Autism Spectrum Disorders

Pervasive Developmental Disorders

Family Resource Booklet

KU CENTER FOR CHILD HEALTH & DEVELOPMENT
The University of Kansas Medical Center

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Learning that your child has an Autism Spectrum Disorder can be overwhelming. It can also be a relief. It is normal to feel a range of emotions and normal for family members to process their emotions differently. Take time to care for yourself and each other.

It is important to remember that your child, after being diagnosed with an Autism Spectrum Disorder, is still the same child as before the diagnosis. It may take time to come to terms with this new information. Learning more about autism can help equip you to provide what is best for your child. Although there is no cure, intervention can decrease some of the characteristics. The earlier an intervention is initiated the better. Treatment, tailored to your child's needs, can result in improved communication, social skills, and behavior.

It is our hope that this resource booklet will be helpful to you. Our goal is to provide family-centered services for all children. Our evaluations are provided by doctors and clinicians who specialize in developmental disabilities. We use current, standardized assessment tools and proven observation methods. Our recommendations are based on researched best practices.

This booklet was developed to assist you in learning about and connecting you with resources in the community and beyond.

For more information on resources, general questions or concerns, please contact the

CCHD Parent Educator at

913 588-5741

pyoung@kumc.edu

TIP: Get connected with other parents. Try locating a support group in your area or bring together parents of children with similar concerns.

What Are The Autism Spectrum Disorders (ASD)?

Autism Spectrum Disorders affect three major areas of development:

Communication **Social Skills** **Behavior**

Communication concerns include delayed speech, lack of gestures such as pointing, or the continuous repeating of certain words or sounds. This can range from an individual who is nonverbal to not being able to interpret body language or to participate comfortably in a two-way conversation.

Social concerns may include poor eye contact, lack of interest in other children, or not being able to appropriately interact with people. This can range from isolating oneself from others socially to experiencing social awkwardness in making and maintaining ongoing relationships.

Behaviors that are repetitive and unusual might include strict adherence to routines or obsessive interests, flapping of hands, or walking on tiptoes. Individuals may exhibit rigidity in thought processes, which can include difficulty with learning abstract concepts, generalizing information, and tolerating changes in routines and/or environments.

When each of these areas are delayed or there is a lack of specific skills, the diagnosis of an *Autism Spectrum Disorder* may be given. Autism is a syndrome, which means that it is a condition defined by the existence of a collection of characteristics. Autism spectrum disorders can usually be reliably diagnosed by age 3, although new research is pushing back the age of diagnosis to as early as 6 months. It is a life-long developmental disability that impairs typical development.

Types of Autism Spectrum Disorders

Autistic disorder

When a child meets all the necessary criteria listed in the *DSM-IV-TR* the diagnosis of Autistic disorder is given. Children with Autistic disorder have problems with language skills that are absent, delayed, or abnormal. They have difficulty in relating to others socially, understanding the give-and-take of everyday interactions, and problems with interpreting what others are thinking. Some children will have intellectual deficits and others may appear to have deficits because it is difficult to obtain reliable scores on intelligence tests due to lack of cooperation. Repetitive behaviors are usually present in the form of odd repetitive motions and/or a persistent preoccupation with objects or routines.

Asperger's disorder (Asperger's syndrome)

A developmental disorder characterized by a lack of social skills; difficulty with social relationships; poor coordination and concentration; and a restricted range of interests with normal intelligence and adequate language skills in the areas of vocabulary

and grammar. An individual with Asperger's Disorder does not possess a significant delay in language development; however, he or she may have difficulty understanding the subtleties used in conversation, such as irony and humor.

PERVASIVE DEVELOPMENTAL DISORDER—NOT OTHERWISE SPECIFIED (PDDNOS)

Children with *PDDNOS* do not fully meet the criteria of symptoms to diagnose any of the four specific types of Pervasive Developmental Disorders (i.e., Autistic Disorder; Rett's Disorder; Childhood Disintegrative Disorder; Asperger's Disorder) and do not have the degree of impairment described in any of the previous listed types. It means that autistic-like characteristics affect the child across developmental areas, but there are not enough characteristics to warrant a diagnosis of Autistic Disorder or Asperger's Disorder.

MEDICAL HOME

Our belief at the CCHD is to encourage the establishment of a *medical home.* As defined by the American Academy of Pediatrics it is a place of care that is continuous, comprehensive, compassionate, and culturally responsive to the needs of families. It involves the cooperation between the parents, pediatrician, and other health care professionals to work together with others that support the child. This typically involves the child's educational and developmental supports. A medical home is particularly important for children with special needs who are likely to require specialized care and services.

As a parent you will probably become quite knowledgeable in regards to your child's developmental disability. You are the constant in your child's life. The knowledge and opinions that you bring to any setting should be recognized and respected.

Source: Adapted from www.aap.org

Diagnostic Evaluations

A variety of assessment tools can help in arriving at a diagnosis. The assessment tools often used include the:

Childhood Autism Rating Scale (*CARS)*
Autism Diagnostic Observation Schedule (ADOS)
Autism Diagnostic Interview-Revised (ADI-R)
Checklist for Autism in Toddlers (CHAT)

Criteria from the *Diagnostic and Statistical Manual of Mental Disorders—4th Edition Text Revision (DSM-IV –TR)* must also be met. This manual is used universally by physicians, psychologists, psychiatrists, and others to evaluate conditions. It lists characteristics specific to autism.

Lesser known *Pervasive Development Disorders* are *Rett's Disorder* and *Childhood Disintegrative Disorder.* These disorders cause severe regression after a period of typical development to the point where the child is extremely impaired.

How Common Are Autism Spectrum Disorders and What are the Causes?

Prevalence

Autism occurs at a rate of about 1 in every 150 persons worldwide. The prevalence of autism has dramatically increased in the past few years. It could be due to a more informed society requesting evaluations. It could be due to better tools for evaluating. It could be due to the increase in early screening of children in school programs. The reasons continue to be explored.

Although it has a biological cause, there are not medical tests to recognize the biological indicators of *Autism Spectrum Disorders.* Research is being done to consider genetic conditions and brain differences, as well as environmental and metabolic effects.

Disorders/Vaccinations

There are theories that *ASD* might be caused by MMR vaccinations, vitamin deficiencies, or food allergies. Research is not conclusive, but at this time evidence does not support these theories in large numbers of children.

Other Conditions

There are conditions where characteristics of autism are frequently present. These include Fragile X syndrome, Phenylketonuria (PKU), and Tuberous Sclerosis. For this reason, when a child is diagnosed with an *Autism Spectrum Disorder*, high resolution chromosomes and Fragile X testing will commonly be recommended. Sometimes lead testing will also be recommended since the effects of lead poisoning can result in characteristics of autism.

Now What Do I Do?

After familiarizing yourself with Autism Spectrum Disorders, you may be asking yourself, "Now what do I do?". This can be a stressful time. You may experience a range of emotions as you adjust to the news. You will also encounter a whole new language of acronyms, terms, and definitions. Along with this you may be trying to navigate unfamiliar territory within the service system. Your physician and/or specialist may have given you specific recommendations for a treatment plan to work toward for your child. Sometimes those recommendations include services in which there may be a wait list or other obstacles that make it difficult to get those services, which is frustrating. It is important to talk with those professionals who are working with your child to find out what you can be doing to help your child.

We have outlined for you in this packet a brief overview describing what Autism Spectrum Disorders is and also where to find information on public and private services. Things to keep in mind to help you learn how to support your child are:

- Contact Infant-Toddler Services or Tiny-K in Kansas, or First Steps (Missouri) if your child is younger than 3 (see early intervention services page 10). Contact your local school district if your child is 3 years and older for early childhood services. If your child is receiving early intervention services then you can learn from these home visits. Ask questions! These professionals are there to help you help your child develop new skills. Talk with and observe closely how specialists play, talk, and praise your child.

- Join a local parent support group. If one is not available in your area then contact Families Together (Kansas) or MPACT (Missouri Parents Act) to connect you with a parent who is sharing a similar experience.

- Contact your local CDDO in Kansas or the Missouri Regional Center in your area. These points of entry offer supports and services for your child and family.

- Follow through on recommendations given by your child's evaluation team on any medical tests or other assessments that may have been recommended. Establish a Medical Home for your child (see page 6).

- Read as much as you can about autism spectrum disorders. Go to your local library to research more about your child's diagnosis or start your research with the websites shared with you in this booklet.

- Carefully investigate therapies that you read about. If you have questions regarding these therapies call your child's doctor or specialist to get their opinion.

- Become aware of and learn about the special education process and the development of an IEP (Individualized Education Plan). You are your child's best advocate and are a valuable team member. You can access information online or by contacting Families Together in Kansas or MPACT in Missouri (see page 12).

- Remember that you can be doing many things with your child at home or in the community. Activities that are part of your natural routine can help to provide opportunities in the areas of social skills and language development. Also, reading books, singing, and simply talking to your child will help to increase your child's vocabulary and provide increased learning opportunities. Try this website for some fun and creative ways to learn at home: http://www.nea.org/parents/ppower.html

Importance of Good Record Keeping

It is important to keep the paperwork you gather organized. Information from medical visits, school meetings, therapies, and other types of support will be accumulating. It will make your life much easier when it is time to find that information when requested. Here are some tips:

- Get 3-ring binder(s) and dividers. Make divider labels that organize the paperwork so it is easily found by you when needed. You may wish to have a binder just for medical and divide it according to office visits; medications prescribed; immunizations; over-the-counter medications recommended by your physician, etc. Other binders may be just for school; therapies; providers; and community resources, etc.

- Keep a hole punch handy to make sure the information you gather gets placed in the binder as it is collected and not left to stack up on you.

- Date all information you keep. It will be very helpful to know when this information was shared with you.

- Keep in mind it is valuable to look back and note the progress your child has made. Good record keeping will make it easier to track your child's progress and determine what interventions were successful.

TREATMENT OPTIONS

There is no **cure** for *ASD.* However there are a variety of treatments that can improve your child's behavior, communication and social skills. The earlier in your child's life that these interventions begin, the more effective they can be. There is no single treatment protocol for all children with autism, but most individuals with ASD respond best to highly structured educational programs. Some of the most common interventions are Applied Behavior Analysis (ABA), Floortime Therapy, Speech Therapy, Occupational Therapy, PECS, SCERTS, Sensory Integration Therapy, Relationship Development Intervention, Verbal Behavior Intervention, and the school-based TEAACH method. More information on the above listed therapies go to www.autismspeaks.org/

Behavioral techniques that work well with our children are derived from *(ABA) Applied Behavior Analysis* and may include *(DTT) Discrete Trial Training.* These methods may be used one on one or in small groups with generalization planned for natural environments. They are primarily used to improve functional skills. They can also be used to teach and reinforce communication and social skills. These techniques can also be used to decrease challenging behaviors.

WHAT MEDICAL OR ALTERNATIVE TREATMENTS ARE SAFE?

There is no medication to specifically treat autism. However, medication can sometimes treat particular symptoms. These symptoms could be poor attention or hyperactivity, and also could be anxiety or aggression. Work closely with your developmental pediatrician, psychiatrist, or your child's doctor so that medications are used safely. Sometimes dosages need to be adjusted or different medicines need to be tried before the most effective medicine or combination of medicines for your child is found. Recording changes in symptoms or your child's response to medication is an important part of your role in working with the doctor.

Several alternative interventions are special diets that eliminate foods containing gluten or casein. These are usually found in breads and dairy products. It is important to provide a balanced diet for our children that include a variety of foods. Be sure to keep food records and report any changes in your child's symptoms if you try this *alternative* treatment. Another treatment some families try is increased doses of vitamins, especially vitamin B6. More invasive *alternatives are* chelation therapy to remove mercury and other chemical substances from the child's bloodstream and the use of secretin injections. All of these *alternative treatments* are considered controversial and research is not available to support their effectiveness on large numbers of children with *Autism Spectrum Disorders.* Should you involve your child with any *alternative therapies,* please inform your child's doctor so that progress and conditions can be monitored.

Challenging Behaviors

There are many ways to address challenging behaviors. If those behaviors are occurring in the school setting or if your child is very young, his early intervention or early childhood education team can include this on the IFSP (Individual Family Service Plan) or the IEP (Individual Education Plan). Most school districts have an autism/behavior specialist who can work directly with your child and/or as a consultant to your child's education team. If those behaviors are occurring at home, you may want to work with a behavior therapist covered by your insurance plan, Medicaid (if your child is eligible), or private pay. Each state has a variety of providers that you can contact.

The following clinic is provided through the CCHD at KU Med Center:
CCHD Developmental Disabilities Pediatric Problem Behavior Clinic
Information can be found on our website at www.kumc.edu/cchd or call 913-588-5900.

Kansas

KS Institute of Positive Behavior Supports (KIPBS) - 785-864-4096 www.kipbs.org. Services covered by Medicaid or private pay.

Early Childhood Autism Project (ECAP) 785-865-5520 ext. 320 Services covered by Medicaid or private pay.

Community Developmental Disability Organization (CDDO) - Child must be 5 years or older, meet eligibility criteria and be on the waiting list for a Medicaid Waiver (CDDOs listed at the back).

Missouri

Regional Center for the Missouri Department of Mental Health, Division of Developmental Disabilities (Centers are listed at the back)

Social skills development

People who have Autism Spectrum Disorders (ASD) often have an impaired ability to develop social skills. They may not naturally understand such things as…

- Facial expressions
- Gestures
- Body language
- Tone of voice
- Interpersonal skills

Direct instruction, peer modeling, and practice in a variety of settings can be a very helpful part of a treatment plan. Teach appropriate social skills while participating in normal daily activities. Typically developing children may serve as peer models.

Center for Child Health and Development (CCHD) at KUMC: Social Skills Training
Girls Night Out—Adolescent and young adult women with developmental disabilities
Social Skills Groups—Frequency of groups and age range will be based on current demand for services. Groups will run 8-12 weeks. Information can be found on our website at ww.kumc.edu/cchd or call 913-588-5900.

Kansas Autism Center for Research and Training will offer training for service providers and school district personnel for implementation of social skills for ASD. Information can be found at www.kcart.ku.edu/

EARLY INTERVENTION SERVICES

For children **under 3** years of age, in-home direct services, will be provided as needed. This may include speech and language therapy, occupational therapy, physical therapy, and early education. An **IFSP (INDIVIDUAL FAMILY SERVICE PLAN)** will be developed to guide these supports and therapies. Each state provides this service at the county level.

In Kansas: Infant Toddler or Tiny K Services 1-800-332-6262
In Missouri: First Steps—MO Intervention Services 1-866-583-2392

Services for ages **three to five years** can be provided by your local school district through their Early Childhood Special Education (ECSE) services. Each district determines how these services are delivered. Some districts provide support and therapies in the community preschool your child can attend. Some districts provide services in a school based preschool. Some use a combination of both sites. An **Individualized Education Plan (IEP)** will replace the IFSP. It will outline which services your child will receive, how, and who will deliver them. A meeting between your child's early intervention services provider and your local school team will help with this transition. If your child has not received services, please contact your local school district Special Education office or your neighborhood school principal to let them know that your child will need services. Public school services are provided at no cost to the family.

The **Autism Waiver** is a service provided through Kansas Social Rehabilitation Services for children from the age of diagnosis through the age of five. If eligible the child and family may receive waiver services for a time period of three years. The waiver is designed to provide intensive early intervention services to children with ASD. The services include respite care, parent support and training, intensive individual supports, consultative clinical and therapeutic services, and family adjustment counseling. To be eligible for the autism waiver the child must receive a diagnosis by a licensed medical doctor or psychologist (Ph.D.). At this time only a limited number of applicants can be served across the state of Kansas. Once the child has been accepted into services an Individualized Behavioral Plan/Plan of Care will be developed with the family by an autism specialist. Applications can be obtained through your local SRS office or the SRS website:
http://www.srskansas.org/hcp/css/Autism/Autism_Preliminary_Application.pdf
or by calling your local Social Rehabilitation Services office.

PRIVATE PROGRAMS

There are many private programs and schools specifically developed to help children with ASD. Some private programs in the KC Metro area can be found online at www.kcautismservices.com. Families may choose to enroll their child in a private program or supplement their public program with private therapy services.

School Age Services

At five years of age in most school districts, children enter kindergarten. The IEP (Individual Education Plan) will be developed, updated and/or revised as needed. Thereafter, the IEP will be updated annually. Every 3 years your child will be re-evaluated by the school to determine eligibility for continued Special Education services. Best practice indicates that children with Autism Spectrum Disorders learn most effectively when taught with a combination of one-on-one and inclusion with typically developing peers. "The presence of peers allows children to imitate and practice more advanced play behaviors." (Wolfberg & Schuler)

If you do not choose to use your local school district services, there are a variety of private providers who offer a range of services, from helping your child with a specific challenge such as social skills or behaviors to setting up extensive home therapy systems.

Beginning at **14 years of age** a statement of transition service needs should be included as part of the student's IEP. This statement should address what the student hopes to learn and/or accomplish before he/she exits school. At **16 years of age** a statement of needed transition services must be written and included in the student's IEP. This plan will determine what actions the student, parent, school district, and outside agencies should accomplish before the student exits school.

Age 18—21 years programs are offered in all school districts for those students who are receiving special education services and their school team has determined they would benefit from this type of program. Typically the focus of the 18—21 program is to develop job skills, increase independent living skills, and learn how to access community supports and activities. The IEP should reflect the student's needs at this time in preparation for living and working in the community. It is important that the IEP team develop transition goals that connects the student to:

- Government supports such as Social Security (SSI) and Medicaid, if needed
- Post-secondary education opportunities
- Division of Vocational Rehabilitation Services for employment and training

When your child enters kindergarten, the IEP team will include a regular education teacher as well as the therapists and specialists. To help you understand how the educational process works and your rights, you can contact your local parent information and training organization in your state:

Kansas: **Families Together 1-800-264-6343 www.familiestogetherinc.org**
Disability Rights Center 1-877-776-1541 www.drckansas.org

Missouri: **MPACT (Missouri Parents Act) 1-800-743-7634 www.ptimpact.com**

Support For School Districts

There are also organizations that work directly with schools. They help educators better understand Autism Spectrum Disorders and develop effective teaching methods. To get more information/support for your child's school:

Kansas:

NEUROLOGICAL DISABILITIES SUPPORT PROJECT (NDSP) 913 588-5943 www.ksndsp.org

PROJECT STAY 785 235-1836 www.projectstay.com

Missouri:

PROJECT ACCESS 1-866-481-3841 www.missouristate.edu/access

Family Support

It is important to build a network of support for your family. This can include extended family members, personal friends, and professionals who work with parents who have a child with a developmental disability.

Kansas:

Families Together 1-800-264-6343 www.familiestogetherinc.org
Families Together provides a Parent-to-Parent mentoring program as well as educational advocacy. There are regional offices located throughout the state.

Missouri:

MPACT (Missouri Parents Act) 1-800-743-7634 www.ptimpact.com
MPACT matches parents with parents by region to offer support and information about special education advocacy.

In the **Kansas City area,** other organizations that offer information and/or support are:

Autism Alliance of Greater Kansas City www.autismalliancekc.org
Autism Society of the Heartland www.autismsocietyoftheheartland.org
Community Disability Network 913-648-2317
Encouraging Families with Exceptional Children Together 816 537-5951 www.efect.org
Family Friends Program, Children's Mercy Hospital 816 234-3676 www.childrensmercy.org
Kansas Center for Autism Research and Training (K-CART) www.kcart.ku.edu
MO Project Access 1-866-481-3841 www.missouristate.edu/access
UMKC Institute for Human Development Resource Center 816-235-1763 www.moddrc.org

There are many private agencies in the Kansas City area and beyond who offer a wide array of services at private pay. The Autism Alliance of Greater Kansas City has compiled a resource directory that lists services by topic.

Autism alliance resource directory
an extensive resource directory for the greater Kansas city area
Go to http://www.kcautismservices.com/

Information and Resources on Autism Spectrum Disorders

GENERAL INFORMATION

Autism Speaks https://www.autismspeaks.org

Amercian Academy of Pediatrics http://www.medicalhomeinfo.org/health/autism.html or the homepage www.aap.org

Kansas Center for Autism Research and Training www.kcart.ku.edu

Kansas Early Autism www.ksearlyautism.org

National Autism Center www.nationalautismcenter.org

National Center for Disease Control www.cdc.gov/ncbddd/autism/

National Dissemination Center for Children with Disabilities http://www.nichcy.org/resources/autism.asp

National Institute of Mental Health www.nimh.nih.gov/health/publication/autism

ADDITIONAL RESOURCES

Kansas Neurological Developmental Supports Project Lending Library www.ksndsp.org
Online lending library to individuals throughout the state of Kansas at no charge.

Kansas Instructional Support Network www.kansasasd.com
This website includes social stories, articles, podcasts, and online training information.

Interactive Collaborative Autism Network http://www.autismnetwork.org/
Online instructional modules include information on characteristics, assessment, and academic, behavioral, communication, environmental, sensory, and social interventions.

What Other Services or Programs are Available to my Child and Family and How Do We Get Them?

Your child and family may be able to access services through community programs in addition to school. These services are based on eligibility criteria. The following pages will describe what criteria needs to be met by a child/adult to qualify for services through Kansas' Community Developmental Disability Organization.

The following is the contact information by state:

Kansas—These services could include Home & Community Based Services, known as HCBS or direct financial support options through your local **CDDO or Community Developmental Disabilities Organization.**

Missouri—These services are provided through organizations known as **Regional Centers.** For more information see: **http://www.dmh.mo.gov/mrdd/mrddindex.htm**

The following pages will explain how to access resources through…

- **Kansas CDDO**
- **Missouri Regional Centers**

ELIGIBLIITY CRITERIA FOR DEVELOPMENTAL DISABILITY

The CDDO in each designated geographic region of Kansas uses the following eligibility criteria determined by Kansas SRS Department of Mental Health and Developmental Disabilities Services. This criterion is not intended to define mental retardation or developmental disabilities, but to define the population who is eligible to receive services.

Mental retardation means substantial limitation in functioning that is manifested during the time from birth to age 18 years and is characterized by significantly below average intellectual functioning co-existing with deficits in adaptive behavior, including related limitations in **two or more** of the following adaptive skill areas:

1. Communication
2. Self-care
3. Home living
4. Social Skills
5. Community use
6. Self-direction
7. Health and Safety
8. Functional Academics
9. Leisure
10. Work

Developmental disability means a condition such as autism, cerebral palsy, epilepsy, or similar physical or mental impairment. In addition, developmental disability is evidenced by severe, chronic limitations which:

Is attributable to a mental or physical impairment or a combination of mental and physical impairments **AND** is manifested before age 22 **AND** is likely to continue indefinitely **AND** results in substantial functional limitations in **three or more** of the following areas:

1. Self-care
2. Understanding and using language
3. Learning and adapting
4. Mobility
5. Living independently
6. Economic self-sufficiency
7. Self-direction in setting goals and accomplishing these goals

AND reflects a need for a combination and sequence of special, interdisciplinary or generic care, treatment, or other services which are lifelong, or extended in duration and are individually planned and coordinated. This does not include individuals who are solely severely emotionally disturbed or seriously and persistently mentally ill or have disabilities solely as a result of infirmities of aging.

For children under age six, developmental disability means a severe, chronic disability which:

- Is attributable to a mental or physical impairment or a combination of a mental and physical impairments **AND**
- Results in **at least three** developmental delays as measured by qualified professionals using appropriate diagnostic instruments or procedures **AND**
- Reflects a need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are lifelong, or extended in duration and individually planned and coordinated **AND** does not include individuals who are solely severely emotionally disturbed or seriously and persistently mentally ill.

Source: Adapted from Johnson County CDDO 11/00 version

WHAT IS A CDDO?

CDDO stands for **C**ommunity **D**evelopmental **D**isability **O**rganization. This is the single point of entry for an individual or family to access services through the developmentally disabled system in **Kansas**. Currently, the state of Kansas has 28 CDDOs which are assigned according to geographic regions or counties. CDDOs are responsible for determining whether or not a person qualifies for services.

Information is gathered from several sources such as the child's parents, doctor(s), and school. CDDO staff work with the person and/or family/guardian to complete the paperwork requirements. A *BASIS* is given once an individual has met the criteria for services through the CDDO. The *BASIS* is an assessment tool to determine the **level of support** an individual needs.

The CDDO is responsible in providing information so the family is aware of service options offered in their county. Once the child's service needs have been identified and service providers have been selected, if applicable, then referrals are made to appropriate agencies.

Services available through the CDDO include (but not inclusive):

- In-home supports—includes supportive home care and respite care; provider helps child in their home and community
- Home modifications– funding to modify home environment to support child's needs
- Van lifts-funding to provide a van lift
- Case management-service coordination
- Licensed Day Services– employment/day program for adults
- Licensed Residential Services-residential program for adults
- Assistive technology funds (adults/individuals no longer in school)

Often funding is not immediately available. The child's name is put on a waiting list. While the child is on the waiting list, case management can be provided **if** the child has Medicaid or chooses to private pay. The **Home and Community Based Waiver (HCBS)** is a MR/DD waiver that funds the services provided through the CDDO. These services are designed to keep a person with developmental disabilities in their home and community rather than in an institutional setting. CDDOs also provide quality assurance monitoring. This is in place to insure that services are being delivered according to Kansas regulations. A CDDO may also serve as a community service provider (CSP). CSPs are licensed agencies that provide day and residential services to adults.

Direct Financial Support for Developmental Disabilities

Supplemental Security Income (SSI) is a federal program in which a monthly payment is made to people with low income, limited resources, and who have a developmental disability. A child under age 18 can qualify if he/she meets Social Security's definition of disability for children, and the parent's income and resources fall within eligibility limits. When a child turns 18 years of age, the parent's income is no longer considered when determining eligibility. One can apply for SSI 30 days prior to their 18th birthday.

The payment amount differs from state to state because some states add to the SSI payment. Although SSI is managed by the Social Security Administration, it is not paid out of Social Security trust funds. SSI is paid for by the U.S. Treasury general funds.

For more information or to apply for SSI call 1-800-772-1213 or visit the website at www.socialsecurity.gov.

Kansas Cash Assistance Program

The Kansas Cash Assistance program is a cash disbursement to the parent(s) of a child with a developmental disability. It is paid quarterly in payments of approximately $623. This money is allocated annually out of state funds, distributed to the local CDDOs, and then sent to the individual families. This assistance depends on the availability of these funds. There is no age limitation and no income guidelines.

- Person must be living with natural, adoptive, or foster parent
- Person and payee parent must be Kansas residents
- Person must meet disability definition of MR/DD

Cash Assistance can be provided during the lifetime of the person as long as the above conditions are met or until the child/person begins receiving HCBS waiver services. Cash Assistance payments are allowed while the child/person is on the waiting list for HCBS waiver services. Once the person is offered HCBS waiver they must take it and then cash assistance is discontinued when the HCBS waiver becomes effective. Children under the age of 5 may apply for cash assistance. To apply for Kansas Cash Assistance contact your local CDDO.

MEDICAID FOR HEALTHCARE AND WAIVER SERVICES

Medicaid, a federally funded medical assistance program, is available for children and adults who meet certain qualifications. Those with developmental disabilities who qualify for Supplemental Security Income (SSI) are one group that is eligible for Medicaid.

Medicaid has many special programs. One program covers healthcare for children under age 18 with developmental disabilities who live in low-income households. Other programs cover HCBS (Home and Community Based Services) waivers for children and adults with developmental disabilities, regardless of income. However, income is considered to determine if and how much a family shares in the cost of provided services.

In Kansas, applications for Medicaid are available from Social and Rehabilitation Services (SRS) area offices. For more information on Medicaid in Kansas see **www.srskansas.org**

In Missouri, applications for Medicaid are available from Department of Social Services (DSS) area offices. For more information on Medicaid in Missouri see **www.dss.mo.gov**

FAMILY FEES FOR WAIVER SERVICES IN KANSAS

In May 2002, the Kansas Legislature passed a proviso, as part of the Omnibus Appropriation Bill that authorizes the Secretary of SRS to collect fees from parents for services provided to their children by an institution or program of the department. Children receiving these services through the following supports are affected by this legislation:

- Family Preservation Program
- Home and Community Based Services waivers—
  Technical Assistance (TA); Severe and Emotionally Disturbed (SED); Mental Retardation/Developmental Disability (MR/DD)

This proviso takes into consideration parent's income; ability to pay based on a sliding scale; parent fee waived if hardship can be demonstrated; and the child cannot lose the Home and Community Based waiver or Family Preservation services if parent fails to pay.

CDDO	COUNTY	CDDO	COUNTY
Achievement Services 215 N. 5th Atchison KS 66062 913-367-2432	Atchison, Jackson	Arrowhead West 1100 E. Wyatt Earp Dodge City KS 67801 620-227-8803	Ness, Hodgeman, Gray, Ford, Kiowa, Pratt, Kingman, Meade, Clark, Comanche, Barber, Edwards, Harper
Big Lakes Dev. Center 1416 Hayes Dr. Manhattan, KS 66502 785-776-9201	Clay, Geary, Pottawatomie, Riley	Brown County Dev. Serv. 400 S. 12th Hiawatha KS 66434 785-742-3959	Brown, Doniphan
CLASS, LTD 1200 E. Merles Evans Dr. Columbus KS 66725 620-429-1212	Cherokee, Crawford, Labette, Montgomery	CDF Training Serv. 1516 Davis Road Ottawa KS 66067 785-242-5035	Coffey, Franklin, Osage
COMCare 615 N. Main Wichita KS 67203 316-660-7630	Sedgwick	Cottonwood 2801 W. 31st St. Lawrence KS 66047 785-842-0550	Douglas, Jefferson
Cowley Co. Dev. Services Strother Field, PO Box 133 Arkansas City KS 67005 620-442-3575	Cowley	Dev. Serv. of NW KS 2703 Hall St. Hays KS 67601 785-625-5678	Cheyenne, Decatur, Ellis, Graham, Logan, Norton, Osborne, Phillips, Rawlings, Rooks, Russell, Sherman, Sheridan, Smith, Thomas, Trego, Wallace
Flint Hills Services 2375 W. Central El Dorado KS 67042 620-321-2325	Butler	Futures Unlimited 24510 North A Wellington KS 67152 620-326-8906	Sumner
Hetlinger Dev. Services 707 S. Commercial Emporia KS 66801 620-342-1087	Chase, Lyon, Morris, Waubansee	Johnson Co. Dev. Supports 10501 Lackman Road Lenexa KS 66219 913-826-2506	Johnson
Multi Community Diversified Services 910 N. Main McPherson KS 67460 620-241-6693	McPherson	Nemaha Co. Training Ctr 12 South 11th Seneca KS 66538 785-336-6116	Nemaha
New Beginning Enterprises 1001 Wilson Neodesha KS 66757 620-325-3333	Chautauqua, Elk, Greenwood, Wilson	Northview Dev. Services 700 E. 14th St. Newton KS 67114 620-283-5170	Harvey, Marion
Occupational Ctr. Of Central Kansas 1710 W. Schilling Road Salina KS 67402 785-827-9383	Cloud, Dickinson, Ellsworth, Jewell, Lincoln, Mitchell, Ottawa, Republic, Saline	Riverside Resources 700 North 3rd St. Leavenworth KS 66048 913-651-6810	Leavenworth

CDDO	COUNTY	CDDO	COUNTY
Southwest Dev. Services 2708 North 11th St. Garden City KS 67846 620-275-7521	Finney, Grant, Greeley, Hamilton, Haskell, Kearny, Lane, Morton, Scott, Seward, Stanton, Stevens, Wichita	Sunflower Diversified Services Westport Addition PO Box 838 Great Bend KS 67530 620-792-1321	Barton, Pawnee, Rice, Rush, Stanton
TARC, Inc. 2701 Randolph Topeka KS 66611 785-232-0597	Shawnee	TECH 1300 East A Hutchinson KS 67504 620-663-1596	Reno
Tri-Ko 301 First St. Osawatomie KS 66064 913-753-3025	Anderson, Linn, Miami	Tri-Valley Dev. Services 3740 S. Santa Fe Chanute KS 66720 620-431-7401	Allen, Bourbon, Neosho, Woodson
Twin Valley Dev. Services 427 Commercial Greenleaf KS 66943 785-747-2251	Marshall, Washington	Wyandotte DD Services 850 State Avenue Kansas City KS 66101 913-573-5503	Wyandotte

MISSOURI DEPARTMENT OF MENTAL HEALTH
DIVISION OF MENTAL RETARDATION/DEVELOPMENTAL DISABILITIES

FACILITY LISTING

ALBANY REGIONAL CENTER
809 North 13th Street
Albany, MO 64402
660-726-5246; TDD 660-726-5844; FAX 660-726-5165
Toll Free: 800-560-8774

Satellite Offices:
Cameron: 207 E. McElwain Dr. 64429
816-632-8876
St. Joseph: 525 Jules #210 64501
816-387-2220

CENTRAL MISSOURI REGIONAL CENTER
1500 Vandiver Drive, Suite 100
Columbia, MO 65202
573-882-9835; TDD 573-882-9835; FAX 573-884-4294
Toll Free: 888-671-1041

Satellite Offices:
Fulton: 911 business 54 65251
573-592-4171/4172
Jefferson City: 1716 Four Seasons Dr #103 65101
573-526-7684
Marshall: 1239 Santa Fe Trail #200 65340
660-886-4690
Moberly: 423 E Logan 65270
660-263-0743
Sedalia: 818 Westwood Ave 65301
660-530-5700

HANNIBAL REGIONAL CENTER
805 Clinic Road, P.O. Box 1108
Hannibal, MO 63401
573-248-2400; TDD 573-248-2415; FAX 573-248-2408
Toll Free: 800-811-1128

Satellite Office:
Warrenton: 3409 N Highway 47 63383
636-456-7914

JOPLIN REGIONAL CENTER
3600 East Newman Road, P.O. Box 1209
Joplin, MO 64802-1209
417-629-3020; TDD 417-629-3020; FAX 417-629-3026
Toll Free: 888-549-6634

Satellite Offices:
Clinton: 1661 N Second 64735
660-885-2368
Nevada: 621 E Highland 64772
417-448-1317

MISSOURI DEPARTMENT OF MENTAL HEALTH
DIVISION OF MENTAL RETARDATION/DEVELOPMENTAL DISABILITIES

FACILITY LISTING CONT'D.

KANSAS CITY REGIONAL CENTER
821 East Admiral Boulevard
Kansas City, MO 64106 (street address) 64141 (PO Box)
816-889-3400; TDD 816-889-3326; FAX 816-889-3325
Toll Free: 800-454-2331

Satellite Offices:
Cass County: 1800 Vine St. Higginsville 64701
816-380-7539
Clay County: 920 S. Kent Liberty 64068
816-792-4281
Lafayette County: Morris Drive, Box 517 Higginsville 64037
660-584-9221

KIRKSVILLE REGIONAL CENTER
1702 East LaHarpe
Kirksville, MO 63501
660-785-2500; TDD 660-785-2500; FAX 660-785-2520
Toll Free: 800-621-6082

Satellite Offices:
Chillicothe: 917 Jackson St. 64601
660-646-4180
Macon: 1716 Prospect Dr. 63552
660-385-1955

POPLAR BLUFF REGIONAL CENTER
2351 Kanell Boulevard
Poplar Bluff, MO 63902
573-840-9300; TDD TDD 573-840-9312; FAX 573-840-9311
Toll Free: 800-497-4214

Satellite Offices:
Dunklin County: 1100 Hwy 25, S Bypass Kennett 63857
573-888-2967
Howell/Shannon County: 3417 Division Dr. #4 West Plains 65775
417-257-7716
Oregon/Ripley County: Route 2, Box 20 Doniphan 63935
573-996-2347
Stoddard County: 1003 Wildwood Dr #B Dexter 63841
573-624-8384

MISSOURI DEPARTMENT OF MENTAL HEALTH
DIVISION OF MENTAL RETARDATION/DEVELOPMENTAL DISABILITIES

FACILITY LISTING CONT'D.

ROLLA REGIONAL CENTER
105 Fairgrounds Road, P.O. Box 1098
Rolla, MO 65402
573-368-2200; TDD 573-368-2200; FAX 573-368-2206
Toll Free: 800-828-7604

Satellite Offices:
Camden County: 131 Rodeo Dr Camdenton 65020
573-346-0329
Franklin County: #1 Liberty Plaza Union 63084
636-583-6732
Osage County: 925 E Main Linn 65051
573-897-2881
St Francois County: 901 Progress Dr #103 Farmington 63640
573-218-6897
Texas County: 101 W Hwy 32 #2 Licking 65542
573-674-3113
Washington County: 24441 W State Hwy 8 Potosi 63664
573-438-6526

SIKESTON REGIONAL CENTER
112 Plaza Drive, P.O. Box 966
Sikeston, MO 63801
573-472-5300; TDD 573-472-5391; FAX 573-472-5308
Toll Free: 800-497-4647

Satellite Offices:
Cape Girardeau: 338 Broadway #310 63701
573-290-5364
Fredricktown: 413 Burris 63645
573-783-2511
New Madrid: 925 Pinnell St 63869
573-748-5809

SPRINGFIELD REGIONAL CENTER
1515 East Pythian, P.O. Box 5030
Springfield, MO 65801-5030
417-895-7400; TDD 417-895-7430; FAX 417-895-7412
Toll Free: 888-549-6635

Satellite Offices:
Mountain Grove: 1801 N Talcott 65711
417-926-5620

ST. LOUIS COUNTY REGIONAL CENTER
211 North Lindbergh
St. Louis, MO 63141-7809
314-340-6500; TDD 314-340-6659; FAX 314-340-6569
Toll Free: 800-374-6458

Satellite Office:
Olivette: 9445 Dielman Rock Island Industrial Dr 63132
314-340-6770

MISSOURI DEPARTMENT OF MENTAL HEALTH
DIVISION OF MENTAL RETARDATION/DEVELOPMENTAL DISABILITIES

FACILITY LISTING CONT'D.

ST. LOUIS CITY REGIONAL CENTER
111 N. 7th St., 6th Floor
St Louis, MO 65801-5030
314-244-8800; TDD 314-244-8805; FAX 314-244-8804
Toll Free: 888-549-6635

Satellite Office:
Mountain Grove: 1801 N. Talcott 65711
417-926-5620