barriers of the individual consumer.

Support Services- such as childcare, transportation, attendant care and other services necessary for an individual to access other services.

Job Development and Job Placement Follow-up- consumers can be assisted in obtaining the appropriate job to include development and job placement plans. Follow-up is provided to insure job maintenance.

Go on line to read two publications:

Transition: [Beyond High School](#) – A transition Guide Book

Resource Manual: [The Rest of My Life: For Youth with Disabilities in Foster Care.](#)

Vocational Rehabilitation District Offices - All Offices are Voice/TTY:

Central Office

209 St. Clair Street, Frankfort, KY 40601

Toll Free: (800) 372-7172 Voice

Toll Free: (888) 420-9874 TTY

All Offices are Voice/

Ashland

411 Nineteenth Street, Ashland 41101

Phone: (606) 920-2338

Bowling Green

955 Fairview Avenue, Suite 100

Bowling Green 42101

Phone (270) 746-7489

Toll Free: (800) 443-6055

Toll Free: (800) 246-6193 TTY

Elizabethtown

409 North Miles Street, Elizabethtown 42701

Phone: (270) 766-5121

Toll Free: (866) 883-0001

Florence

8020 Veterans Memorial Drive, Suite 100

Florence 41042

Phone: (859) 371-9450

Phone: (859) 371-0803 TTY

Toll Free: (877) 371-9451

Frankfort

229 West Main Street, Suite 302

Frankfort 40601

Phone: (502) 564-7629

Toll Free: (888) 640-0134

Harlan

110 Professional Lane, Suite 203

U.S. Hwy 421 South

Harlan 40831

Phone: (606) 573-3890

Lexington

301 East Main Street, Lexington 40507

Phone: (859) 246-2185

Toll Free: (888) 211-7276

Toll Free: (888) 990-9098 TTY

Louisville

410 West Chestnut Street, Suite 100

Louisville 40202

Phone: (502) 595-4173

Toll Free: (800) 456-3334

Toll Free: (866) 862-3848 TTY

Madisonville
1071 Thornberry Drive
Madisonville 42431
Phone: (270) 824-7549
Toll Free: (888) 640-2713

Morehead
200-34 South #4
Morehead 40351
Phone: (606) 783-1527
Toll Free: (866) 744-5632 TTY

Owensboro
121 East Second Street, Suite 7
Owensboro 42303
Phone: (270) 687-7308
Toll Free: (888) 640-2811
Toll Free: (800) 241-5821 TTY

Paducah
2929 Lone Oak Road
Paducah 42003
Phone: (270) 575-7304

Whitesburg
415 Highway 2034, Suite C
Whitesburg, 41858
Phone: (606) 633-9332

West Liberty
P.O. Box 84, 563 B Main Street
West Liberty, 41472
Phone: (606) 743-7978
Toll Free: (800) 440-2530

Office for Vocational Rehabilitation also operates:
CARL D. PERKINS VOCATIONAL TRAINING CENTER
5659 Main Street
Thelma, KY 41260
Phone: (606) 788-7080
Fax: (606) 788-7076
Toll Free in Kentucky Only: (800) 443-2187
Deaf Services: (877) 600-6111 TTY
Web site: <http://cdpytc.ky.gov>

Eligibility Requirements: People with disabilities

The Mission of the Carl D. Perkins Vocational Training Center is to provide services to individuals with disabilities so they may achieve suitable employment and independence.

Services include: Assisted Living (nursing services available 24 hours under the supervision of a licensed physician, Rehabilitation Technology, Case Management, Deaf Services, Drivers Education, Evaluation, Job Placement, Occupational, Physical and Speech Therapy, Mental Health services and Outpatient services.

OFFICE FOR THE BLIND
P.O. Box 757, 209 Clair Street
Frankfort, KY 40602-0757
Phone: (502) 564-4754
Toll Free: (800) 321-6668 or (877) 592-5463
Fax: (502) 564-2951
TDD: (502) 564-2929
Email: blind@ky.gov
Web site: <http://blind.ky.gov>

Local Offices – Call toll free:

Ashland - (800) 334-6881
Elizabethtown – (800) 760-6891
Frankfort – (800) 321-6668
Louisville – (800) 346-2115
Paducah – (800) 334-6945
Somerset – (800) 895-38636

Bowling Green – (800) 222-1215
Florence – (800) 334-6895
Lexington – (800) 291-8424
Owensboro – (800) 334-6929
Prestonsburg – (800) 334-6940

Eligibility Requirements: Individuals, age sixteen and older, who want to work and have a visual disability that impedes their ability to get and keep a job. A doctor's statement is needed.

Services include: Medical Restoration, i.e. surgery; Post secondary training – tuition, tutors, note takers, etc. Services which may be needed outside class but related to the education process such as tuition, tutors, note takers, etc.; Assistive technology – i.e. voice for computer, large print reading material; Orientation and mobility – i.e., cane skills are taught, travel training; Bioptic driving – for people whose vision can be corrected to 20 over 60. Bioptic is mounted in the lens of eyeglasses; job placement – i.e., work with employers, provide supported employment.

JOB TRAINING/WORK HABILITATION/ADULT DAY CARE

MENTAL HEALTH/MENTAL RETARDATION REGIONAL BOARDS (MHMR)

Publicly-funded community services for Kentuckians with mental health, mental retardation, and substance abuse problems are provided through Kentucky's 14 regional mental health and mental retardation (MHMR) boards. Regional boards are private, nonprofit organizations established by statute and serve residents of a designated multi-county region. Board members are community volunteers.

For information about mental health, mental retardation or substance abuse services, contact the local office of your regional MHMR board. Although each has a name, they are commonly referred to as Comprehensive (Comp) Care.

THE KENTUCKY DEPARTMENT FOR MENTAL HEALTH AND MENTAL RETARDATION SERVICES

C/O The Commissioner's Office

100 Fair Oaks Lane 4E-B

Frankfort, KY 40621

Web site: <http://chfs.ky.gov/mhmr/>

The mission of the Department for Mental Health and Mental Retardation Services is to provide leadership in partnership with others, to prevent disability, build resilience in individuals and their communities, and facilitate recovery for people whose lives have been affected by mental illness, mental retardation or other developmental disability, substance abuse or an acquired brain injury.

The mission of the *Division of Mental Retardation (DMR)* is to take the lead, in partnership with other key stakeholders, in building the capacity of communities and systems to provide individually determined supports for individuals with mental retardation and other developmental disabilities, and their families that increase their opportunities for choice and inclusion as valued citizens of Kentucky's communities.

The critical functions of DMR include: set the standards for best practice, provide information and technical assistance, acquire and disperse fiscal resources and administer grants and contracts, monitor, evaluate and ensure accountability for outcomes for individuals.

It is the responsibility of DMR to provide an array of supports for individuals with mental retardation and developmental disabilities. This is accomplished through contracting for services through the 14 Regional Mental Retardation Boards and other qualified private providers.

Services that are funded by DMR and provided in varying degrees by each of the Regional Mental Retardation Centers and their affiliates include: case management, residential services, vocational services, respite services, crisis intervention services, leisure/recreation services, in-home support and habilitative services.

DMR comprises two branches – the Supports for Community Living Waiver Branch and the Community Support Branch.

Region I – Four Rivers Behavioral Health

425 Broadway
Paducah, KY 42001
Phone: (270) 442-7121
24 Hour Crisis & Information Line
Toll Free: (800) 592-3980
Web site: <http://www.4rbh.org>

Counties Served:

Ballard, Callaway, Carlisle, Fulton
Graves, Hickman, Livingston
Marshall and McCracken

Region II – Pennyroyal

735 North Drive
Hopkinsville, KY 42240
Phone: (270) 886-5163
24 Hour Line: Toll Free: (877) 473-7766 or
In Christian County- Phone: (270) 881-9551
Web site: <http://www.pennyroyalcenter.org>

Counties Served:

Caldwell, Christian, Crittenden
Hopkins, Lyon, Muhlenberg, Todd,
Trigg

Region III – River Valley Behavioral Health

1100 Walnut Street
Owensboro, KY 42301
Phone: (270) 689-6500
First Appointments & Referrals:
Point of Entry: (270) 683-4039 or
Toll Free: (800) 769-4920
Web Site: <http://www.rvbh.com>

Counties Served:

Daviess, Hancock, Henderson
McLean, Ohio, Union, Webster

Region IV – Lifeskills

P.O. Box 6499
Bowling Green, KY 42102-6499
Phone: (270) 842-0161
24 Hour Crisis Line:
Toll Free: (800) 223-8913
Web site: <http://www.lifeskills.com/>

Counties Served:

Allen, Barren, Butler, Edmonson
Hart, Logan, Metcalfe, Monroe
Simpson, Warren

Region V – Communicare

320 Ring Road
Elizabethtown, KY 42701
Phone: (270) 769-5301
Web site: www.communicare.org

Counties Served:

Breckenridge, Grayson, Hardin
Larue, Marion,
Meade, Nelson, Washington

Region VI – Seven Counties Services, Inc.

3717 Taylorsville Road
Louisville, KY 40220
Phone: (502) 589-4313
Phone: (502) 589-4259 TDD
24 Hour Crisis Line:
Toll Free: (800) 221-0446
Web site: <http://www.sevencounties.org>

Counties Served:

Bullitt, Henry, Jefferson, Oldham
Shelby, Spencer, Trimble

Region VII – NorthKey Community Care

1201 South Ft. Thomas Avenue
Ft. Thomas, KY 41075-2421
Phone: (859) 781-5586
24 Hour Crisis Line:
Phone: (859) 331-3292
Toll Free: (877) 331-3292
Web site: www.northkey.org

Counties Served:

Boone, Campbell, Carroll,
Gallatin, Grant, Kenton, Owen
Pendleton

Region VIII- Comprehend, Inc.

741 Kenton Station Road
Maysville, KY 41056
Phone: (606) 759-7161
Email: mrdd@comprehendinc.com
Web site: www.comprehendinc.com

Counties Served:

Bracken, Fleming, Lewis, Mason,
Robertson

****Region X – Pathways, Inc.***

P.O. Box 790
Ashland, KY 41105-0790
Phone: (606) 329-8588
Toll Free: (800) 562-8909
Web site: www.pathways-ky.org
****There is no Region IX***

Counties Served:

Bath, Boyd, Carter, Elliot, Greenup,
Lawrence, Menifee
Montgomery, Morgan, Rowan

Region XI – Mountain MH/MR Board

104 South Front Avenue
Prestonsburg, KY 41653
Phone: (606) 886-8572
Web site: www.mtcomp.org

Counties Served:

Floyd, Johnson, Magoffin
Martin, Pike

Region XII – Kentucky River Community Care

115 Rockwood Lane
Hazard, KY 41701
Phone: (606) 436-5761
Crisis Line:
Toll Free: (800) 262-7491 TTY/TDD
Web site: <http://www.krcenet.com>

Counties Served:

Breathitt, Knott, Lee, Leslie
Letcher, Owsley, Perry, Wolfe

Region XIII – Cumberland River MH/MR Board

P.O. Box 568
Corbin, KY 40702
Phone: (606) 528-7010
Web site: www.cumberlandriver.com

Counties Served:

Bell, Clay, Harlan, Jackson, Knott
Laurel, Rockcastle, Whitley

Region XIV – Adanta MH/MR Board

259 Parker's Mill Road
Somerset, KY 42501
Phone: (606) 679-7348
Emergency Crisis Line
Toll Free: (800) 633-5599 TDD/TTY
Web site: <http://www.adanta.org>

Counties Served:

Adair, Casey, Clinton
Cumberland
Green, McCreary, Pulaski, Russell
Taylor, Wayne

Region XV – Bluegrass MH/MR Board

1351 Newtown Pike
Lexington, KY 40511
Phone: (859) 253-1686
Fax: (859) 255-4866
24 Hour Crisis Line:
Toll Free: (800) 928-8000
Web site: <http://www.bluegrass.org>

Counties Served:

Anderson, Bourbon, Boyle, Clark, Estill
Fayette, Franklin, Garrard, Harrison,
Jessamine, Lincoln, Madison, Mercer,
Nicholas, Powell, Scott, Woodford

SECTION 5

**FAMILY/
FRIENDS/
RECREATION/
LEISURE**

FAMILY/FRIENDS/RECREATION/LEISURE

“A community that excludes even one of its members is not a community.”

Dan Wilkens, Nth Degree, Lucky, Ohio

It's exciting to hear stories from parents who have enrolled their child with a disability in a local dance or karate class or have joined the Boy Scouts or the Girl Scouts – activities typical families use and enjoy. One by one, these families are breaking silent barriers.

Thanks to the Americans with Disabilities Act (ADA), increased numbers of county and community parks are becoming handicapped accessible, more sidewalks have curb cuts and private businesses are making strides in becoming accessible. It's not perfect; therefore calling ahead may eliminate frustrations.

Many parents have successfully encouraged their sons/daughters to take part in a variety of community activities. Weekly newspapers and cable TV list community sponsored events open to and appropriate for all residents. Concerts in the parks, parade watching, mall walking, an Easter egg hunt at the local library and county fairs can be enjoyable and inexpensive.

Area churches provide a variety of community and membership events. Some churches have made extraordinary attempts to include people with disabilities by providing ramps, elevators and interpreters.

Schools are required to encourage participation in the school's extracurricular activities. Students are to be extended the *opportunity* to participate but will need to follow the guidelines for participation as do the other students. It wouldn't make sense to have a student join the Spanish Club if they do not have some ability to speak Spanish. Certainly there are clubs and events that everyone would enjoy - attending football or basketball games, pep rallies, decorating for the homecoming parade, going to the prom – wearing that beautiful gown on the arm of a handsome young man in a tux – priceless.

Two great prom stories – A young man who was a “big man on campus” – good looking, smart, football player and peer tutor – double dated for the prom with the young man with whom he was tutoring. He has since gone on to college but still spends time with the young man.

Another great story, a beautiful young lady, also a peer tutor, went to the prom with the young man she was tutoring as her date. Her parents drove her to the young man's house to pick up her date. *Her* parents still treasure the look on the faces of the *young man's parents* when they arrived, took pictures and left for the special event. Imagine.....

EASTER SEALS CAMP KYSOC

KENTUCKY EASTER SEAL SOCIETY - CARDINAL HILL HEALTH CARE SYSTEMS

1902 Easterday Road

Carrrollton, KY. 41008

Phone: (502) 732- 5333

E-mail: FUN@KYSOC.ORG

Web site: www.cardinalhill.org

The Kentucky Easter Seal Society offers summer recreational programs at Camp KYSOC, located in Carrrollton, Kentucky. The camp offers week programs, day programs, and weekend respite camping. For more information, contact the Camp Director at the Carrrollton, Kentucky office.

KENTUCKY STATE PARKS

Capital Plaza Tower

500 Mero Street, 11th Floor

Frankfort, KY 40601-1974

Phone: (502) 564-2172

Fax: (502) 564-9015

The Kentucky Department of Parks has 1192 accommodations in 17 resort parks. There are a total of 51 accessible lodge rooms and 21 accessible cottages throughout the system. This represents approximately 6 percent of the total inventory. Accessible bathrooms include a mixture of roll in and transfer showers along with some bathtubs. All 17 lodges have TTY equipment available for use along with closed caption televisions upon request. All 17 resort parks have unrestricted accessibility to our dining areas. All dining areas are barrier free.

The Kentucky Department of Parks has 18 Americans with Disabilities Act (ADA) accessible facilities throughout the system of 50 parks. Aquatic facilities at Lake Barkley and Lake Cumberland State Resort Parks are indoor facilities along with being ADA accessible. The Kentucky Department of Parks has a total of 38 parks with ADA accessible playground facilities. There are a total of 52 accessible playgrounds. All ADA playgrounds have transfer platforms/stations rather than ramps. Approximately 10% of these playgrounds do not have accessible routes. The Kentucky Department of Parks offers trails in four parks that meet ADA trail guideline recommendations.

The Kentucky Department of Parks has incorporated ADA accessibility in its campground design standards during the last ten years. Currently there are four campgrounds that have accessible campsites and several with accessible bathhouses. Call for a description of a specific parks you may be interested in visiting.

POWER MINISTRIES

PO Box 6706

New Albany, IN 47151

Toll Free: (812) 945-4117

Fax: (812) 945-4118

Web site: www.powerministries.org

Eligibility Requirements: The New Purpose Retreats Program is open to people of all ages with all types of disabilities. There are certain limitations that can apply in individual cases. For complete information and dates contact Power Ministries.

Power Ministries partners with established church camps to provide a Christian-based experience (New Purpose Retreats) for people with disabilities. A day at a New Purpose Retreats program will include recreation, lessons that coincide with the theme, worship times, crafts and several special activities. The New Purpose Retreats program maintains a one to one camper to volunteer ratio. The nursing staff is led by a registered nurse at every session. In 2006, there were 12 Retreats in Kentucky. There are also two other Retreats close to Kentucky in the neighboring states.

SPECIAL OLYMPICS OF KENTUCKY

State Office

105 Lakeview Court

Frankfort, KY 40601

Phone: (502) 695-8222

Toll Free: (800) 633-7403

Web site: <http://www.soky.org/>

Louisville Office

1230 Liberty Bank Lane, Suite 140

Louisville, KY 40222

Phone: (502) 326-5002

Eligibility Requirements: Individuals, ages eight years of age or older and: 1. have been identified by an agency or professional as having an intellectual disability as determined by their localities or 2. have a cognitive delay, as determined by standardized measures such as intelligent quotient or "IQ" testing or other measures that are generally accepted within the professional community in that Accredited Program's nation as being a reliable measurement of the existence of a cognitive delay or 3. have a closely related developmental disability. A "closely" related developmental disability" means having functional limitations in both general learning (such as IQ) and in adaptive skills (such as in recreation, work, independent living, self-direction or self care).

However, persons whose functional limitations are based solely on physical, behavioral, or emotional disability or a specific learning or sensory disability are not eligible to participate as Special Olympic athletes, but may be able to volunteer.

A national organization whose mission is to provide year round sports training and athletic competition in a variety of Olympic type sports and activities while giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy, and participate in sharing of gifts, skills, and friendship with their families, other athletes, and the community.

Many local areas have organized Special Olympic groups. Activities may vary in each locale. Examples of activities may include golf, bowling, roller-skating, swimming, art, basketball, cheerleading, track and field, fishing, soccer and participation in the State summer games.

Visit their web site to check out the different locations.

TALKING BOOK SERVICE

Kentucky Archive and Libraries

300 Coffee Tree Road

Frankfort, KY 40601

Phone: (502) 564-8300

Toll Free in Kentucky: (800) 372-2968

Web site: www.kdla.ky.gov/collectionsktbl.htm

Eligibility Requirements: who has difficulty reading standard print material or who is unable to hold a book and turn the pages is eligible for the service. The individual's condition may be temporary or permanent as long as a competent authority endorses the application. A "competent authority" is a librarian, health professional, teacher, social worker, government agency staff.

Individuals with dyslexia or other reading disabilities may qualify for service as long as the condition is the result of organic dysfunction. A statement signed by a medical doctor is required for this type of disability. However, a "competent authority" cannot endorse the application for these types of disabilities. A statement signed by a medical doctor is required.

To obtain an application form: Phone toll free: (800) 372-2968 or download one from the web site: <http://kdla.ky.gov/collections/ktblapplication.pdf> Your local library may have the application.

The cooperating Talking Book Library will mail postage-free, containers of talking book discs or cassette books for a loan period of one month. To return the books, simply return them to the container in which they were mailed, reverse the mailing card and place it in the mailbox. Walk-in service may also be available.

The Talking Book Library will provide patrons with a specially created cassette player on which to listen to books. Books are recorded on standard audio cassettes designed to play at half commercial speed (15/16 IPS) and using four tracks. This configuration can pack up to six hours of reading time onto one cassette. This allows the use of fewer tapes and protects the author's copyright, since they will not play on regular cassette players. Please note that textbooks are not included in this service

The players are specially designed for those who are blind. They have large keys with raised symbols. An instruction tape comes with it. Special attachments, such as headphones, pillow speakers and sound amplifiers are available by special request. Repairs or replacement will be made at no cost to the patron.

In 2008, the system will change to Flash Digital Technology – the books will be on a card the size of a credit card and the "player" will be the size of a deck of cards.

THERAPEUTIC HORSEBACK RIDING AND HORSEMANSHIP

Central Kentucky Riding for Hope (NARHA Premier Accredited Center)*

Kentucky Horse Park

P.O. Box 13155

Lexington, KY 40511

Phone: (859) 231-7066

Email: denise@ckrh.org

Website: www.ckrh.org

Milestones, Inc. (NARHA Premier Accredited Center)*

12372 RiggsRd.

Independence, KY 41051

Phone: (270) 782-6496

E:mail: ponymiles@aol.com

New Beginnings Therapeutic Riding, Inc. (NARHA Premier Accredited Center)*

306 Matlock Old Union Road

Bowling Green, KY 42104

Phone: (270) 782-6496

E:mail: newbeginningstrc@hotmail.com

Website: www.nbtr-bg.org

The Luci Center

P.O. Box 936

Shelbyville, KY 40066-0936

Phone: (502) 220-4308

E:mail: lucicenter@aol.com

Website: www.thelucicenter.org

***NARHA Centers – Just as other professions use accreditation and licensing systems to improve the well-being of their industries, therapeutic equine professionals have a distinction of their own. The Premier Accredited Center Program offers centers the chance to demonstrate their excellence in providing quality, professional equine assisted activities. This voluntary process recognizes NARHA centers that have met established industry standards.**

SECTION 6

FINANCIAL ASSISTANCE

FINANCIAL ASSISTANCE

“Parents need to be active and involved, so they know what is available and what the trends are. What we wanted for our daughter changed over time as more options became available. People who are active and involved are the ones who are first in line for services. That’s just how it is. We started with the Acquired Brain Injury (ABI) Waiver and were able to switch to the Supports for Community Living Waiver (SCL). Now, our daughter is living in her own apartment with some supports and has started her own business with the assistance of the Vocational Rehabilitation’s Supported Employment staff and the Department’s Project Asset. We knew about these programs because we have been advocates and active in state committees for many years.”

Dick and Jean Covert, Lexington

AUTISM BENEFIT – KENTUCKY HEALTH PLAN

Research the Legislation: <http://www.lrc.ky.gov/kar/806/017/460.htm>

Questions? Contact the Kentucky Office of Insurance at 1-800-595-6053

Insurers offering health benefit plans in the Commonwealth of Kentucky provide coverage, including therapeutic, respite and rehabilitative care, for the treatment of autism of a child covered under their health insurance plan. The coverage is subject to a five hundred-dollar maximum benefit per month, per covered child. The limit does not apply to other health conditions and services for the child not related to the treatment of autism.

Under the legislation, autism is defined as:

A total of six or more items from subparagraphs 1, 2, and 3 of this paragraph with at least (2) from subparagraph 1 and one each from subparagraph 2 and 3.

1. Qualitative impairment in social interaction, as manifested by at least two of the following:
Marked impairment in the use of multiple nonverbal behaviors such as eye to eye gaze, facial expression, body postures and gestures to regulate social interaction and/or failure to develop peer relationships appropriate to developmental level and/or a lack of spontaneous seeking to share enjoyment, interest or achievement with other people and/or lack of social or emotional reciprocity.
2. Qualitative impairments in communication as manifested by at least one of the following:
Delay in, or total lack of, the development of spoken language and/or in individuals with adequate speech, marked impairment in the ability to imitate or sustain a conversation with others and/or stereotyped and repetitive use of language or idiosyncratic language and/or lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental levels.
3. Restricted repetitive and stereotyped patterns of behavior, interests and activities as manifested by at least one of the following: encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus and/or apparently inflexible adherence to specific, nonfunctional routines or rituals and/or stereotyped and repetitive motor mannerisms and/or persistent preoccupation with parts of objects and/or delays or abnormal functioning in at least one of the following areas, with onset prior to age three years: social interaction and or language as used in social communication and or symbolic or imaginative play and or the disturbance is not better accounted for by Rett’s Disorders or Childhood Disintegrative Disorder.
4. As used in this section, “child” means a person two through twenty-one years of age.

CABINET FOR HEALTH AND FAMILY SERVICES (usually referred to as the Cabinet for Human Resources) has a vast array of services. A few of the programs/benefits are discussed. Check out their web site for more information: <http://chfs.ky.gov/> or <http://chfs.ky.gov/dms/services.htm>

TEMPORARY AID TO NEEDY FAMILIES (TANF-formerly AFDC)

KENTUCKY TRANSITIONAL ASSISTANCE PROGRAM – KTAP

Eligibility Requirements: Needy families, which include a minor child deprived of parental support through unemployment, death, voluntary or involuntary absence, or incapacity - who meet the resource limit of \$2000 with certain exclusions. Property, vehicles or insurance are not included; meet income/resource guideline.

Needy child means under the age of 16, age 16 through 18 if a high school graduate; age 16 through 18 if attending school; living in the home of specified relatives.

- Temporary short term assistance available to stabilize families and allow them to maintain self-sufficiency
- Available to K-TAP eligible families, not currently receiving cash payments
- For families with an ongoing means of support, but with verified short term needs
- Payment to resolve crisis, not to exceed \$1500 maximum
- Benefits such as cash or vendor payments, job preparation activities, work support services, child care, housing assistance, referral for child support and other services

MEDICAID (MEDICAL) CARD

Those who can obtain a Medicaid Card (sometimes called a Medical Card):

- (1) An individual is a recipient of TANF (Temporary Aid for Needy Families)
- (2) An individual is a recipient of Supplemental Security Income (SSI) or
- (3) An elderly and/or disabled individual not receiving SSI or TANF.

The Medicaid Card can be used to pay for most medical bills, i.e., visits to doctors, dentists, clinics, x-rays, prescriptions, medicines, mental health care, hospital stays, medical transportation, and more.

When using a Medicaid Card be sure to ask if the doctor or dentist accepts the Medicaid Card.

If you are not eligible for the basic medical card because your income is slightly higher than the guideline amount, be sure to inquire about state programs, similar to medical assistance, for people who need help paying for Medicare services.

Qualified Medicare Beneficiary (QMB) coverage is available to individuals enrolled and receiving Medicare Part A benefits. This coverage provides for payment of the Medicare Part A and Part B premiums, and payment of Medicare coinsurance and deductibles (hospital and physician). Increased income limits and resource limits are used in the eligibility determination.

Specified Low Income Medicare Beneficiary (SLMB) - pronounced "slimby", to qualify you must be eligible for Medicare Part A (even if not currently enrolled) but NOT financially eligible for medical assistance and have limited income and assets.

FOOD STAMPS

Food Stamps can be spent the same as money with some exceptions, i.e., paper goods, soaps, alcohol, and cigarettes. Coupons are now being replaced with electronic benefits cards.

The amount of Food Stamps issued to an individual or family is based on a sliding scale formula. To become eligible, the gross monthly income and the size of the household must meet regulations. Next, expenses (i.e., rent and utilities) are considered. If a person is aged or has a disability, medical expenses can be considered (medical expenses are not included in the average household). Eligibility may be re-determined at three, six or twelve-month intervals.

KENTUCKY CHILDREN'S HEALTH INSURANCE PROGRAM (KCHIP)

The mission is to provide health insurance coverage to low income, uninsured children in Kentucky. KCHIP staff knows that access to health care is very important in maintaining good health. We also know that prevention is a big part of health care. Immunizations, well child

checkups and other preventive services provided through KCHIP help children get & stay healthy.

To apply: Go to the local office in your county – listed under The Cabinet for Health & Family Services. Office hours: 8:00 a.m. to 4:30 p.m. Monday through Friday. Need help?

Call toll free (877) KCHIP 18.

When you apply take:

Proof of income: For earned, paycheck stubs for the last two months for all people in the home; and for unearned, take Social Security–Supplemental Security Income (SSI) or pension award letters.

Proof of childcare: copies of receipts or statement from care provider

Health insurance information if your child has been insured during the last six months:

Name of insurance company, group number and policy number, effective date,
Name of policyholder, names of people who are (were) covered.

You may be asked for additional information that must be completed and returned within 10 days, or you will have to start the process again. If eligible, a letter is mailed saying that you are eligible and if you owe a premium. Only families with children over certain income limits owe a premium. Two premium payments are due the first time only (because you pay in advance). The child's card will be mailed after the premium is paid. If the premium is not paid, the KCHIP card will not be issued.

For more information, visit their web site:

<http://chfs.ky.gov/NR/rdonlyres/32F08135-DA28-4A8B-8B79-8AC6DD1137C9/15241/HowtoApply.pdf>

HABITAT FOR HUMANITY

Kentucky Region: Mid-America – IN, KY, OH, TN

Campus Chapters Coordinator

Toll Free: (800) HABITAT, Ext. 2412

Email: youthprograms@habitat.org

Habitat for Humanity is a non-profit Christian housing ministry who partners with families to build homes and offer no-interest mortgages. Since its founding in 1976 by Millard & Linda Fuller, Habitat for Humanity International has built and rehabilitated more than 150,000 houses with families in need.

The philosophy of Habitat for Humanity is summarized in its description of the Fund for Humanity, “What the poor need is not charity but capital, not caseworkers but co-workers. And what the rich need is a wise, honorable and just way of divesting themselves of their overabundance. The Fund for Humanity will meet both of these needs. Money for the fund will come from shared gifts by those who feel they have more than they need and from non-interest bearing loans from those who cannot afford to make a gift but who do want to provide working capital for the disinherited. . . The fund will give away no money. It is not a handout.

Habitat for Humanity Campus Chapters are located at: Apollo High School, Berea College, Brescia University, Centre College, Georgetown College, Morehead State University, University of Kentucky and Western Kentucky University. In Northern Kentucky, phone: (859) 654-1198.

HART SUPPORTED LIVING GRANTS

Department for Aging & Independent Living

Division of Quality Living

275 East Main Street, 3W-F

Frankfort, KY 40621

Phone: (502) 564-6930, Ext. 4048

See description in the RESPITE, COMMUNITY LIVING, RESIDENTIAL Section

THE KENTUCKY FAMILY CAREGIVER PROGRAM

Grandparent Resources

The Kentucky Family Caregiver Program is one in which the state is providing assistance, including grants or vouchers, to grandparents who are primary caregivers of their grandchildren. To be eligible the grandparent must...

1. Be a Kentucky resident
2. Be the primary caregiver for the child
3. Be related to the child by birth, marriage, or adoption
4. May not be residing in the same house as the grandchild's parent
5. May not reside in a house that is owned by the grandchild's parent
6. May not receive a monthly payment for kinship care
7. May not have annual household income that exceeds 150 percent of the federal poverty level

An applicant shall sign and submit to a district an "Application for Kentucky Family Caregiver Services." There after the applicant shall receive a written notice of eligibility or non-eligibility from a district within thirty (30) days of submitting all forms. An applicant/grandparent shall apply or reapply for the Kentucky Family Caregiver Program each fiscal year. The maximum total of assistance *per grandchild* that a grandparent can receive, including a grant or voucher, is *\$750 each year*. Contact your Area Agency for Aging. *Offices are listed under CONSUMER DIRECTED OPTIONS in this section of the booklet.*

KENTUCKY HOUSING CORPORATION (KHC)

1231 Louisville Road

Frankfort, KY 40601

Phone: (502) 564-7630

Toll free in Kentucky only: (800) 633-8896

Web site: <http://www.kyhousing.org/>

Kentucky Housing Corporation, created by the 1972 General Assembly, is a self-supporting, public corporation of the Commonwealth of Kentucky administratively attached to the Finance and Administration Cabinet. A portion of KHC funds are derived from the interest earned through the sale of tax-exempt mortgage revenue bonds. From these proceeds, KHC has made homeownership possible for over 60,000 low and moderate-income Kentucky families. KHC also operates through the receipt of fees for administering federal programs including rental assistance that makes safe, decent, affordable housing available to more than 27,000 low-income Kentuckians. Other programs additionally offered by KHC include rental housing production financing, homeownership education/counseling and a variety of rental assistance, housing rehabilitation and home repair initiatives.

MEDICAID WAIVERS

Medicaid can pay for services to help an eligible individual with significant needs continue to live at home through Waiver Programs.

KyHealth Choices is the new name for Kentucky Medicaid. It represents a much improved Medicaid program for members and providers. KyHealth Choices will help Kentucky stretch resources to best meet the needs of members and encourage Medicaid members to be personally responsible for their own health care. Visit their web site: <http://chfs.ky.gov/dms/kyhealthchoices.htm>

WAIVER PROGRAMS

Web site: <http://chfs.ky.gov/dms/mhmr.htm>

A waiver is one way that Medicaid enables an individual with mental retardation, developmental disabilities, or significant health care needs to live at home. While some eligibility requirements are "waived" for these programs, the individual must require a protective level of care related to daily living skills or skilled medical care. The financial criterion is based only on the income of the individual. Since waiver programs pay for services for a *limited number of people*, openings can fill up quickly and there may be a waiting list.

The Home and Community Based (HCB) Waiver

Web site: <http://chfs.ky.gov/dms/hcb.htm>

HCB Waiver provides Medicaid coverage to individuals who are elderly, or disabled, and who may, without these services, be admitted to a nursing facility. These individuals must meet nursing facility level of care to be eligible to participate in the HCB Waiver program.

The services offered under the HCB Waiver program are provided by Home Health agencies enrolled in the Medicaid program as HCB Waiver providers. These services are available statewide for individuals who are eligible to receive HCB Waiver services. There is a provision for Medicaid eligibility to be determined under a special income level for individuals who otherwise meet all requirements for receiving HCB Waiver services.

Services Available: Assessment services entail a comprehensive assessment of the HCB Waiver recipient, care planning and reassessments. Case management services provide location, coordination and monitoring of the HCB Waiver recipient's services. Homemaker service is a service that consists of general household activities such as meal preparation and routine household care. Personal care services are medically oriented and are related to the HCB Waiver recipient's physical requirements. Respite care service is short-term care provided to an HCB Waiver recipient due to the absence of or to provide relief to the primary caregiver. Minor home adaptations are changes or additions made to the HCB Waiver recipient's living environment to make it possible for the individual to remain in the current living arrangement. Attendant care service is a hands-on care of an HCB Waiver recipient. Adult Day Health Care services are provided on a regularly scheduled basis. These services are of a medical nature and ensure optimal functioning of an HCB Waiver recipient.

Acquired Brain Injury (ABI)

Web site: <http://www.mhmr.ky.gov/mhsas/Brain%20Injury%20Services.asp>

ABI is an injury to the brain that is not hereditary, congenital or degenerative. Acquired Brain Injury includes central nervous system injury from physical trauma, anoxia or hypoxic episodes and allergic conditions, toxic substances, and other acute medical/clinical incidents. Services and Supports for People with Brain Injuries which will enhance existing community supports, promote independence and personal productivity, are provided in the least restrictive environments, and are accessible, available, and effective.

NEW - Michelle P. Waiver

The Michelle P. Waiver is expected to be operational January 1, 2008. This waiver program was developed to serve Kentucky residents as an alternative to institutional care for individuals with intellectual or developmental disabilities. These individuals must meet the level of care criteria for placement in an Intermediate Care Facility for the Mentally Retarded or a Developmental Disability (ICF/MR/DD) and whose services in an ICF/MR/DD would qualify for payment under the State Plan for Medical Assistance. This program is designed to allow an individual to remain in or return to the community in the least restrictive setting. Michelle P. waiver services are not available to an individual while an inpatient of a hospital, nursing facility or ICF/MR/DD.

The new waiver program will provide home and community based services (personal care, homemaker services, respite, adult day health, attendant care, and minor home adaptations), case management services, behavioral supports, community living supports, supported employment and adult day training. Individuals may receive up to fifty hours of services each week. The waiver will not provide residential supports.

Person centered principles will be utilized in the development of the waiver member's plan of care. This plan of care includes an in-depth self-assessment which includes the member's goals and preferences. Michelle P. waiver services will be provided by various community-based licensed and certified agencies. Participant directed opportunities will enable waiver members to choose an alternate deliver of their non-medical waiver services by offering waiver members the opportunity to recruit and employ individuals in the community to serve as providers through the

Consumer Directed Option (CDO)

Supports for Community Living (SCL)

Web site: <http://www.mhmr.ky.gov/mr/default.asp?page=scl.asp>

SCL is a Home and Community-Based Waiver under the Kentucky Medicaid program developed as an alternative to institutional care for individuals with mental retardation or developmental disabilities. SCL allows individuals to remain in or return to the community in the least restrictive setting. Individuals with mental retardation or developmental disabilities meeting requirements for Medicaid requirements are eligible for these services. For more information call (502) 564-7702.

SCL offers the following supports and services. They are based on the individual's goals, choices and priorities as identified through an individual support plan.

Adult Day Training, Behavior Supports, Case Management, Children's Day Habilitation, Community Living Supports, Physical Therapy, Occupational Therapy, Psychological Services, Residential Supports, Respite, Speech Therapy and Supported Employment

The staff for the SCL program is based in Frankfort and throughout the state to provide regional support to all SCL providers statewide. Resources available on this website include provider resources, detailed information about services offered, application information, and training opportunities.

Supports for Community Living Field Based Staff, Division of Mental Retardation

Alice Blackwell, Branch Manager

100 Fair Oaks Lane 4W-C Frankfort, KY 40621-0001

Phone: (502) 564-7702, Ext. 4566

Phone: (502) 564-5777 TTY Fax: (502) 564-8917

Gwen Alston, Area Administrator
P.O. Box 129
Fountain Run, KY 42133-0129
Phone: (270) 434-4549
Fax: (270) 434-4548
Email: Gwen.Alston@ky.gov

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Ashland, KY 41105
Phone: (606) 929-9418
Fax: (606) 929-9508
Email: Melissa.Goble@ky.gov

Sherri Bradley, SCL Investigator
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Phone: (859) 246-2714
Fax: (859) 246-2590
Email: Sherri.Bradley@ky.gov

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Email: Kathy.Gilliam@ky.gov

Al Collinsworth, SCL Investigator
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Lexington, KY 40522-1725
Phone: (859) 269-0135
Fax: (859) 269-0146
Email: Al.Collinsworth@ky.gov

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Phone: (270) 598-9909
Fax: (270) 598-7240
Email: Melanie.Fraser@ky.gov

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Hazard, KY 41702
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Email: Cindy.Combs@ky.gov

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Fax: (270) 843-2143
Email: Kelly.Hackett@ky.gov

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Lexington, KY 40523-3520
Phone: (859) 245-0792
Fax: (859) 245-0919
Email: Deanna.Darrell@ky.gov

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Bowling Green, KY 42102-7667
Phone: (270) 781-6743
Fax: (270) 843-4696
Email: Doris.Duncan@ky.gov

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Frankfort, KY 40601
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Fax: (502) 564-8917
Email: Susan.Duvall@ky.gov

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Fax: (859) 246-2590
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Fax: (270) 487-1259
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Email: Tina.Milliner@ky.gov

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Fax: (859) 246-2590
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Fax: (502) 564-8917
Email: Michelle.Hulse@ky.gov

Lisa Hyde, Area Administrator
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Richmond, KY 40476
Phone: (859) 625-1931
Fax: (859) 625-1931
Email: Lisa.Hyde@ky.gov

Marsha Lindsey, Area Administrator
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Bowling Green, KY 42102-4407
Phone: (270) 393-8429
Fax: (270) 393-8409
Email: Marsha.Lindsey@ky.gov

Donna Reynolds, Area Administrator
P.O. Box 987
Morehead, KY 40351
Phone: (606) 784-2383
Fax: (606) 784-2413
Email: Ddonna.Reynolds@ky.gov

Tammy Reynolds, Area Administrator
Western State Hospital
Russellville Road – P.O. Box 2200
Hopkinsville, KY 42241
Phone: (270) 886-4370
Fax: (270) 886-4857
Email: Tammy.Reynolds@ky.gov

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Annville, KY 40402-0487
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Fax: (606) 364-2695
Email: Brenda.Robinson@ky.gov

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Fax: (502) 564-8917
Email: Kristy.Ryan@ky.gov

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Prospect, KY 40059
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Fax: (502) 292-2872
Email: Tao.Shi@ky.gov

Lisa Dunlap Ott, Area Administrator
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Florence, KY 41022-0034
Phone: (859) 525-1982
Fax: (859) 525-2170
Email: Lisa.Ott@ky.gov

Jennifer Wright, SNAP Assessor (Eastern Kentucky)
100 Fair Oaks Lane 4E-E
Frankfort, KY 40601
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Fax: (502) 564-8917
Email: Jennifer.Wright@ky.gov

Kimberly Raybourne, Provider Recruitment Specialist
P.O. Box 1437
Crestwood, KY
Phone: (502) 243-1818
Fax: (502) 243-0818
Email: Kimberly.Raybourne@ky.gov

CONSUMER DIRECTED OPTION – KENTUCKY INDEPENDENCE PLUS PROGRAM (CDO)

This program is for current Medicaid waiver members only. CDO lets the Medicaid waiver member make choices on how the individual's non-medical Medicaid waiver services are provided. Services that can be Consumer Directed are:

Home and Community Based Waiver (HCB): respite, personal care, homemaking and attendant care. *Supports for Community Living (SCL):* community living, respite and adult day training. *Acquired Brain Injury (ABI):* companion care, respite and personal care and the new *Michelle P.* waiver program.

With CDO, you can recruit, hire and supervise your own workers to provide services approved in your plan of care. You can hire family members, friends, neighbors or others recruited by you, such as provider agencies. You can “blend” your CDO plan by continuing with the services that are working for you and Consumer Direct other services. If you feel CDO doesn't work for you, simply return to the way you are currently receiving services.

A Support Broker will help you develop a plan of care and spending plan. You will receive assistance with setting the duties of the worker(s), recruiting them, setting the hours and payment. The Support Broker will work with an agency called a Financial Management Agency. To get started with CDO or to get more information, contact your **AREA AGENCY ON AGING**:

Barren River Area Agency on Aging
P.O. Box 90005, 177 Graham Avenue
Bowling Green, KY 42102-9005
Phone: (270) 781-2381
Toll Free: (800) 598-2381
Fax: (270) 842-0768

Big Sandy Area Agency on Aging
100 Resource Drive
Prestonsburg, KY 41653
Phone: (606) 886-2374
Toll Free: (800) 737-2723
Fax: (606) 886-3382

Bluegrass Area Agency on Aging
699 Perimeter Drive
Lexington, KY 40517
Phone: (859) 269-8021
Toll Free: (800) 490-2002
Fax: (859) 269-7917

Buffalo Trace Area Agency on Aging
P.O. Box 460, 201 Government Street, Suite 300
Maysville, KY 41056
Phone: (606) 564-6894
Toll Free: (800) 998-4347
Fax: (606) 564-0955

Cumberland Valley Area Agency on Aging
P.O. Box 1740, 342 Old Whitley Road
London, KY 40743-1740
Phone: (606) 864-7391
Toll Free: (800) 795-7654
Fax: (606) 878-7361

FIVCO Area Agency on Aging
1212 Bath Avenue, Suite 650
Ashland, KY 41101
Phone: (606) 929-1366
Toll Free: (800) 499-5191
Fax: (606) 327-0023

Gateway Area Agency on Aging
Court House Annex, 19 Main Street
P.O. Box 1070
Owingsville, KY 40360
Phone: (606) 674-6355
Fax: (606) 674-6658

Green River Area Agency on Aging
3860 U.S. Highway 60 West
Owensboro, KY 42302
Phone: (270) 926-4433
Toll Free: (800) 928-9094
Fax: (270) 684-0714

KIPDA
11520 Commonwealth Drive
Louisville, KY 40299-2340
Phone: (502) 266-6084
Fax: (502) 266-5047

Kentucky River Area Agency on Aging
917 Perry Park Road
Hazard, KY 41701-9545
Phone: (606) 436-3158
Toll Free: (800) 928-5723
Fax: (606) 436-2144

Lake Cumberland Valley Area Agency on Aging
P.O. Box 1570, 2384 Lakeway Drive
Russell Springs, KY 42642
Phone: (270) 866-4200
Toll Free: (800) 264-7093
Fax: (270) 866-4212

Lincoln Trail Area Agency on Aging
P.O. Box 604, 613 College St. Road
Elizabethtown, KY 42702-0604
Phone: (270) 769-2393
Toll Free: (800) 264-0393
Fax: (270) 769-2993

Northern Kentucky Area Agency On Aging
P.O. Box 668, 22 Spiral Drive
Florence, KY 41042-1399
Phone: (859) 283-1885
Fax: (859) 283-8178

Pennyrile Area Agency on Aging
300 Hammond Drive
Hopkinsville, KY 42240
Phone: (270) 886-9484
Toll Free: (800) 928-7233
Fax: (270) 886-3211

Purchase Area Agency on Aging
P.O. Box 588, 1002 Medical Drive
Mayfield, KY 42066
Phone: (270) 247-7171
Toll Free: (877) 352-5183
Fax: (270) 251-6110

Federal Agency on Aging
Agency on Aging - Washington
Phone: (202)619-0556 or (202) 619-0724
Ombudsman Line, Toll Free: (800) 372-2991
Regional Agency on Aging, Phone: (404) 562-7600

Model Waiver II services are community based waiver ventilator services. These services are provided to a recipient who is dependent on a ventilator and would otherwise require a nursing facility level of care in a hospital based nursing facility. Skilled private duty nursing and respiratory therapy are covered services under this waiver. All services must be prior authorized.

Check the web site: <http://chfs.ky.gov/dms/mwii.htm>

MEDICARE PRESCRIPTION PLAN / PART D

Medicare's new prescription drug coverage, sometimes called Medicare Part D, began January 1, 2006. A choice of prescription drug insurance plans is available through private insurance companies. Participation is income driven; therefore you will pay a monthly insurance premium plus a portion of the prescription cost through a co-payment.

Medicare prescription insurance plans are open to everyone who is eligible for Medicare. This includes individuals who are 65 years of age or older or younger people who receive Social Security Disability Income (SSDI) or who have kidney failure. Medicare provides an overview of the prescription drug plan.

- [Medicare and You](#) is a booklet that has information on the changes in prescription drug coverage.
- [Medicare Prescription Drug Plan Finder](#) will help you identify plans through a personalized search or through a search by state.

Contact Social Security for your copy. Call toll free: (800)-772-1213

MODEST NEEDS FOUNDATION

115 East 30th Street, Floor 1

New York NY 10016

Phone: (212) 463-7042

E-mail: questions@modestneeds.org

Web site: www.ModestNeeds.org

Modest Needs exists to prevent otherwise financially self-sufficient individuals and families from entering the cycle of poverty, when this might be avoided with a small amount of well-timed financial assistance. Modest Needs helps to restore the financial self-sufficiency of individuals who are willing to work but are temporarily unable to do so because they do not have the means to remit payment for a work-related expense. Modest Needs works to empower permanently disadvantaged individuals who otherwise live within their limited means to continue to live independently, despite a temporary, unexpected financial setback. In keeping with its mission, Modest Needs offers three types of grants: Self-Sufficiency Grants, Back-to-Work Grants and Independent Living Grants. Modest Needs makes Self-Sufficiency Grants by remitting payment to a creditor for an emergency expense for which the individual or family could not have prepared. Modest Needs makes Back-to-Work Grants by remitting payment for a small work-related fee or expense on behalf of a temporarily unemployed individual. Independent Living Grants are made by remitting payment to a creditor, for an expense on behalf of persons who are permanently unable to work but who nevertheless are living independently on the limited income to which they are entitled. Call the phone number or go to the web site for more information on how to apply

PRESCRIPTION ASSISTANCE

Financial assistance for prescription medications is available in many forms including co-payment coupons, discounts, and free medications for those who qualify financially. Please remember that your physician's office may be able to obtain samples of certain medications. Medicaid may also provide a prescription benefit. Additional assistance may be available through a Medicare prescription plan.

- www.AccessToBenefits.com helps people find programs to save money on prescriptions.
- www.FreeMedicineProgram.com has a mission to help patients obtain prescription medications free of charge.
- www.HelpingPatients.org is a web site designed to help patients find assistance programs for which they may qualify for through the Pharmaceutical Research and Manufacturers of America (PhRMA) and its 48 member companies obtaining prescription medication free-of-charge from available programs.
- www.Merck.com offers a patient assistance program, which provides its medicines free, or at a discount to those who cannot afford them.
- www.NeedyMeds.com is a comprehensive listing of patient assistance programs that provide no cost prescription medication to eligible participants. You can find information organized by program, company, and brand name as well as links to state resources, Medicaid information and articles on patient assistance programs.
- www.RxAssist.com is designed to provide health care providers with information to access pharmaceutical manufacturer's patient assistance programs.
- www.RxOutreach.com offers generic medications to qualified individuals.
- www.TogetherRxAccess.com is a prescription savings program for qualified individuals and families without prescription drug coverage.
- <http://www.scbn.org/pap.html> works with you and your doctor in a partnership for prescription assistance to get you the medication help that you need for only a fraction of the would be costs of the free medication that you receive.

SOCIAL SECURITY ADMINISTRATION

Toll Free: (800) 772-1213

Web site: www.socialsecurity.gov

Supplemental Security Income (SSI)

SSI is a federal program that pays monthly checks to people who are disabled, blind, and/or aged, and have

limited income and assets. People who receive SSI checks may also receive Social Security checks if they meet eligibility requirements.

Eligibility:

Age and Disability: An adult, age 18 and over, may be eligible if a mental or physical disability prevents the person from working for at least 12 months or is expected to result in death. A child under the age of 18 may be eligible. Social Security assesses the disability and the effect on everyday life in determining eligibility.

Social Security generally works with a state agency to decide whether the person is disabled or blind within the meaning of the law.

Assets and Income: In the case of a child, the family's income and assets are considered for eligibility. When the person is 18 or over, the family's income and assets are no longer considered for eligibility--only those of the individual. A person can have some assets and income and still qualify for SSI benefits.

You Can Work and Still Get SSI. If you want to work, there are special rules to help. You may be able to continue to get some money from SSI while you work. As you earn more money, your SSI checks will go down or stop. Even if your SSI checks stop, you may be able to keep your Medicaid coverage. The social Security staff can tell you more about the rules to help people who are disabled work.

Your SSI Payment: The basic Federal SSI payment for an eligible person or for an eligible couple may change each year. You may not get the basic federal payment amount. You may get less if you have income or if your husband or wife or parents have income.

Any time you have questions about SSI, call 1-800-772-1213. Ask for the free Booklet "SSI".

Other Considerations: A person with a disability must accept vocational rehabilitation services if offered. There are some United States residency and citizenship requirements.

After SSI payments begin, changes in income, assets, and living arrangements must be reported. The Social Security personnel are available to give information about the reporting process.

Usually people who receive SSI also receive a Medicaid (medical) Card and may become eligible for other state and county programs. If you are eligible for Social Security or other money benefits, you must apply for them.

TRAUMATIC BRAIN INJURY (TBI)

Trust Fund Benefit Management Program

Administered by:

Eckman/Freeman

P.O. Box 23578

Lexington, KY 40523

Toll Free: (800) 447-4984

Email: info@kybraininjuryfund.org

Web Site: <http://chfs.ky.gov/dms/Traumatic+Brain+Injury+Trust+Fund.htm>

Eligibility Requirements:

Medical eligibility: People with a partial or total disability caused by injury to the brain are eligible to receive support from TBI's Benefit Management Program. Injuries to the brain may be the result of physical trauma, damage resulting from a lack of oxygen, allergic conditions, toxic substances and other medical incidents, including damage caused by drug overdoses or alcohol poisoning. Eligible individuals have impaired cognitive abilities or impaired brain function.

Financial eligibility: People with brain injury and without viable funding sources for needed services are eligible to receive support from the TBI Benefit Management Program. There are no caps for family income levels used to screen for services. Lack of adequate funding may be the result of the exhaustion of current benefits or benefits exclusion.

Exclusions: Not covered under this program are: medications, institutionalization, hospitalization or services for anyone who is a resident of an institution or hospital.

The TBI Benefit Management Program is committed to helping people with traumatic brain injury maintain the highest quality of life possible through its services and support. The program encourages recipients to regain their independence through self-determination and local programming and services. This unique program gives individuals with brain injury the opportunity and support to enjoy community living. Services include: case management, community residential services, companion services, occupational therapy, prevocational services, psychological services, respite, speech and language services, structured day programs, supported employment and other services or supports.

Benefit Limits: Because the TBI Benefit Management Program is designed to supplement existing efforts to provide for individuals with brain injury, there are benefit limits. The benefit limit is \$15,000 per individual per year with a lifetime maximum of \$60,000. The program is not designed to provide intensive treatment or long-term support. However, the cost for case management services does not count against the person's annual or lifetime benefit cap.

To apply: Call toll free: 1-800-447-4984 between 8:00 a.m. and 5 p.m., Eastern Standard Time.

UNITED WAY HELPLINE - 211

This is a comprehensive information, referral and crisis telephone service that serves as a centralized clearinghouse to link people in need of services with appropriate community resources. It is accessible 24 hours, 7 days per week. Simply call 211.

Areas Currently Served in Kentucky:

Only 29 of 120 counties in Kentucky have access to information and referral call centers. Currently there are multiple locally-driven 2-1-1 initiatives in the planning stages or already operating.

Four Northern Kentucky counties – Boone, Campbell, Kenton and Grant - have fully operational 2-1-1 services through the efforts of United Way of Greater Cincinnati/Northern Kentucky.

Jefferson and 12 contiguous counties – Nelson, Trimble, Carroll, Henry, Bullitt, Oldham, Hardin, Shelby and Spencer Counties in Kentucky, and Clark, Floyd and Harrison Counties in Indiana – have established 2-1-1.

Clark County was the pilot community for the first 2-1-1 in the Lexington Bluegrass area and is now fully functioning. Other counties in the area are in the planning stages.

Representatives from all of these local initiatives are involved in the development of the statewide 2-1-1 plan. For information on 2-1-1 in other states or nationally, please visit www.211.org for the latest information.

SECTION 7

HEALTH/ DENTAL/ THERAPEUTIC CARE

HEALTH/DENTAL/THERAPEUTIC CARE

When our child, Cash, was first diagnosed with autism, we were totally intent on doing therapy with him. So intent, that the entire family “was involved in therapy.” Our home became a clinic. I was working myself to death trying every therapy that I heard about. Our family was falling apart. I decided that we needed to back off – “close the clinic” and re-establish our family and our home. When we did that, we began to appreciate Cash as our son rather than our child with a disability.

Ellen Nicholson, Manchester

As your son or daughter approaches adulthood, it is necessary to change from the pediatrician to a general practitioner. Often the family pediatrician will ignore the age limitation and continue to see the child with a disability during the teen years. The person with a disability may have specialists who will continue treating a disorder throughout the patient’s lifetime - - some may not.

When changing doctors, the family doctor should be consulted for referrals to those physicians he/she feels will be sensitive to your adult child’s health needs.

Medicaid covers services provided by participating health clinics. These services include basic diagnostic and therapeutic services, basic laboratory services, emergency services and services provided through agreement or arrangements.

Be sure to check the physician’s policy regarding Medicaid or Medicare.

DENTISTRY

CABINET FOR HEALTH AND FAMILY SERVICES (CHFS)

20 East 7th Street

Covington KY 41011

Phone: (859) 292-6660

Toll Free: (800) 635-2570

Web Site: www.chfs.ky.gov

On Friday, October 27, 2006, the Cabinet for Health and Family Services (CHFS) announced that more Kentucky children would be able to receive much-needed dental services due to recent changes designed to improve the oral health of KY Health Choices members. Specifically, the changes focus on dental prevention and treatment for children by increasing the reimbursement fee for Medicaid child dental services by 30 percent. An additional oral examination visit for children and an orthodontic reimbursement has been added to the Medicaid package as well.

CARDINAL HILL HEALTH CARE SYSTEM - EASTER SEAL OF KENTUCKY

Web site: www.cardinalhill.org

Services

In Lexington:

Cardinal Hill Rehabilitation Hospital

2050 Versailles Road

Phone: (859) 254-5701

Same Lexington Location:

Cardinal Hill Center-Outpatient Services

Phone: (859) 367-7125

Cardinal Hill Home Care

Phone: (859) 367-7148

Cardinal Hill Rehabilitation Unit

At Samaritan Hospital

310 South Limestone Street

Lexington, KY 40508

Phone: (859) 226-7700

In Louisville:

Cardinal Hill Rehabilitation Center/Easter Seals of Louisville
9810 Bluegrass Parkway
Phone: (502) 584-9781

In Northern Kentucky:

Cardinal Hill Special Hospital
Long Term Acute Care Hospital
At St. Luke Hospital East
85 North Grand Avenue
Ft. Thomas, KY 41075
Phone: (859) 572-3880

Cardinal Hill of Northern Kentucky
Adult Day Health Care
31 Spiral Drive
Florence, KY 41042
Phone: (859) 525-1128, Ext. 236
Referral Fax: (859) 525-1125
Adult Day Health Care Fax: (859) 371-0899
Email: lmw@chhs-nky.org

Cardinal Hill Healthcare System provides quality physical rehabilitation for children and adults. Services may include physical therapy, occupational therapy, speech-language pathology and respiratory therapy. Services also include inpatient, outpatient or home health care. Adult Day Care is available at some locations. Contact the location nearest you to find out what services are offered in that city.

COMMISSION FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

982 Eastern Parkway
Louisville, KY 40217
Phone: (502) 595-4459
Toll Free: (800) 232-1160
Fax: (502) 595-4673
Web site: <http://chfs.ky.gov/ccshcn/>

Eligibility Requirements: Children up to age 21 who are Kentucky residents who have a condition that usually responds to medical treatment that is provided within the program and meets financial guidelines.

The Commission for Children with Special Health Care Needs (CCSHCN) is a statewide healthcare program that provides treatment, including clinic services, office visits, tests, and medications, physical, occupational and speech therapy, audiology services, durable medical equipment, and more for Kentucky children with certain medical disabilities from birth to age 21. Services are provided for the following: asthma (severe), burns, cerebral palsy, cleft lip and palate, craniofacial, cystic fibrosis, ear, eye, hand, heart, hemophilia – pediatric (and adult), juvenile rheumatoid arthritis, neurology, neurosurgery, orthopedic, reconstructive surgery, scoliosis, seizures, spina-bifida. Other conditions may also be given individual consideration. The Commission does not cover primary medical care. All services must be authorized in advance by your care coordinator. For a listing of CCSHCN regional offices, see Early Childhood/School Age Services Section.

Regional Offices:

Ashland
5850 U.S. 60, Summit Plaza
Ashland, KY 41102
Phone: (606) 929-9155
Fax: (606) 929-9833
Toll Free: (800) 650-1329

Barbourville

110 Johnson Lane
P.O. Box 1330
Barbourville, KY 40906-5330
Phone: (606) 546-5109
Fax: (606) 546-4199
Toll Free: (800) 348-4279

Counties Served:

Boyd, Carter, Elliott, Floyd,
Greenup, Magoffin

Bell, Clay, Harlan, Jackson
Laurel, Rockcastle, Knox, Whitley

Bowling Green

495 Three Springs Road
Bowling Green, KY 42104
Phone: (270) 746-7816
Fax: (270) 746-7877
Toll Free: (800) 843-5877

Allen, Barren, Butler, Edmonson
Hart, Logan, Metcalf, Monroe
Simpson, Warren

Covington

2014 Eastern Avenue
Covington, KY 41014
Phone: (859) 815-1345
Fax: (859) 815-1346
Toll Free: (888) 542-4453, Ext.5135

Boone, Campbell, Carroll
Gallatin, Grant, Kenton
Owen, Pendleton

Elizabethtown

580 B Westport Road
Elizabethtown, KY 42701
Phone: (270) 765-6982
Fax: (270) 769-5121
Toll Free: (800) 995-6982

Breckinridge, Grayson, Hardin
Larue, Marion, Meade, Nelson
Washington

Hazard

68 Independence Drive
Hazard, KY 41701
Phone: (606) 435-6167
Fax: (606) 435-6164
Toll Free: (800) 378-3357

Breathitt, Knott, Lee, Leslie
Letcher, Owsley, Perry, Wolfe

Hopkinsville

712 West 15th Street
Hopkinsville, KY 42240
Phone: (270) 889-6047
Fax: (270) 889-6050
Toll Free: (800) 727-9903

Caldwell, Christian, Crittenden
Hopkins, Livingston, Lyon
Muhlenberg, Todd, Trigg

Lexington

333 Waller Avenue, Suite 300
Lexington, KY 40504
Phone: (859) 252-3170
Fax: (859) 225-7155
Toll Free: (800) 817-3874

Anderson, Bourbon, Boyle
Clark, Estill, Fayette, Franklin,
Garrard, Harrison, Jessamine
Lincoln, Madison, Mercer
Nicholas, Powell, Scott,
Woodford

Louisville (Central Office)

982 Eastern Parkway
Louisville, KY 40217-1566
Phone: (502) 595-4459
Fax: (502) 595-4673
Toll Free: (800) 232-1160

Bullitt, Henry, Jefferson
Shelby, Spencer, Trimble
Oldham (and statewide)

Morehead

214 West First Street
Morehead, KY 40351
Phone: (606) 784-3049
Fax: (606) 784-1388
Toll Free: (800) 928-3049

Bath, Bracken, Fleming,
Lewis, Mason, Menifee,
Montgomery, Morgan
Robertson, Rowan

Owensboro

1600 Breckenridge
P.O. Box 1823
Owensboro, KY 42302-1823
Phone: (270) 687-7038
Fax: (270) 687-7040
Toll Free: (877) 687-7038

Daviess, Hancock, Henderson
McLean, Ohio, Union, Webster

Paducah

400 Park Avenue, Bldg. D
Paducah, KY 42001
Phone: (270) 443-3651
Fax: (270) 441-7119
Toll Free: (800) 443-3651

Ballard, Calloway, Carlisle
Fulton, Graves, Hickman
Marshall, McCracken

Prestonsburg

5000 KY Route 321
Prestonsburg, KY 41653
Phone: (606) 889-1761
Fax: (606) 889-1766
Toll Free: (800) 594-7058

Floyd, Johnson, Magoffin
Martin, Pike

Somerset

Professional Plaza
401 Bogle Street, Suite 104
Somerset, KY 42503
Phone: (606) 678-4454
Fax: (606) 679-5599
Toll Free: (800) 525-427

Adair, Casey, Clinton
Cumberland, Green, McCreary
Pulaski, Russell, Taylor, Wayne

EASTER SEALS WEST KENTUCKY

801 North 29th Street
Paducah, KY 42001
Phone: (270) 444-9687
Toll Free: (866) 673-3565
Fax: (270) 444-0655
Email: <http://eswky.easterseals.com>

Easter Seals West Kentucky represents nearly half a century of helping people with physical and mental challenges to gain greater independence by providing quality services. Begun in 1954 through the merger of the McCracken County Cerebral Palsy Organization and the Crippled Children's Clinic, Easter Seals West Kentucky serves nineteen counties in Western Kentucky, plus areas in southern Illinois and southeastern Missouri.

Services provided by Easter Seals West Kentucky are: Inclusive Child Care, Intervention Services, Adult Day Services, Employment Connections and Production Services.

DEPARTMENT FOR PUBLIC HEALTH

Kentucky Cabinet for Health Services
Office of the Secretary
275 East Main Street
Frankfort, KY 40621
Web site: <http://chfs.ky.gov/agencies/health/>

Web site of local Health District's locations:

<http://chfs.ky.gov/NR/rdonlyres/F37BDF08-7C60-4E61-B001-29B8D2A68FE6/0/AlphaLHDListing90607.pdf>

**To contact the Cabinet by phone, you may call the Office of the Ombudsman:
Toll Free: (800) 372-2973 Voice or (800) 627-4702 TTY**

The Department for Public Health (DPH) coordinates a diverse group of programs that impact the health of all Kentuckians, including public health emergency, preparedness, maternal and child health, chronic disease, nutrition and wellness, environmental health, epidemiology, the state public health laboratory and working with the state's network of local health departments.

The Health Districts May Provide The Following:

Children

Prenatal Clinic
Post Partum
Family Planning
Blood Pressure Screening
Screening programs in
Coordination with the schools

Well Child Clinic
Early & Periodic Screening Clinic
Hearing & Vision
***WIC**
Immunization Health Records

***WIC**, funded by the U.S Department of Agriculture provides specific nutritious foods along with nutrition education to the participant at no cost. Services are provided to income eligible and nutritionally at-risk pregnant, breast-feeding and postpartum women, infants and children up to five years old. People who receive Medicaid or food stamp benefits automatically meet the income requirements for the WIC program. Income means the income received by the household during the month prior to application for WIC; it means all cash income. The Health Department staff with proof of income determines financial eligibility. To apply bring: proof of household income, i.e. pay stubs, W-2 forms, current medical card, proof of residence, i.e. current bill with your address, bank statement, lease agreement, mortgage agreement; proof of identity, i.e. drivers license, social security card, shot record, birth certificate, current medical card.

Adults

Adult Immunization
Identification & treatment of
Sexually transmitted diseases
TB Tests
Instruction for cancer

Nutrition classes
Diabetes Control Program
Hypertension Program
Pap smears-breast self-examination

Skilled Nursing, Speech Language Pathology, Physical Therapy, Occupational Therapy, Personal Care and medical supplies are provided to qualified patients with physician orders. EPSDT special services, Medicaid, Medicaid Wavier and indigent care are offered.

Health Department Services can include: Home services such as skilled nursing, personal care, respite, physical therapy, speech therapy, homemaker, nutrition services referrals, etc. WIC, Preconception Services, Prenatal, Family Planning, Pediatric Outreach and Follow-up, Preschool Clinics, Child Car Seats, SIDS/ Grief Counseling, Sexually Transmitted Disease, Aids Community Education, Smoking Cessation, Cancer, Diabetes, TB, Cardiovascular Disease, Communicable Diseases, Immunizations, Genetics and Metabolic Screening (PKU, Galactosemia, Sickle Cell, Congenital Hypothyroidism) and other community, school and environmental programs.

HEALTH KENTUCKY & KENTUCKY PHYSICIANS CARE PROGRAM

Phone: (800) 633-8100

Web site: <http://www.healthkentucky.org/>

Apply at your County Department for Community Based Services.

Eligibility Requirements:

1. Applicant must be a Kentucky resident between the ages of 19-64

2. Applicant cannot be covered by any other insurance including, Medicaid, Medicare, KCHIP, or Disability (SSI)
3. Income level for applicant must be at or below Federal Poverty guidelines. This can be determined when completing the application.

What is Health Kentucky? For many Kentucky residents the option of having access to healthcare does not exist. Families and individuals live in fear that one medical catastrophe could mean ruin for their future. A simple cold cannot be treated without incurring mounting medical bills. For those residents that are ineligible for any state programs, few options are left but the need still exists.

Addressing this need, Health Kentucky was created in 1984. Health Kentucky and the Kentucky Physicians Care Program's vision is that all uninsured Kentuckians living in poverty have access to quality healthcare.

Health Kentucky and the Kentucky Physicians Care program are unique because they encompass support solely from volunteers. Over 2000 physicians, 350+ pharmacies, and 6 major pharmaceutical manufacturers, 127 acute care hospitals volunteer their time and services to assist the Health Kentucky clients. They receive no incentives, rebates or monetary distributions for the services they provide. These volunteers make up the "safety net" that over 40,000 Kentuckians rely on. Support for Health Kentucky comes from private contributions and special events.

Health Kentucky cannot:

1. Pay past medical bills
2. Pay for prescriptions other than those approved for their program
3. It does not aid with motor vehicle accident or work related injuries
4. Assist with disability determination
5. Cannot assist patients in crisis (no immediate approval can be granted-application process takes 7-10 working days)

Health Kentucky was designed to aid those Kentuckians who are unable to afford quality healthcare. It is designed for *preventive care and not emergencies*.

THE UNDERWOOD AND LEE CLINIC

1800 Bluegrass Avenue, Suite A

Louisville, KY 40215

Phone: (502) 368-2348

The mission of the Underwood and Lee Clinic is to provide patient-centered, comprehensive dental services to people with intellectual and other developmental disabilities in a compassionate and professional clinic environment. And, to serve as the Commonwealth's premier center of excellence in delivering quality dental care and educating the next generation of dental professionals in the delivery of services to these patients. And, to continue to be a regional and national force in Developmental Disabilities Dentistry research and in the promotion of an improved standard of dental care for Americans with mental retardation and developmental disabilities.

The Clinic accepts private insurance as well as Medicaid. Call for an appointment – walk-ins will not be accepted.

SECTION 8

LEGAL/ ADVOCACY SERVICES

LEGAL/ADVOCACY SERVICES

“I would go to conferences and when guardianship wills and trusts were discussed, I let it go by me because our children are young and so are we. But then I got cancer. Just as I finished my last treatment, my husband had a major heart attack. Now, we are “paying attention” and are developing our plans. We know that our plans may change throughout the years but, it is better to change plans than to have nothing in place to protect our children.”

Trudy Abshire, Richmond

Until a person reaches the age of 18, parents are considered the “natural” guardians. According to Kentucky law, at age 18 children are “freed” from parental control. The law presumes the individual is capable of exercising the rights of an adult (regardless of the severity or complexity of the disability) unless the **court** has determined that the person is unable to care for their personal or financial needs.

Until 1982, legally disabled people in Kentucky were called “incompetent.” Those appointed to manage their affairs were called “committees.” When a person was declared incompetent, they lost almost all of their civil rights regardless of their abilities to manage some of their own affairs. There were major changes in the laws.

On July 1, 1982 a law went into effect which states that a person whose functional abilities are impaired can be declared disabled only in those areas in which they are actually unable to care for themselves or manage their finances. All rights, which they are able to exercise, are retained.

Under the new law, the terms “guardian” and “conservator” replaced the term “committee.” The term “disabled” replaced “incompetent.” The procedure by which a person is determined disabled was changed to provide more safeguards for the person with a disability.

Parents and grandparents concerned for the future of their adult child often establish savings accounts, trusts, and write wills to prepare for the future. However, eligibility for benefits such as SSI and Medicaid Cards are dependent on the adult’s absence of income and assets. These benefits also provide eligibility for other services. It is wise to check with your attorney before establishing a personal source of funds for your son or daughter (grandchild).

Kentucky’s Protection and Advocacy has developed a handbook, [Thinking About Guardianship](#). Contact them for a copy. Read more about Protection and Advocacy in the agency listing.

874K - THE UNITED COALITION
120 Sears Avenue, Suite 212
Louisville, KY 40207
Phone: (502) 894-0222
Fax: (502) 894-0635
Email: advocacyaction@bellsouth.net

The 2000 Census data shows that 874,156 Kentuckians have a disability – the number does not include those under five or those in institutions or prisons. This Coalition is made up of members of local and state organizations advocating for people with disabilities.

Their vision is: barriers to services are eliminated, whether they be physical, regulatory, financial, or attitudinal; the individual and his or her circle of support are informed so that they can exercise their freedom to make choices; individuals are able to gain and maintain employment and have the opportunity to become tax payers; all citizens are secure and protected in their communities; all persons, including educational, medical and judicial systems personnel, are educated about disabilities; and there is increased awareness of disabilities and reduction of the stigma often associated with them.

THE ARC OF KENTUCKY
706 East Main Street, Suite A
Frankfort, KY 40601
Phone: (502) 875-5225
Toll Free: (800) 281-1272
Fax: (502) 875-5226
Email: arcofky@aol.com
Web site: www.arcofky.org



The Arc of Kentucky is a part of a national grassroots movement whose majority of members are parents of children with intellectual and developmental disabilities. Local, State and National Arcs, through advocacy, are changing the nature of services from institutional to community options.

Its vision is for people with intellectual and developmental disabilities to be contributing members of schools, work places, churches, synagogues, neighborhoods and the community. The Arc values services and supports that enhance the quality of life through interdependence, friendship, choices and respect for individuals with intellectual and developmental disabilities.

The Arc of Kentucky has consistently developed advocacy-training programs. These training programs are open to individuals who have a disability and/or family members. Under the grants, expenses, often including respite, are included. Current initiatives are:

Advocates in Action – Self-Determination/Leadership Training. An innovative training program designed to train individuals with disabilities, family members, siblings of family members with disabilities and professionals working with people with disabilities.

Participants will hear the most up-to-date information on the most crucial issues facing individuals with disabilities and their families. There will be two statewide events; the first scheduled for this fall and the second in January. Participants must agree to attend both sessions.

Family to Family – Health Information and Education Initiative of Kentucky. One of ten agencies in the U.S., the Arc of Kentucky was awarded a Family to Family Health Information & Education grant in 2004. Through this project families have been provided training and information on special health care needs. It also provides a central information center and peer-to-peer support network. The statewide family-run center housed at The Arc of Kentucky office:

- Provides education and training opportunities for families with children who have special health care needs;
- Collaborates with existing Family to Family Health Care & Education Centers;
- Promotes the philosophy of individual and family-directed support;
- Connects families of children with special health care needs with other families who have similar needs and experiences.
- Gives families the opportunity to share information and support;
- Links families with local, state and national resources for families, including conferences, workshops, support groups, councils, agencies, web sites, books, newsletters, etc.; and
- Provides guidance for those who would like to become support families and parents.

The vision of The Arc's Family to Family Initiative is to enhance the ability of all Kentuckians to make responsible health care choices through education, training, mentoring, resources, and networking opportunities.

Aging Caregiver Project – Through funding from the Cabinet for Health and Family Services, Department for Aging and Independent Living, The "Kentucky Resource Market" One Stop Shop for Aging Caregivers, The Arc provides training regionally for individuals with disabilities, parents, family members, siblings, friends and service providers. The training series included "An Overview of Available Services and Supports – Planning Future Supports and Services for a Loved One with an Intellectual or Developmental Disability" and Estate Planning Workshops – Creating a Safe and Secure Future for a Loved One with an Intellectual or Developmental Disability."

They have produced several handbooks – [Kentucky General Assembly – Quick Resource Guide for Legislative Advocates](#) and [Hot Tips for Legislative Advocates](#). The Arc of Kentucky publishes [Hot Stuff](#), an accounting of disability news of the day laced with advocacy opinion. Contact the Arc for your copies.

ARMS COALITION

Advocates for Reforming Medicaid Services (ARMS) is a wide ranging coalition that includes family members, advocates and providers of long term care –aging and disability services concerned about changes in Kentucky’s Medicaid program. Thirty-five groups have joined together to seek changes in Kentucky’s Medicaid program that will ensure that beneficiaries have reasonable, high-quality and cost-effective choices of long-term care services and that consumers will be advised of changed in Medicaid. For more information, call The Arc of Kentucky, Toll Free: (800) 281-1272.

CHILDRENS LAW CENTER

104 East Seventh Street

Covington, KY 41011

Phone: (859) 431-3313

Fax: (859) 655-7553

Email: childrenslaw@fuse.net

Web Site: <http://www.childrenslawky.org/>

The Center was established in 1989 to protect and enhance the legal rights and entitlements of children in Kentucky through quality legal representation, research and policy development, training and education to attorneys and others regarding the rights of children. Our priorities include juvenile justice, child welfare, and education issues generally, as well as emphasis on improving the quality of and accessibility to legal representation, for children in Kentucky and Ohio.

The Children's Law Center represents young people in a variety of legal and administrative proceedings including child abuse and neglect matters, special education and other school issues, homelessness, juvenile justice issues, and "multi-system" cases. It also does training and education, research and public policy development, information and referral and develops special projects related to children and the law.

KENTUCKY COMMISSION ON DEAF AND HARD OF HEARING (KCDHH)

632 Versailles Road

Frankfort, KY 40601

Phone: (502) 573-2504

Toll Free: (800) 372-2907

Web site: <http://www.kcdhh.ky.gov/>

The Commission provides legislative advocacy on behalf of people who are deaf or hard of hearing. It also offers information and referral, advocacy and interpreter referral services. It also produces publications, maintains a resource library and manages a telecommunications access program for eligible Kentuckians.

KENTUCKY CONSUMER ADVOCATE NETWORK (KYCAN)

10510 LaGrange Road #103

Louisville KY 40223

Phone: (502) 245-5281

Toll Free: (800) 564-8034

Fax: (502) 245-6390

Email: kentuckycan@bellsouth.net

Web site: www.kycan.org

The mission of the Kentucky Consumer Advocate Network (KYCAN) is to empower mental health consumers to have hope, to take personal responsibility, advocate, educate, and to represent the consumer community before public and governmental bodies. Kentucky Consumer Advocate Network is Statewide, serving everyone in the community. No person or place in the Commonwealth is ever too far away for KYCAN to offer peer support services. Kentucky Consumer Advocate Network enjoys teaching and visiting on the site. If you would like for someone to come and present information about the Advance

Directive, Voting, How to Advocate, or even teach a BRIDGES Course or WRAP class, contact the office at the toll-free number. KYCAN has excellent references. If you would like to join KYCAN or have questions about a membership, call the office number or visit the website.

**KENTUCKY COUNCIL ON DEVELOPMENTAL DISABILITIES (KCDD)
DEPARTMENT FOR HEALTH/MENTAL RETARDATION SERVICES
100 Fair Oaks Lane, 4EF
Frankfort, KY 40621-0001
Phone Toll Free: (877) FOR-KDDC or (502) 564-7842
Fax: (502) 564-9826
Web site: <http://chfs.ky.gov/kcdd/>**

The KCDD mission statement is to create change through visionary leadership and advocacy so that people have choices and control over their own lives. The Council believes that people with developmental disabilities are citizens with the same rights and responsibilities as other citizens. They have the right to life, liberty, and the pursuit of happiness. People with developmental disabilities have the right to make choices for themselves and have control over their own lives. The Kentucky Council on Developmental Disabilities (KCDD) was authorized by Executive order of the Governor, in accordance with Public Law 106-402, the Developmental Disabilities Assistance and Bill of Rights Act.

Eligibility is open to individuals who have a disability, an immediate family member or guardian of a person with a developmental disability

KCDD has a limited pool of funds to make available as financial assistance for advocates (individuals with disabilities and or their families) in the developmental disabilities field to participate in conferences and short term educational programs. The Council provides this support as a method of capacity building for Kentucky. Through participation in regional and national conferences, Kentucky advocates can share information about local initiatives and learn from their counterparts in other communities. If a person attends a conference or educational program with Council support, two things are expected in return. First, a report to the Council describing what was learned and shared during the program and how the information applies to meeting the needs of Kentuckians with disabilities. Second, the individual will serve as a resource person to whom the Council can refer other citizens who are looking for information on the topic.

Apply for assistance to attend conferences or educational programs or advocacy by making a request. Include the conference brochure, dates, and location along with the amount of money being requested and the amount that the individual applying is contributing to the total cost. Enclose a copy of the conference brochure. Council travel policy complies with Kentucky State Travel Regulations.

For assistance in developing a request or for further information, call (502) 564-7842 or toll free, (877) 367-5332.

Check legislation by going to the web site www.kentuckydisability.org . The site allows you to:

- Spotlight state legislation concerning disabilities
- Find/contact your legislators
- Write letters, email or phone follow-up
- Send yourself e-alerts to track progress of bills important to you.

KENTUCKY'S LEGAL AID

Web site: <http://www.kyjustice.org/Home/PublicWeb/LegalSvcs>

Eligibility Requirements: Kentucky's legal services programs serve several groups of vulnerable Kentuckians: People 60 years old and older, those who meet income guidelines and in some cases, people who are victims of domestic violence.

Kentucky's legal services programs are independent, tax-exempt non-profit organizations that receive state funds and federal grants from the Legal Services Corporation, which also provided the funding for this website. Legal services programs also receive local support, including grants and donations.

Kentucky has four programs that provide a wide range of legal services to low income and elderly Kentuckians:

Program:

Appalachian Research & Defense Fund, Inc.

102 North Front Avenue
Prestonsburg, KY 41653
Phone: (606) 886-3876
Toll Free: (800) 556-3876
Web site: <http://www.ardfky.org>

Counties Served:

Adair, Bell, Breathitt, Casey, Clay, Clinton, Cumberland, Estill, Floyd, Garrard, Harlan, Jackson, Johnson, Knott, Knox, Laurel, Lawrence, Lee, Leslie, Letcher, Lincoln, McCreary, Madison, Magoffin, Martin, Monroe, Owsley, Perry, Pike, Powell, Pulaski, Rockcastle, Wayne, Whitley, Wolfe

Services: The Appair staff provides legal advice and representation to those facing a full range of poverty law problems including family law, housing, public benefits, consumer issues, utility cutoffs, employment and education law.

Kentucky Legal Aid – Main Office

520 East Main Street, P.O. Box 1776
Bowling Green, KY 42102
Phone: (270) 782-1924
Fax: (270) 782-1993
Email: klaid@klaid.org
Note: After 5:00 p.m. (CT) (270) 782-1926
Toll Free: (800) 782-1924 Clients only
Web site: <http://www.klaid.org>

Allen, Ballard, Barren, Butler, Caldwell, Calloway, Carlisle, Christian, Crittenden, Daviess, Edmondson, Fulton, Graves, Green, Hancock, Hart, Henderson, Hickman, Hopkins, Livingston, Logan, Lyon, McCracken, McLean, Marshall Metcalfe, Muhlenberg, Ohio, Simpson, Taylor, Todd, Trigg, Union, Warren, Webster

Services: Attorneys and other staff provide direct legal assistance to low-income families and individuals to resolve serious economic and social problems. Priority is given to cases that affect the client's ability to achieve long term self sufficiency. Benefits Counseling helps elderly and disabled people improve their quality of life by assisting clients to obtain benefits for which they qualify. Also provided are emergency and long term legal assistance to victims of domestic violence.

Legal Aid of the Bluegrass

302 Greenup Street
Covington, KY 41011
Toll Free: (800) 888-8189
Fax: (859) 431-3009
Web site: <http://www.lablaw.org>

Anderson, Bath, Boone, Bourbon, Boyd Boyle, Bracken, Campbell, Carroll, Carter Elliott, Fayette, Fleming, Franklin, Gallatin, Grant, Greenup, Harrison, Jessamine, Kenton, Lewis, Mason Menifee, Mercer, Montgomery, Morgan, Nicholas, Owen, Pendleton, Robertson, Rowan, Scott, Woodford

Call for services.

Legal Aid Society

416 West Muhammad Ali Blvd., Suite 300
Louisville, KY 40202
Phone: (502) 584-1254
Toll Free: (800) 292-1862 – Kentucky only
Fax: (502) 584-8014
Web site: <http://www.laslou.org>

Breckinridge, Bullitt, Grayson, Hardin, Henry, Jefferson, Larue, Marion, Meade, Nelson, Oldham, Shelby, Spencer, Trimble, Washington

Services: The only organization in Louisville and the surrounding counties that provides free civil legal services. Those assisted include the elderly, children, victims of domestic violence and other vulnerable groups.

Look for pro bono programs near you. Volunteer lawyers help realize the promise of justice for all. The "justice gap" in Kentucky is so severe that only 20 percent of low income Kentuckians' legal needs are addressed at present.

Statewide:

Kentucky Volunteer Lawyer Program, The Access to Justice Foundation

Primary Address: 535 West Second Street, Suite 101

Lexington, KY 40508-1284

Phone: (859) 255-9913, Ext. 18

Fax: (859) 231-5356

KENTUCKY DISABILITIES COALITION (KDC)

P.O. Box 1589

Frankfort, KY 40602

Phone: (502) 875-1871 Voice/TDD

Toll Free: (800) 977-7505

Fax: (502) 875-1982

Email: kydis@mis.net

Web site: www.geocities.com/kydisabilitiescoalition

The Kentucky Disabilities Coalition is a statewide alliance of consumers, family and professional groups dedicated to promote a better life for all Kentuckians with disabilities of all ages.

Visit their web site for more information on their activities.

KENTUCKY POOLED SPECIAL NEEDS TRUST (KPSNT)

C/O Cedar Lake Foundation

7984 New LaGrange Road

Louisville, KY 40222

Phone: (502) 425-5323

Fax: (502)-326-0092

Eligibility Requirements: Kentuckians with Intellectual and Developmental Disabilities

The Kentucky Pooled Special Needs Trust (KPSNT) has been established to give parents, family members and guardians the opportunity to put money aside for a person with mental retardation/developmental disability while assuring protection of the governmental benefits they currently have or may receive in the future. A person with mental retardation can open a sub-account for themselves.

KPSNT is made up of multiple sub-accounts, which are opened by Grantors (person who sets up the sub-account and provides the initial funds) for the Beneficiary (the person with mental retardation/developmental disability) who is the primary focus of the Trust and who is the intended recipient of distributions from the Trust.

Benefits of KPSNT are: legal fees have been paid by KPSNT, the trustee has been established and has experience with people with mental retardation, and a large sum of money is not needed to open a sub-account. For more information, call and send for their brochure.

KENTUCKY SELF-ADVOCATES FOR FREEDOM

A grassroots organization, it promotes self-advocacy for individuals with developmental disabilities.

Web site: www.kyselfadvocates.org/

MASSMUTUAL – FINANCIAL GROUP

2365 Harrodsburg Road, Suite A-300

Lexington, KY 40504

Phone: (859) 223-4141

Fax: (859) 223-0499

Email: cwheeler@finsvcs.com

MassMutual has carried the Exceptional Parent Symbol of Excellence since receiving it in 2004 in recognition of its commitment and service to people with disabilities and other special needs and their families. Mass Mutual helps families with financial planning for the future of a dependent child/adult with special needs. Check your phone book for other MassMutual offices in your community.

Met DESK

Web site: <http://www.jtgentry.metlife.com/>

Met DESK, MetLife's Division of Estate Planning for Special Kids, helps families with financial planning for the future of a dependent child/adult with special needs. Met DESK has a working relationship with the Autism Society of America, The Arc, Special Needs Advocate for Parents, National Organization for Rare Disorders and National Down Syndrome Society. Call the Metropolitan Life office in your area for more information.

NATIONAL ALLIANCE ON MENTAL ILLNESS, Kentucky Affiliate (NAMI Kentucky)

10510 LaGrange Road, Building 103

Louisville, KY 40223

Phone: (502) 257-5081

Toll Free: (800) 257-5081

Web site: <http://www.nami.org/MSTemplate.cfm?micrositeID=157>

National Alliance on Mental Illness (NAMI) is comprised of the parents, children, spouses, brothers and sisters, and friends of persons with serious and persistent mental illness throughout the state of Kentucky -- as well as those persons themselves.

NAMI Kentucky is a self-help organization that is part of a nation-wide network devoted to improving the lives of the seriously mentally ill and decreasing the prevailing stigma associated with mental illness. The national organization was founded in 1979 by 284 people. NAMI Kentucky is an affiliate. There are now over 1200 affiliate groups located in all 50 states. NAMI Kentucky represents over 1300 members/ households and has 22 affiliates plus newly forming affiliates throughout the state.

NAMI Kentucky is a non-profit 501(c) 3 organization. Our primary focus is to provide support, education and advocacy for those who have severe mental illnesses as well as their families. We strive as an organization to educate ourselves and the general public about the prevalence of mental illnesses, alternative treatments and the need for community facilities and services. We advocate for the rights of all persons affected by severe mental illness and for services to help those with mental illnesses to achieve the highest degree of independence and productivity possible. We encourage and support research on the cause and treatment of mental illnesses.

Call the state office for the local chapter near you.

PROTECTION AND ADVOCACY (P & A)

100 Fair Oaks Lane, 3rd Floor

Frankfort, KY 40601

Phone: (502) 564-2967

Toll Free: (800) 372-2988

Fax: (502) 564-0848

E-mail: <http://www.kypa.net/contact/question.html>

Web site: www.kypa.net

Eligibility Requirements: Information, referral and training are available to all. Individual representation is provided to children and adults in Kentucky who have a disability and (because of limited resources) whose situation fits a current agency priority.

Protection and Advocacy provides information, referral, and training on legal rights and disability related issues. Legally based advocacy is provided to people with disabilities.

Protection and Advocacy has numerous booklets and pamphlets which are available free by calling their office. A few titles are: Guardianship, How to Negotiate an Arc Meeting, Assistive Technology, Partners, Tips on IEPs, Kentucky Department of Education Formal Complaint, Kentucky Department of Education Mediation Book, Functional Behavior Assessment, 504 – The Other Service Option Parents and Students Need to Understand. Overview and comparison of Individuals with Disabilities (Improvement) Education Act (IDEA), Section 504 and Americans with Disabilities Act (ADA), Tips on Transition and the Office of Civil Rights (OCR)

STATE COORDINATOR FOR THE AMERICANS WITH DISABILITIES ACT

Norb Ryan, Kentucky ADA Coordinator

Education Cabinet

500 Mero Street

Capital Plaza Tower, 2nd Floor

Frankfort, KY 40601

Phone: (502) 564-3850, ext. 219

Email: NorbJ.Ryan@ky.gov

Web Site: <http://ada.ky.gov/>

Questions about the Americans with Disabilities Act (ADA)? Call or email.

SECTION 9

**RESPITE/
COMMUNITY
LIVING/
RESIDENTIAL**

RESPIRE/COMMUNITY LIVING/RESIDENTIAL

“After having a major heart attack, I realized that my wife, Connie, alone would not be able to handle the care our daughter Beth required. Institutional care was never an option for Beth.

I began to plan what would be the optimal residential situation for her. One part of that was that she should have the permanency that owning a home would give. I started talking to people and found those who were willing to follow the plan. The end result was Beth had her own home – five minutes from us, and five minutes from the hospital. I participated in the hiring, and sometimes the ‘letting go’ of staff. I met the neighbors on both sides of the house and across the street – I told them about Beth and her roommates. Not only were they neighbors, they were extra eyes for Beth. It about killed us to have her move out but Connie and I were comfortable that the plan was working for Beth; that she was well taken care of and happy in her own home.”

Doug Riddell, Frankfort

RESPIRE - (res-pit), a noun: pause, intermission, and reprieve.

Taking a break from one another is important to members of all families. For the person with a disability and their family, respite increases its significance when used as a deterrent to long-term institutionalization. Camping and weekend recreation programs should be considered respite opportunities.

RESIDENTIAL – There are many myths about “residential”. There is a community misconception that residential services are readily available. It is not unusual to hear parents say, “We are going to take care of “John ” as long as we can. We will only place him in an institution (group home, etc.) when we no longer can take care of him.” Professionals also believe that residential services are easily obtained.

One of the key factors is the funding source. Be sure to read the Financial section of this booklet.

The fact is residential services (community options, group homes, supervised apartments, nursing homes, institutions) have long waiting lists. Throughout the state and nation, there is a critical shortage of residential services, especially community-based residential options.

Families have declined an opening – preferring to wait until they can no longer take care of “John”. When that day comes - as it inevitably will, it is doubtful an opening will still be available. The result is that instead of a planned, supported, transition, the dependent individual, remaining family and the social service system enter crisis mode. Crisis solutions often hinge on availability. Options depend on what, when and where there is an opening - rather than a choice.

Each person may have a mental image of what is a residential program. For some, it is an institution. Institutions still exist in Kentucky.

Residential can best be described as a range of services. The move to keep people in their own communities spurred the development of group homes. There are also other types of living arrangements which may include living with a foster family, either as a child or as an adult, semi-independent living such as living in a boarding house arrangement or perhaps, living in an apartment with both family and staff support.

Increasingly, individuals with disabilities and their families are assuming greater autonomy in developing their community living plans. Supported Living Grants, Consumer Directed Options and Self Determination are some examples of a growing trend toward funds following the individual rather than service agencies.

Families need to plan for the future. Contact local residential agencies and discuss the types of alternatives currently available and those that need to be developed. Discuss the entrance criterion. The “rule of thumb” is the greater dependence of the resident, the greater supervision needed. With more independence (the ability to manage one’s own basic self-help needs, travel independently, assume household responsibilities), less supervision will be required and the environment will be less restrictive and more options available.

CENTERS FOR INDEPENDENT LIVING (CIL)

Centers for Independent Living (CIL) treat housing, transportation, attendant services, employment and discrimination as the interlocking problems that they are. They serve people with all kinds of disabilities, not just one group. CIL's have a package of services which include: information and referral, peer counseling, advocacy and independent living skills training. These programs teach self-help skills, inform people about existing disability programs and create new services to fill gaps. CIL's are non-profit and community-based are controlled by consumers – individuals who live with a disability – and are set up to achieve equal participation in our communities for people with disabilities.

CIL's maintain comprehensive files on the availability of resources, including a listing of accessible housing in the community. They can also help with more information on transportation and how to use it. Centers also assist in completing the Assistive Technology Loan Board application.

Center for Accessible Living
305 West Broadway, Suite 200
Louisville, KY 40202
Phone: (502) 589-6620
Phone: (502) 589-6690 TTY
Fax: (502) 589-3980
Email: info@calky.org
Web site: <http://www.calky.org>

Center for Accessible Living
1051 North 16th Street, Suite C
Murray, KY 42071
Phone: (270) 753-7676
Toll Free: (888) 261-6194
Phone: (270) 767-0549 TDD
Fax: (270) 753-7759
Email: info@calky.org

Disability Coalition of Northern Kentucky
525 West 5th Street, Suite 19
Covington, KY 41011
Phone: (859) 431-7668
Toll Free: (800) 648-6057 TTD/TTY/Voice
Fax: (859) 431-7668
Email: dcnky@fuse.net

BEST CIL, Inc.
624 Eastwood Avenue
Bowling Green, KY 42103
Phone: (270) 796-5992
Toll Free: (866) 286-3608
Fax: (270) 796-6630
Email: bestcil@bestcil.org
Web site: www.bestcil.org

Pathfinders for Independent Living
105 East Mound Street
Harlan, KY 40831
Phone: (606) 573-5777

Independence Place
824 East Euclid Avenue, Suite 101
Lexington, KY 40502
Phone: (859) 266-2807
Email: independenceplace@qx.net

In ten different regions in Kentucky, a full range of services is offered, including: comprehensive case work and coordination, group homes based in the local community, speech and occupational therapies, adult foster care and therapeutic foster care for children. Services vary from city to city.

HART SUPPORTED LIVING GRANTS
Kentucky Department of Mental Health/Mental Retardation
100 Fair Oaks Lane 4E-E
Frankfort, KY 40601
Phone: (502) 564-7702

Eligibility Requirements: Eligibility is quite broad. The Americans with Disabilities Act (ADA) definition is used - a physical or mental impairment - individuals who have a record or history of an impairment or are regarded as having a physical or mental impairment that substantially limits one or more major life activities. Major life activities include limitations in walking, talking, seeing, hearing, caring for oneself or working.

In 2006, the statute's name was changed to honor Jane Hart, the person who worked tirelessly to get this innovative legislation passed. Jane and her husband were the parents of two children, one of whom had an intellectual, developmental disability.

The law defines Hart-Supported Living as “grants which provide a broad category of highly flexible, individualized services which, when combined with natural unpaid or other eligible paid supports” provide the necessary assistance for the individual to live in the community. The statute requires that the Hart-Supported Living program promote:

- *Choice* over how, when and by whom supports are provided and over where and with whom a person with a disability lives;
- *Responsibility* of the person with a disability and his or her representative for managing grants and the provision of service under the grant;
- *Freedom* to live a meaningful life and to participate in the community with members of the general citizenry;
- Enhancement of *health and safety*;
- *Flexibility* of services that change as the person's needs change without the individual having to move elsewhere for services;
- Use of *generic* (not specifically for people with disabilities) and *natural supports*
- Well planned and proactive *opportunities* to determine the kinds and amounts of support desired, with the meaningful participation of the individual, the individual's family or guardian where appropriate, friends and professionals;
- *Home ownership or leasing* with the home belonging to the person with a disability, that person's family, or to a landlord to whom rent is paid.

The person who has a disability, their family or guardian designs a plan and creates the budget. They control the plan and the funds unless they wish to contract with a service provider to provide those services. The plan must focus on the needs of the individual. Each plan will be as different as the individuals who are writing it. Grants may be written for on-going supports in the community, one time funding or a combination of both supports and one-time requests. Deadline date for completed grants is April 1 of each year for possible funding starting July 1. This is a firm deadline. The Hart Supported Living program is administered by the Mental Health/Mental Retardation Regional Boards but are open to anyone who meets the Americans with Disabilities Act (ADA). Contact the Hart Supported Living Coordinator in your region or in Frankfort:

State Supported Living Coordinator

Department for Aging and Independent Living
275 East Main Street, 3WF
Frankfort, KY 40621-0001
Phone: (502) 564-6930
Fax: (270) 442-3268
Email: vondah.Vanderhorst@ky.gov

Region I – Four Rivers

425 Broadway, Suite 203
Paducah, KY 42001
Phone: (270) 442-5088
Email: wbrooks@wkrmhmr.com

Region II – Pennyroyal

P.O. Box 614
Hopkinsville, KY 42241
Phone: (270) 885-1601
Fax: (270) 887-9221
Email: mjohnson@pennyroyalcenter.org

Counties Served:

Ballard, Callaway, Carlisle, Fulton
Graves, Hickman, Livingston
McCracken, Marshall

Counties Served:

Caldwell, Christian, Crittenden
Hopkins, Lyon, Muhlenberg, Todd,
Trigg

Region III – River Valley

1100 Walnut Street, P.O. Box 1637
Owensboro, KY 42302
Phone: (270) 689-6500
Fax: (270) 689-6677
Email: sallyphillips@rvbh.com

Counties Served:

Daviess, Hancock, Henderson
McLean, Ohio, Union, Webster

Region IV – Lifeskills

P.O. Box 6499
Bowling Green, KY 42102-6499
Phone: (270) 901-5000, Ext. 1326
Fax: (270) 842-0054
Email: rhudson@lifeskills.com

Counties Served:

Allen, Barren, Butler, Edmonson
Hart, Logan, Metcalfe, Monroe
Simpson, Warren

Region V – Communicare

320 Ring Road
Elizabethtown, KY 42701
Phone: (270) 769-3377
Fax: (270) 769-6974
Email: apeters@communicare.org

Counties Served:

Breckenridge, Grayson, Hardin
Larue, Marion,
Meade, Nelson, Washington

Region VI – Seven Counties

3717 Taylorsville Road
Louisville, KY 40220
Phone: (502) 459-8221
Fax: (502) 459-8225
Email: bkrall@sevencounties.org

Counties Served:

Bullitt, Henry, Jefferson, Oldham
Shelby, Spencer, Trimble

Region VII – NorthKey

1201 South Ft. Thomas Avenue
Ft. Thomas, KY 41075-2421
Phone: (859) 781-5586
Fax: (859) 356-2549
Email: scrowley@northkey.org

Counties Served:

Boone, Campbell, Carroll,
Gallatin, Grant, Kenton, Owen
Pendleton

Region VIII- Comprehend

741 Kenton Station Road
Maysville, KY 41056
Phone: (606) 759-7161
Fax: (606) 759-4895
Email: chughes@comprehendinc.com

Counties Served:

Bracken, Fleming, Lewis, Mason,
Robertson

***Region X – Pathways**

P.O. Box 790
Ashland, KY 41105-0790
Phone: (606) 329-8588, Ext. 4072
Fax: (606) 325-4585
Email: prhodes@pathways-ky.org

Counties Served:

Boyd, Carter, Elliot, Greenup,
Lawrence, Bath, Menifee
Montgomery, Morgan, Rowan

Region XI – Mountain

104 South Front Street
Prestonsburg, KY 41653
Phone: (606) 886-4363
Fax: (606) 886-4434
Email: kryan@mtcomp.org

Counties Served:

Floyd, Johnson, Magoffin
Martin, Pike

Region XII – Kentucky River

115 Rockwood Lane
Hazard, KY 41701
Phone: (606) 436-5761, Ext. 255
Fax: (606) 436-0400
Email: Vicky.hudson@krccnet.com

Counties Served:

Breathitt, Knott, Lee, Leslie
Letcher, Owsley, Perry, Wolfe

Region XIII – Cumberland River

P.O. Box 568
Corbin, KY 40702
Phone: (606) 528-7010
Fax: (606) 528-9623
Email: kwake@cumberlandriver.com

Counties Served:

Bell, Clay, Harlan, Jackson, Knott
Laurel, Rockcastle, Whitley

Region XIV – Adanta

259 Parker's Mill Road
Somerset, KY 42501
Phone: (606) 679-4782, Ext. 227
Fax: (606) 678-5296
Email: lhandy@bluegrass.org

Counties Served:

Adair, Casey, Clinton
Cumberland
Green, McCreary, Pulaski, Russell
Taylor, Wayne

Region XV – Bluegrass

3161 Custer Drive, Suite 4
Lexington, KY 40517
Phone: (859) 272-7483, Ext. 246
Fax: (859) 272-9685
Email: kebrockman@bluegrass.org

Counties Served:

Anderson, Bourbon, Boyle, Clark, Estill
Fayette, Franklin, Garrard, Harrison,
Jessamine, Lincoln, Madison, Mercer,
Nicholas, Powell, Scott, Woodford

**Please note there is no Region IX.*

PERSONAL CARE ATTENDANT PROGRAM

DEPARTMENT FOR AGING AND INDEPENDENT LIVING

Contact for this Program is the Area Agency on Aging. Check the Consumer Directed Option (CDO) found in the FINANCIAL Section of this booklet

Web site: <http://chfs.ky.gov/agencies/os/dail/pcap.htm>

Eligibility Requirements: Participants must be 18 or older, have severe, physical disabilities with permanent or temporary recurring functional loss of two or more limbs, need at least 14 hours but no more than 40 hours of attendant care per week, be mentally capable of instructing and supervising attendants and be capable of preparing payroll and required employer tax statements.

The Personal Care Attendant Program helps severely physically disabled adults at risk of being institutionalized to live in their own homes and communities by subsidizing costs of personal attendant services. The personal care attendant, hired by the physically disabled adult, helps with personal care, housekeeping, shopping, travel, self-care procedures, meal preparation and other day-to-day activities.

SECTION 10

TECHNOLOGY

TECHNOLOGY

“Technology for me, a person who is blind, has made it easier to do what everyone else does. There are very few things that I cannot do because of technology – from the tape recorder, the talking watch, the computer that reads the daily newspaper and my mail to writing checks and the envelope to mail it. Now, with the Global Positioning Satellite (GPS) in cars, I believe that technology will lead to the day that I can travel anywhere independently and who knows, someday to drive.”

Tom Fricke, Ft. Wright

KENTUCKY ASSISTIVE TECHNOLOGY SERVICES (KATS)

KATS Network Coordinating Center

Charles McDowell Center

8412 Westport Road

Louisville, KY 40242

Phone: (502) 429-4484

Toll Free: (800) 327-KATS (5287)

TDD: (502) 429-7116

Fax: (502) 429-7114

Email: katsnet@iglou.com

Web site: <http://www.katsnet.org>

Eligibility Requirements: Children and adults with disabilities.

The KATS Network is “consumer” driven, i.e. it has an Advisory Council dominated by individuals with disabilities. It consists of a statewide network of organizations and individuals connecting to enhance the availability of assistive technology devices and services to improve the productivity and quality of life for individuals with disabilities. Through advocacy activities and capacity building efforts, the mission of this collaborative system is to make assistive technology information, devices and services easily obtainable for people of any age and any disability.

Services may include but are not limited to: Assistive Technology Services for Early Intervention, School Work, Home Leisure or Recreation * Loan Library of Assistive Devices * Adaptive Equipment and Toys * Funding Information & Referral * Assessments & Evaluations for Adaptive Equipment * Consultations on Appropriate Technologies * Workplace Accessible Technology * Vocational Assessments * Environmental Controls * Device Demonstrations * Recycled Assistive Technology Devices * Training and Technical Assistance * Plus affiliation with the Kentucky Assistive Technology Loan Corporation which provides low interest loans.

There are six regional assistive technology centers:

Appalachia Assistive Technology Partners at:

Carl Perkins Rehab Center &
5659 Main Street, Thelma, KY 41260-8609
Phone: (606) 789-1440, Ext. 139
Toll Free: (800) 443-2187
Fax: (606) 789-6341
Email: MelissaK.Hall@ky.gov
Web site: <http://cdpvtc.ky.gov/>

Cumberland River Comprehensive Care Center
1203 American Greeting Road
MAIL: P. O. Box 568, Corbin, KY 40702
Phone: (606) 528-7081, Ext. 255
Fax: (606) 528-5401
Web Site: www.cumberlandriver.com/as_tech.html

Bluegrass Technology Center

961 Beasley Street, Suite 140, Lexington, KY 40509-4120
Phone: (859) 294-4343 Voice/TDD
Toll Free: (800) 209-7767
Fax: (859) 294-0704
Email: office@bluegrass-tech.org
Web site: <http://www.bluegrass-tech.org>

Enabling Technologies of Kentuckiana (enTECH)

Spalding University, 851 South Fourth Street
Louisville, KY 40203
Phone: (502) 992-2448
Toll Free: (800) 896-8941, Ext. 2648
Fax: (502) 585-7104
Email: enTECH@spalding.edu
Web site: <http://www.spalding.edu/entech>

Redwood Assistive Technology Center

71 Orphanage Road, Ft. Mitchell, KY 41017
Phone: (859) 331-0880
Toll Free: (800) 728-9807
Fax: (859) 331-6177
Email: redwoodtech@redwoodrehab.org
Web site: <http://www.redwoodrehab.org>

Western Kentucky Assistive Technology Center

Wendell Foster Campus 815 Triplett Street
Owensboro, KY 42302
Phone: (270) 689-1738
Toll Free: (800) 209-6202
Fax: (270) 852-1491
Email: wkate@wfcampus.org
Web site: <http://www.wfcampus.org>

KENTUCKY ASSISTIVE TECHNOLOGY LOAN CORPORATION (KATLC)**KY Assistive Technology Loan Program**

209 St. Clair Street
Frankfort, KY 40601
Toll free: (877) 675-0195,
Fax: (502) 564-1268
Email: EDU.katlc@ky.gov
Web site: <http://www.katlc.ky.gov/>

Eligibility Requirements: Any individual who has been a resident of Kentucky for at least six consecutive months, and who either has a disability that permanently affects a major life activity, or is a parent, guardian or caretaker of an individual with a disability. The purpose of the loan must be to purchase assistive technology to be used by the individual with a disability. A nonprofit organization that provides assistive technology to individuals with disabilities may also apply if they can demonstrate how the adaptive equipment will be used for their potential customers.

Purpose: The Kentucky Assistive Technology Loan Corporation (KATLC) offers low interest loans through its lending partner, Fifth Third Bank, for qualified applicants who need any type of equipment or home modification that will increase an individual's mobility or enable them to become more independent. Whether it's a wheelchair, modified vehicle, hearing aids, or accessible entry to a home, individuals with disabilities are often faced with a costly and immediate need that most insurance programs do not cover. Assistive technology is defined as "any item, piece of equipment or device that enables an individual with a disability to improve his or her independence and quality of life". Examples may include hearing aids, computers, augmentative communication devices, wheelchair ramps, and van lifts. If you are not sure if the item you need qualifies under the program's guidelines, please ask.

The minimum amount that can be borrowed is \$500 and the maximum amount is \$25,000. The length of the loan is determined by the life expectancy of the assistive technology.

If assistance to fill out the forms or an alternative format is needed or if you want to check on the status of your application, please contact KATLC at the above address, by calling or by e-mail.

KENTUCKY ASSISTIVE TECHNOLOGY EXCHANGE (ATEX)

Contact the KATS Network – Toll Free: (800) 327-5287

Web site: www.katsnet.org/

Used assisted technology, home modifications, specialized equipment and more are listed on this web site. Sellers list the item, condition and selling price. Names and phone or email addresses are listed. Buy or sell on this site. If you would like to submit an item to be posted on the exchange list, please e-mail the KATS Network Coordinating Center Web Master at the address above.

SORENSEN VRS

Check out the Web site: <http://www.sorensonvrs.com/what/index.php>

Sorenson Video Relay Service (VRS) is a free service for the deaf and hard-of-hearing community that enables anyone to conduct video relay calls with family, friends, or business associates through a certified ASL interpreter via a high-speed Internet connection and a video relay solution (or VRS call).

There is no cost for any video relay calls completed through Sorenson VRS within the continental U.S. Deaf or hard-of-hearing individuals who use sign language to communicate can receive a free Sorenson VP-100 videophone. However, an application for a free Sorenson VP-100 videophone must be submitted. The Sorenson VRS sales team will first check to make sure that:

1. The application has been completely filled out.
2. The deaf or hard-of-hearing individual has a high speed Internet connection of at least 256K
3. An installer is available to set up the videophone for the deaf or hard-of-hearing individual

Due to the high demand for the free Sorenson VP-100 videophone, it can sometimes take several weeks for a videophone to be installed.

All VRS companies are funded by a federal fund administered by NECA (National Exchange Carriers Association) that funds traditional Telecommunication Relay Service (TRS). These funds are made available by a federal law, the Americans with Disabilities Act (ADA), which requires functional equivalency in telecommunications access. Sorenson Communications is reimbursed for the minutes of Sorenson Video Relay Service (VRS) calls that are interpreted. Sorenson Communications is not reimbursed for equipment that is supplied including videophones, routers, switches, or any other equipment.

SECTION 11

TRANSPORTATION

TRANSPORTATION

Speaking on “Disability as a Civil Right” at a NAACP conference in North Carolina, Scottie O’Neal, Executive Director of Disability Solutions in Hartsville, South Carolina was giving a presentation emphasizing that all the groups of Americans who had been disenfranchised by discrimination needed to band together and become one voice. An audience member stood and said how could Scottie know what was civil rights discrimination since he was white. He went on to talk about the courage it took for Rosa Parks to get out of her seat and walk to the front of the bus and sit down.

Scottie responded that he acknowledged and applauded the efforts and changes Rosa Park’s action brought about. “We know it took a lot for her to move to the front of the bus, but when we talk of discrimination and transportation, people with disabilities who use a wheelchair are still to this day sitting on the curb waiting just for the opportunity to get on the bus. And, it doesn’t matter which end.”

Scottie O’Neal, Hartsville, South Carolina

MEDICAID

Medicaid may pay for medical transportation. Check with the Cabinet for Health and Family Services listed in the FINANCIAL ASSISTANCE section of this booklet.

SECTION 12

**GLOSSARY OF
ACRONYMS**

GLOSSARY OF ACRONYMS COMMONLY USED IN KENTUCKY HUMAN SERVICES

504	Section 504 of the Rehabilitation Act of 1973
AAMR	American Assn. on Mental Retardation - changed to American Assn on Intellectual And Developmental Disabilities (AAIDD)
AAWB	American Assn. of Workers for the Blind
ABI	Acquired Brain Injury
ABA	Applied Behavior Analysis
ADA	Americans with Disabilities Act
AFB	American Foundation for the Blind
AAIDD	American Assn on Intellectual and Developmental Disabilities – changed from American Assn on Mental Retardation (AAMR)
APSE	Association of Persons in Supported Employment
ARC	Admissions and Release Committee (education term)
ARMS	Advocates for Reforming Medicaid Services
ASDN-KY	Autism Spectrum Disorders Network of Kentucky
ASHA	American Speech and Hearing Assn.
AXIS I	Diagnosis of Mental Health/Clinical Disorders
AXIS II	Diagnosis of Mental Retardation/Personality Disorders
AXIS III	Diagnosis of General Medical Conditions
AXIS IV	Psychosocial and Environmental Problems
BIAK	Brain Injury Association of Kentucky
CAP	Corrective action plan (education term)
CAP	Client Assistance Program (Protection & Advocacy)
CASE	Council for Administrators & Supervisors of Special Education (CEC)
CBI	Community based instruction
CCC	Comprehensive Care Centers
CEC	Council for Exceptional Children (includes gifted and culturally diverse students)
CCSHCN	Commission for Children with Special Health Care Needs
CHFS	Cabinet for Health and Family Services, recently changed from Cabinet for Families and Children (CFC), generally referred to as Cabinet for Human Resources or the Cabinet
DAIL	Department for Aging & Independent Living
DCBS	Division for Community Based Services, Cabinet for Health and Family Services
DD	Developmental Delay (eligibility category for special education services under IDEA in Kentucky) or Developmental Disability
DEC	Division for Early Childhood (part of Council for Exceptional Children CEC)
DME	Durable medical equipment
DMH	Division of Mental Health
DMR	Division of Mental Retardation – Developmental Disabilities
DMS	Department for Medicaid Services
DPH	Department for Public Health
DSM IV	Diagnostic and Statistical Manual of Mental Disorders – 4th Edition
DVR	Department for Vocational Rehabilitation
EBD	Emotional-behavior disability (eligibility category for special education services under IDEA in Kentucky)
EPSDT	Early and periodic screening diagnostic and treatment benefit
ESS	Extended School Services (under Kentucky’s Education Reform Act, KERA)
ESY	Extended School Year (under IDEA)
FAPE	Free appropriate public education
FBA	Functional Behavior Assessment
FERP0A	Family Educational Rights and Privacy Act
FMD	Functional Mental Disability (under Mental Disability eligibility category for special education services under IDEA in Kentucky)
FRC	Family Resource Center

FRYSC	Family Resource and Youth Services Center
HANDS	Health Access Nurturing Development Services
HCBS	Home and community based services (waiver) for elderly & disabled Individuals
HHA	Home Health Agency
HI	Hearing Impairment (eligibility category for special education services under IDEA in Kentucky)
HIPA	Health Insurance Portability and Accountability Act of 1996 (Federal)
ICF/MR	Intermediate Care Facility/ (people) with Mental Retardation
IDEA	Individuals with Disabilities Education Act (Individuals with Disabilities Education <i>Improvement Act</i> – 2004)
IEP	Individual education program (plan)
IFSP	Individualized Family Service Plan
JTPA	Job Training Partnership Act
KAAMR	Kentucky Chapter of the American Assn. on Mental Retardation
KAR	Kentucky Administrative Regulation
KARC	Former name of <i>The Arc of Kentucky</i>
KATC	Kentucky Autism Training Center
KATS	Kentucky Assistive Technology Services
K-CHIP	Kentucky’s Children’s Health Insurance Program
KCDD	Kentucky Council on Developmental Disabilities
KDC	Kentucky Disabilities Coalition
KDE	Kentucky Department of Education
KEA	Kentucky Education Assn.
KEIS	Kentucky Early Intervention System
KERA	Kentucky Education Reform Act
KIDS	Kentuckians Interested in Down Syndrome
KPFC	Kentucky Partnership of Families and Children
KRS	Kentucky Revised Statute
KSB	Kentucky School for the Blind
KSBA	Kentucky School Board Assn.
KSD	Kentucky School for the Deaf
KSHA	Kentucky Speech and Hearing Assn.
K-TAP	Kentucky Transitional Assistance Program (formerly Aid to Dependent Children-AFDC))
LD	Specific Learning Disability (under category for special education services under IDEA in Kentucky)
LDA	Learning Disabilities Assn. Of America (formerly Assn. For Children with Learning Disabilities, ACLD)
LEA	Local Educational Agency (also any other public institution agency including The Kentucky School for the Blind (KSB) and The Kentucky School for the Deaf (KSD)
MCHB	Maternal and Child Health Bureau
MCO	Managed Care Organization – a Medicare Advantage health plan
MD	Multiple Disabilities (eligibility category for special education services under IDEA in Kentucky)
MMD	Mild Mental Disability (under Mental Disability eligibility category for special education services under IDEA in Kentucky)
MFP	Money Follow the Person
NAMI	National Alliance for the Mentally Ill
NAVH	National Assn. For Visually Handicapped
NCLB	No Child Left Behind (formerly ESEA)
OCR	Office for Civil Rights under the U.S. Department of Education
OI	Orthopedic Impairment (eligibility category for special education services under IDEA in Kentucky)
OHI	Other Health Impaired (eligibility category for special education services under IDEA in Kentucky)

OSEP	Office for Special Education Programs under the U.S. Department of Education – Office for Special Education and Rehabilitation Services
OSER	Office for Special Education and Rehabilitation Services, U.S. Department of Education
OT	Occupational Therapy
OVR	Office of Vocational Rehabilitation (sometimes referred to as Vocational Rehabilitation, DVR or BVR)
P&A	Protection and Advocacy System
PC	Primary Care
PCP	Person Centered Planning
PCCM	Primary Care Case Management
PECS	Picture Exchange Communication System
POE	Point of Entry
PRO	Immediate Peer Review Organization (Medicare)
PT	Physical Therapy
SCL	Supports for Community Living
SL	Supported Living Grants
SLP	Speech Language Pathologist
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
SNF	Skilled Nursing Facility
TANF	Temporary Assistance to Needy Families (Federal – formerly Aid to Families with Dependent Children – AFDC)
TASH	Formerly named the Assn. For Persons with Severe Handicaps – the organization now describes itself by the functional abilities of the individuals for whom they advocate.
TBI	Traumatic Brain Injury (eligibility for special education services under IDEA in Kentucky)
TEFRA	Tax Equity & Fiscal Responsibility Act of 1982 (Federal Act)
TCS	Therapeutic Child Support Services
The ARC	Formerly the National Assn. for Retarded Citizens
UCP	United Cerebral Palsy
UAP	University Affiliated Program
VI	Visual Impairment (eligibility for special education services under IDEA in Kentucky)

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JOIN
THE ARC OF KENTUCKY
FAMILY TO FAMILY HEALTH
INFORMATION & EDUCATION INITIATIVE
NOW!

In Kentucky

Several thousand children have chronic or acute health conditions that may limit their school and play activities.

All children deserve quality health care.

**Where do families turn?
for guidance?
A friendly voice?
Words of encouragement?**



Kentucky Family to Family can help.



**Connect
With another family who has
knowledge or experience
that you need**



OR

Sign Up

**With Kentucky Family to Family Health Information &
Education Initiative
as a support family**



**The Arc of Kentucky
FAMILY TO FAMILY HEALTH INFORMATION & EDUCATION INITIATIVE
Registration Form**

Kentucky Family to Family Health Information & Education Initiative is a network for families that have children with special health care needs. We offer opportunities for families to connect with one another to share experiences, information, and/or support.

We, as families of people with special needs, often find that our best source of information, resource and support comes from other families who have lived with similar experiences. Thank you for helping us build a Family to Family resource network in Kentucky.

By completing the information below, you are agreeing to act as a Family to Family resource for other families of people with special needs in Kentucky. **The information you provide in the starred areas below (*) will be published in the Family to Family database and Family Resource Directory.** You have the option to accept phone calls or e-mails from families of people with special needs. You also have the option to share your personal knowledge and experience in the areas you check on the opposite side of this form. Please return completed forms to: **The Arc of Kentucky Family to Family Health Information & Education Initiative, 706 East Main St., Suite A, Frankfort, KY 40601(1-800-281-1272) (502) 875-5225, fax: (502) 875-5226, or email: ArcofKY@aol.com**

PLEASE PRINT

*Name: _____ *Email _____

Address: _____ *City: _____ State: _____ Zip: _____

*Phone #: _____ *Language(s) spoken: _____

*Preferred time to be contacted by phone: ___ Day ___ Evening ___ No preference

Your family members special need, birth date, and gender (if you have more than one family member with special needs, please list each one separately):

<u>Special Needs</u>	<u>*Birth Date</u>	<u>*Gender</u>
_____	_____	_____
_____	_____	_____
_____	_____	_____

*Do you belong to any groups or organizations or participate in any activities that relate to people with special needs and their families? If so, please list: _____

Please check those that apply:

_____ I am willing to have other families contact me by **phone** and permit Kentucky Family to Family to publish my phone number for this purpose.

_____ I am willing to have other families to contact me by **email** and permit Kentucky Family to Family to publish my email address for this purpose.

How did you hear about Family to Family? _____

Signature _____ **Date** _____

Note: You can retract or update this information at any time by calling or emailing The Arc of Kentucky Family to Family Information & Education Initiative.

(Do not feel that you need to be an EXPERT to check an area – just that you have some experience. Views families share with each other will be based on personal life experience and should not substitute for the advice of qualified professionals.) **I/We have some experience in the areas checked below and would welcome the chance to share those experiences with other families.**

EDUCATION:

- | | |
|------------------------------------------------------------------|-----------------------------------------------------|
| <input type="checkbox"/> Early Intervention | <input type="checkbox"/> Hospital schooling |
| <input type="checkbox"/> Navigating the transition to pre-school | <input type="checkbox"/> Home schooling |
| <input type="checkbox"/> Navigating the special education system | <input type="checkbox"/> School bus issues |
| <input type="checkbox"/> School inclusion | <input type="checkbox"/> School athletics and clubs |
| <input type="checkbox"/> After school care | <input type="checkbox"/> 504 Plans |
| <input type="checkbox"/> IEP Plans | |

HEALTH CARE- (including behavioral health):

- | | |
|----------------------------------------------------------------------------------|-----------------------------------------------------------------------------|
| <input type="checkbox"/> Diet and nutrition interventions | <input type="checkbox"/> Hygiene, grooming, self-dressing |
| <input type="checkbox"/> Navigating SSI/Medicaid system | <input type="checkbox"/> Social skills |
| <input type="checkbox"/> Challenges of caring for medically fragile person | <input type="checkbox"/> Grieving and loss |
| <input type="checkbox"/> Accessing/managing/supervising in-home supports | <input type="checkbox"/> Accessing specialty clinics |
| <input type="checkbox"/> Acquiring durable medical equipment (including diapers) | <input type="checkbox"/> Primary care physicians familiar with disabilities |
| <input type="checkbox"/> Positive behavior support with disabilities | <input type="checkbox"/> Hospital stays |
| <input type="checkbox"/> Issues of multiple disability | <input type="checkbox"/> Health policies/insurance |
| <input type="checkbox"/> Accessing dental care | |
| <input type="checkbox"/> Feeding problems | |

TECHNOLOGY:

- Augmentative communication
- Assistive technology for learning
- Low Tech devices

TRANSPORTATION:

- Public transit
- Specialized vans
- Air travel (accessibility, metal detectors)

COMMUNITY INCLUSION:

- | | |
|-------------------------------------------------------------------------------|---------------------------------------------------------|
| <input type="checkbox"/> Child care | <input type="checkbox"/> Community safety (e.g. police) |
| <input type="checkbox"/> After school care ID registration, home safety tips) | |
| <input type="checkbox"/> Inclusion in community recreational activities | <input type="checkbox"/> Taking family vacations |
| <input type="checkbox"/> for children | |
| <input type="checkbox"/> for teens | |
| <input type="checkbox"/> Inclusion in faith communities | |
| <input type="checkbox"/> Support groups | |
| <input type="checkbox"/> For person with disability | |
| <input type="checkbox"/> For family members | |

EMPLOYMENT AND ADULT SUPPORTS:

- | | |
|------------------------------------------------------------------------------------|-----------------------------------------------------|
| <input type="checkbox"/> Accessing meaningful employment in the community | <input type="checkbox"/> Understanding the adult DD |
| <input type="checkbox"/> Working with the Office of Rehabilitation Services System | |
| <input type="checkbox"/> Creative-housing supports for adults with disabilities | <input type="checkbox"/> Person directed funding |
| <input type="checkbox"/> Living independently | |

PLANNING FOR THE FUTURE:

- | | |
|-----------------------------------------------------------------------------|----------------------------------------------------|
| <input type="checkbox"/> Alternatives to guardianship | <input type="checkbox"/> Self-determination |
| <input type="checkbox"/> Special needs estate planning (wills, trust, etc.) | <input type="checkbox"/> Supported decision-making |
| <input type="checkbox"/> Person-centered planning | |

OTHER AREA(S) NOT LISTED ABOVE (please specify) _____

