Resource Guide for Local Providers:

Addressing the Needs of Children and Youth with Co-occurring Intellectual/Developmental Disabilities and Mental Health Needs

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Introduction

This Guide is developed to provide information and tools for use at the local level primarily for providers serving children and youth with co-occurring Intellectual or Developmental Disabilities (IDD) and mental health challenges (sometimes referred to as “dually diagnosed”). It is specifically targeted at increasing collaboration and integrated care to better meet their needs. Based on suggestions from providers in the field for what they thought would be helpful to other providers across the state, Section 1 gives an overview of the relevant systems involved in serving this population, Section 2 describes the need for collaboration between systems, and Section 3 offers suggestions for developing a collaborative approach. The Appendices contain specific tools and resources to support the information found in the body of the document.

Section 1: Systems Serving Children and Youth

The Medicaid Programs in Kansas

Overview. Before reviewing specific systems, it is important to highlight the Medicaid program, which is a key funding source for some services for this population. Medicaid was originally enacted under the Social Security Act of 1965 to enable states to furnish medical assistance and other services to certain individuals with limited financial resources. Medicaid is a jointly financed program between the federal government and states, with the federal government providing matching dollars for allowable state spending.

States administer Medicaid services, and the federal government provides oversight. In order to participate in the program, each state must have a state Medicaid plan on file describing how it will comply with the federal core requirements. More information about the Kansas Medicaid State Plan can be found here: http://www.kdheks.gov/hcf/Medicaid/state_plan.html. The Secretary of Health and Human Services may approve “waivers” that allow states to use federal Medicaid funds in ways not otherwise allowed under federal rules. Medicaid waivers are designed to permit states to be more flexible in providing health care options, allowing them to save money and consumers to have more freedom of choice. Waivers allow states to offer services not typically available under Medicaid, such as attendant care and other home and community based services (HCBS) for individuals who would otherwise be institutionalized. Services provided under certain waivers are available to children who need them without regard to parental income or financial resources, although a copay or obligation may be required.
Kansas Programs. KanCare is the name through which the State of Kansas administers Medicaid. Two of the state’s Medicaid Waiver programs under KanCare are particularly relevant to children with co-occurring serious emotional disturbance and intellectual/developmental disabilities. Each is reviewed below.

Intellectual/Developmental Disabilities (IDD) Waiver. The IDD Waiver program is managed by the Kansas Department of Disability and Aging Services (KDADS). KDADS contracts with twenty-seven local Community Developmental Disability Organizations (CDDOs). See Appendix A. Each CDDO acts as a single point of entry for determining if eligibility criteria for the IDD Waiver has been met. If eligibility requirements are met, then a functional assessment is completed. Once access to services is granted, the CDDO will work with the family or guardian in choosing a community service provider.

The IDD Waiver may provide day supports, overnight respite care, personal assistant services, residential supports, supported employment, financial management services, assistive services, medical alert rental, sleep cycle support, specialized medical care, supportive home care, and wellness monitoring for individuals with developmental disabilities (DD) and individuals with intellectual disabilities (ID) aged five and older.

Serious Emotional Disturbance (SED) Waiver. The SED Waiver is also managed by KDADS. KDADS contracts with Community Mental Health Centers (CMHCs) in 26 regions to provide services, although families have choice as to who provides some of the services for their child.

The SED Waiver provides attendant care, independent living/skills building, short term respite care, parent support and training, professional resource family care and wraparound facilitation for individuals with serious emotional disturbance (SED) aged 4 to 18, with an age exception possibility for participants under the age of 4 and over the age of 18 (through age 21) who are at risk for state psychiatric hospitalization.

Managed Care Organizations (MCOs). MCOs are insurance companies that negotiate and contract with providers and medical facilities to provide healthcare services to their members. They are responsible for enrolling a network of service providers, providing care coordination for service recipients, authorizing or denying requests for services, and paying providers for services. MCOs operate a “closed provider network,” meaning that each organization that wants to provide services in that MCO’s geographical area must undergo a separate enrollment and credentialing process. The MCO decides which agencies will be authorized to provide
services within their network. It may deny access to certain agencies but must have sufficient capacity to allow individuals to access services ("KanCare - Providers." State of Kansas, 2015).

The State of Kansas has contracted with three MCOs to provide services to those consumers who receive Medicaid/KanCare, including those receiving services under the IDD and SED Waivers. See Appendix C. Each of these three MCOs, Amerigroup Kansas, Inc., Sunflower Health Plan, and UnitedHealthcare, utilizes Care Coordinators\(^1\) (CCs). The CC works with the individual member and family, the member’s targeted case manager if there is one and other providers to develop a plan of care consistent with the member’s needs and the MCO’s rules.

CDDOs and CMHCs may also have their own employees or affiliates who can collaborate and work with CCs in developing care plans. For example, UnitedHealthcare’s “IDD Waiver-Frequently Asked Questions for Members” explains to individuals that the care coordinator is “the person from your MCO who will work with you and your targeted case manager to develop your plan of care and make sure you have the services you need” (UnitedHealthcare, 2014).

**Individual Systems**

For children with both IDD and mental health needs, other child-serving systems may also be involved.

**The CMHCs.** Community Mental Health Centers provide other services in addition to those offered through the SED Waiver. Individuals can receive individual, group and family therapy as well as medication services, depending on need. Many payment mechanisms are used for these non-Waiver services including Medicaid, private pay/sliding scale and commercial insurance.

**CDDOs.** CDDOs can connect individuals and their families with Targeted Case Management (TCM) services to help with coordination of supports and development of support plans while waiting for IDD Waiver services. The CDDOs may provide some services or may work with affiliated Community Service Providers. Unlike in the mental health system, the majority of direct care services for youth with IDD are only available through the IDD Waiver.

**Schools.** In addition to CDDOs and CMHCs, it is important to consider the role of schools. A variety of complex federal and state statutes provide certain educational rights to children with mental illness and IDD and place certain responsibilities on schools. Notably, the federal *Individuals with Disabilities Education Act (IDEA)*, and the updating of the Kansas State

\(^1\) Sunflower calls staff in these types of positions “case managers.”
Regulations in 2008 are designed to ensure that all children with disabilities receive a free appropriate public education that meets their unique needs and prepares them for further education, employment, and independent living. See: 
and
http://www.ksde.org/Agency/DivisionofLearningServices/EarlyChildhoodSpecialEducationandTitleServices/SpecialEducation/Legal(SpecialEducation)/StatutesandRegulations.aspx

The Kansas Special Education Process Handbook (http://www.ksde.org/Portals/0/SES/PH/PH-complete.pdf) attempts to clarify and define the legal requirements of IDEA and state laws and regulations. It sets forth numerous requirements that schools must follow to identify and meet the needs of children with a variety of special needs, ranging from those with learning disabilities to SED (called “emotional disturbance” in the revised IDEA) (Kansas State Department of Education, 2014). Thus, while they are not providers under either the IDD or SED Waivers, schools provide important services that may complement those provided under both Waivers. For this reason, schools should ideally be involved to some degree in collaboration and coordination efforts between CDDOs and CMHCs. The best outcomes generally occur when systems work together to develop comprehensive support plans for individuals.

Child Welfare. There are times when children with IDD and mental health challenges may become involved with their local child welfare system because of concerns about child abuse or neglect. When this occurs, coordination with the child welfare system is important as it adds additional individuals and agencies into the child’s and his/her family’s life: the Kansas Department for Children and Families, court system, child welfare contractor staff, and the foster family, among potential others. Children in out-of-home placements not only have the initial move out of their primary residence but they may also have subsequent moves. These moves may be near their home community or it may be at a distance, which may make involvement of natural supports more challenging. Appendix D shows the current agencies contracted with the State of Kansas to provide foster care services to children and youth.

Section 2: The Importance of Collaboration

Overview. Children and youth with Intellectual/Developmental Disabilities (IDD) are not immune from experiencing mental health challenges and vice versa. It is difficult to state exactly how many children have challenges related to both IDD and mental health. There is concern that the available data may underrepresent the true rate due to individual
communication difficulties that can make it hard to identify and diagnosis need. For example, research suggests that there are a number of youth ending up in the juvenile justice or foster care systems who are not being correctly identified as having dual IDD and mental health needs (Jacobstein, Stark, & Laygo, 2007). There have, however, been some attempts to roughly quantify the number of children falling into this category, with comorbidity rate estimates ranging from 30-50% of youth with intellectual disabilities having mental disorders and 30-35% of individuals with intellectual or developmental disorder experiencing a psychiatric disorder (Einfeld, Ellis & Emerson, 2011; NADD, n.d.)

Regardless of their numbers, children with co-occurring mental illnesses and IDD are a particularly vulnerable population. Data show that individuals with IDD experience a higher rate of trauma than the general population. Studies exploring maltreatment rates for children with disabilities have generally found that they are at a heightened risk for abuse and neglect and that the risk may be even higher than estimated due to underreporting and communication issues (Child Welfare Information Gateway, 2012; Charlton, Kliethermes, Tallant, Taverne & Tishelman, 2004). Adults with dual diagnosis generally have higher rates of homelessness, institutionalization, and incarceration (NADD, 2009). Thus, it is crucial to promptly and properly identify and serve children with mental illness and IDD.

Due to a number of historical factors, many services and systems for the treatment of mental illness and IDD are currently organized as though individuals have either mental illnesses or developmental disabilities, but not both (Shriver, 2001). In most states, those with co-occurring disorders face service barriers due to a lack of coordination and collaboration across service systems, with stakeholders in both service systems tending to agree that adequate community based services often are unavailable (National Association of State Mental Health Program Directors, 2004). The National Association of State Mental Health Program Directors has noted that “differences in culture, language, and perception impede communication across service systems, contribute to misunderstandings and tensions in the development of treatment/service plans for individuals served by both service systems, and isolate individuals with both conditions from the mainstream of either service system” (National Association of State Mental Health Program Directors, 2004).

Yet, we know that children with both IDD and mental health needs can and do thrive with proper support. Thus, it is essential that providers in different agencies collaborate in order to effectively address the needs of children identified as having both mental illness and IDD needs. Without effective communication and coordination of efforts, there is a high risk that these children will not receive the level of care they need and deserve.
University of Kansas Survey. Preliminary findings from a recent survey conducted in the fall of 2014 by the University of Kansas School of Social Welfare’s Center for Children and Families validate the need for collaborative efforts in serving children with both IDD and mental health needs in the State of Kansas. Mental health, IDD, and school staff (n=52) indicated that they believed that staff in their agencies understood the needs of children with both IDD and mental health challenges and had the skills to identify these children. However, they did not feel that staff understood the roles and responsibilities of other agencies and systems in serving these children. In particular, they noted that a lack of clarity in knowing which agency and system should take the lead was a challenge, though they clearly felt that systems are better able to help children and families when agencies collaborate rather than work independently. Particular challenges in working with other agencies and systems that were identified were: lack of current policies and practices to guide and support cross-systems work, lack of state level supports to promote cross-systems work, and a lack of community services to provide for children/youth with both IDD and mental health needs.

Narrative comments included the following additional themes and details: There is a gap in professionals educated and skilled at serving the needs of this population; the systems disagree about who’s responsible; there is role confusion, particularly in relation to who should take the lead in providing services and coordinating care; a “silo approach” leads to services that either address IDD or mental health needs but not both at the same time; and the level of needs are overwhelming the resources in all systems, particularly the schools.
Section 3: Strategies for Increasing Collaboration

There is a need for increased collaboration between mental health, IDD, and partnering agencies. Yet it is important to keep in mind that this situation is not unique to Kansas. Many, if not most states would benefit from better coordination of services. The current lack of synchronicity between systems relates to the way, as a nation, we have historically categorized and compartmentalized mental health needs and IDD. The different agencies and systems serving these populations are not at fault. In order to move forward and better integrate mental health and IDD services, it’s critical to take a positive approach focused on the unique knowledge and strengths that agencies and individuals have to offer. With this in mind, numerous possibilities exist for increasing collaboration. The following information is presented in a question and answer format, aligned with common issues faced at the local level.

**In order to collaborate, we need to be able to share information. How is that possible?**

**Sharing Health Information under HIPAA and Kansas Law**

**HIPPA, the Privacy Rule and KHITE.** As directed by the Health Insurance Portability and Accountability Act (HIPAA), the U.S. Department of Health and Human Services has issued Standards for Privacy of Individually Identifiable Health Information (the Privacy Rule). The Privacy Rule sets forth standards for the use and disclosure of individuals’ health information, called “protected health information (PHI).” In the past, the State of Kansas had its own laws and regulations that imposed additional requirements in this area beyond the Privacy Rule. To eliminate the complexity and confusion caused by having two sets of standards, the State passed the Kansas Health Information Technology and Exchange Act (KHITE) in 2011. KHITE aligned the existing laws and regulations of Kansas with HIPAA and the Privacy Rule. Thus, health care providers who comply with the Privacy Rule established under HIPAA will now be in compliance with Kansas health information privacy standards.

**Covered Entities and Protected Health Information (PHI).** Organizations that are subject to the Privacy Rule are called “covered entities.” Health care providers, regardless of size, who electronically transmit health information in connection with certain transactions, are covered entities. The Privacy Rule protects all PHI, which includes "individually identifiable health information" held or transmitted by a covered entity or its business associate, in any form or media, whether electronic, paper, or oral.

**Permitted Information Sharing.** A covered entity is permitted to use and disclose PHI, without an individual’s authorization, for certain purposes, under certain situations. One such purpose
is for the treatment activities of a health care provider. “Treatment” encompasses the provision, coordination, or management of health care and related services among health care providers, consultation between health care providers regarding a patient, and the referral of a patient from one health care provider to another. 
(http://www.hhs.gov/ocr/privacy/hipaa/understanding/summary/)

This means that in most cases, covered entities may share an individual’s PHI among themselves in order to treat that person. One limitation to this general principle is that the Privacy Rule provides individuals with the right to request that a covered entity restrict disclosures of PHI. Covered entities are not required to agree to such a request, but if they do, they must abide by the agreement (except when PHI is needed for emergency treatment). There are also special protections provided to psychotherapy notes.

The Role of Health Information Organizations. Providers should also be aware that KHITE was amended in 2013 to permit Health Information Organizations (HIOs) to create centralized, electronic Health Information Exchanges designed to facilitate the sharing of individual health data among providers. Currently, two HIOs – KHIN and LACIE – are approved in the state. See http://www.kanhit.org/provider_faqs.htm. It is important to note while individuals have a right to “opt out” of having their PHI made available through these exchanges, this does not restrict the ability of health providers to share PHI with one another for treatment purposes outside of HIOs, consistent with the Privacy Rule (as described above).

For more information on this subject, see Appendix E.

Memorandum of Understanding
Another approach to collaboration can involve creating and executing a Memorandum of Understanding or MOU. The purpose of an MOU is to clearly state which partners are involved, what the roles and agreements are of all partners involved, and to execute the agreement by way of signatures by each partners’ leadership. An MOU can be modified to fit the exact nature of the situation involved. It can involve the sharing of data, funds, or time. A sample template for modification is shown in Appendix F.

How can we figure out where to start?
Whether you are reaching out to new partners or building on existing relationships, there are always opportunities to do more. The following tools are designed for holding a meeting to bring people together and, working together, identify where you might want to start collaborating at the agency level.
**Partnership Matrix** – When you are working with children, youth and their families, there are often many perspectives to consider. As you think about convening a meeting to talk about collaboration, use the matrix in Appendix G to identify who you want to have at the table. And don’t forget to invite several people to represent the family perspective. Although it may seem that different agencies can represent family voice, it is never the same as having multiple people at the table whose only role is the family perspective.

**Readiness Tool** – There are many ways that communities can begin working together. However, it is essential that the community is ready to undertake the work. The tool in Appendix H can be used for partners to think about what they are interested in doing together and where collectively they might want to start.

**How can we improve our identification and referral processes?**

Staff from CDDOs and CMHCs can begin by working together to develop a standard protocol for identifying children with both IDD and mental health needs, sharing information across systems, and coordinating treatment. Information to support that process follows.

**Referral Process between CMHC and CDDO**

The following process originated between a CDDO and CMHC in Southeast Kansas. It is offered as a process that can be modified to support local partnering.

1. The mental health staff person obtains a signed consent from the parent that allows the mental health center to send the diagnostic sheet and psychological evaluation, the parents’ names and address, and the youth’s social security number, date of birth and Medicaid number to the CDDO.
2. This information is faxed directly from the CMHC to the CDDO which greatly reduces the time before the CDDO can conduct a functional assessment.
3. Ideally, the CDDO staff person will reply to the referring CMHC following the functional assessment to let that staff know the outcome of the referral and any service specific information that may be started (e.g., DD Targeted Case Manager name and contact information, service provider selected, etc.)

Similar processes can be set up with other providers as well (e.g., schools, child welfare, etc.). Additionally, partners can develop summary sheets that highlight eligibility and potential available services to share with other agencies and families, including contact information for obtaining additional information.
**NADD’s Diagnostic Manuals**
The National Association for the Dually Diagnosed (NADD) and the American Psychiatric Association created two texts useful for work with this population.
The first is a modification of the DSM-IV TR. See:


The second is called Mental Health & Intellectual Disability: A Training Manual in Dual Diagnosis. See:

https://netforum.avectra.com/eweb/shopping/shopping.aspx?site=nadd&webcode=shopping&prd_key=9140939-e1db-4beb-87d3-c94a2c7df12a

**MH First Aid USA**
Mental Health First Aid USA offers an adaption of the international training program originally created in Australia that teaches how to help people experiencing mental health challenges or who are in crisis. Among other things, it teaches: signs of addictions and mental illnesses; a five step action plan to assess a situation and provide help; the impact of mental and substance use disorders; and local resources and where to turn for help. The lead organizations promoting the program in the U.S. include the National Council for Behavioral Health, the Missouri Department of Mental Health and the Maryland Department of Health and Mental Hygiene.

The course runs eight hours and is offered in different formats including Youth Mental Health First Aid, which is designed to help individuals understand how to help youth age 12-18. Courses are typically provided in a single, eight hour session, or in two four hour sessions spaced over a short period of time. Individual training instructors must be certified by Mental Health First Aid USA to teach the curriculum, which involves completing a five day instructor training. Instructors are typically staff from behavioral health provider organizations, local/state mental health agencies, or mental health/addictions advocacy organizations. People from many backgrounds sign up for this training including law enforcement, educators, faith-based persons, etc.

Peer-reviewed studies published in Australia have demonstrated its effectiveness. Research has shown that individuals completing the program gain increased knowledge of signs, symptoms and risk factors of mental illnesses and addictions; learn to identify different types of professional and self-help resources for individuals with mental illness or addiction, have increased confidence in their abilities to help individuals in distress and are more likely to do so, and show increased mental wellness themselves. Mental Health First Aid USA is listed in the
Substance Abuse and Mental Health Services Administration’s National Registry of Evidence-based Programs and Practices.

Numerous Community Mental Health Centers in Kansas offer Mental Health First Aid trainings. A searchable list of currently offered classes is available at:

http://www.mentalhealthfirstaid.org/cs/take-a-course/find-a-course/.

Source: http://www.mentalhealthfirstaid.org/cs/

The different systems don’t know very much about each other? What information might help?
There are a variety of ways to share information and increase the ability to effectively coordinate. This section provides some basic information along with other ideas and resources.

Approaches to Eligibility
While it is beyond the scope of this Resource Guide to provide information on the eligibility for every agency, highlights for overall eligibility for the DD and SED Waivers are given below.

- **IDD Waiver** – Eligibility for this Waiver begins with establishing that either an intellectual disability exists before age 18 or a developmental disability exists before age 22. Once this is established, a functional assessment is conducted, which currently is the BASIS. Details can be found using the following three links:


  [http://www.aging.ks.gov/HCBSProvider/IDD_Provider_Index.html](http://www.aging.ks.gov/HCBSProvider/IDD_Provider_Index.html)

  Note: while the information in the above links has some dated information in it (e.g., some of the terms and agency names), conversations with KDADS confirms that this is the most current information publically available on the web.

- **SED Waiver** – In order to qualify for the SED Waiver a Qualified Mental Health Professional determines eligibility based on various items including but not limited to 1) a clinical assessment using the Child and Adolescent Functional Assessment Scale
(CAFAS) and the Child Behavior Checklist (CBCL); 2) functional assessment and risk of need for state psychiatric hospitalization, and c) need for services based on medical necessity. See Appendix I for details. More information about the SED Waiver can be found as follows. Please note that the SED Waiver is currently up for renewal so details are subject to change as a result of that process.

Overview which includes links to various forms and other information:

https://www.kdads.ks.gov/commissions/csp/behavioral-health/providers/sed-waiver

SED Waiver Manual:


**Services Available through the IDD and the SED Waivers**

An overview of the services available through the two Waivers along with a brief description are available in Appendix J.

**Cross Training**

Different agencies/perspectives can partner to offer training to each other at the local level. Topics could include eligibility for SED and DD, services and programming available, referral protocol, sharing family voice, etc. It doesn’t have to be formal – it can be as simple as having another agency or perspective come in to share information during a regularly scheduled staff meeting and then reciprocating at a later date.

**Other Resources:**

By no means exhaustive, the following resources are good starting places for additional information for serving this population.

- **NADD** – The National Association for the Dually Diagnosed (NADD) is a not-for-profit membership association established for professionals, care providers and families that promotes the understanding of and services for individuals who have developmental disabilities and mental health needs. NADD provides trainings and has published numerous books on this subject, such as *Mental Health & Intellectual Disability: A Training Manual in Dual Diagnosis*. They also hold an annual conference. See: [http://thenadd.org/](http://thenadd.org/)
• National Child Traumatic Stress Network (NCTSN) – Given the higher rate of trauma experienced by this population, resources for identifying and addressing trauma are important. See www.nctsn.org. Additionally, NCTSN, the Hogg Foundation, and Safe Place are working together on a training for this population. Although still in development and currently limited to Texas, it offers promise of a comprehensive training curriculum and toolkit. See: http://www.txcouncil.com/userfiles/files/Training%20Initiative%20on%20Trauma%20Informed%20Care.pdf


• Common Acronyms – Appendix K has a list of acronyms commonly used when working with this population.

Resources specific to Kansas include:

• Families Together – http://www.familiestogetherinc.org/
  (316) 945-7747
  Families Together, Inc. is the Parent Training and Information Center serving families of children and youth with disabilities and/or special health care needs from birth through 21 years old.

• National Alliance on Mental Illness (NAMI) Kansas - http://www2.nami.org/MSTemplate.cfm?Site=NAMI_Kansas
  (800) 539-2660
  With its affiliates, NAMI Kansas provides programs of education, support, and advocacy for people living with mental illness, their families, and friends. It is a chapter of the nation NAMI organization.

• Keys for Networking – http://www.keys.org/
  (800) 499-8732
  Keys for Networking is a non-profit, family-run organization providing peer-to-peer information, support, and education to families raising children behavioral, education, emotional, mental health, physical health, and substance abuse problems. Keys for Networking is the Kansas statewide organization of the Federation of Families for Children's Mental Health.
References


NADD. The Importance of Integrated Services in a Downturned Economy. NADD Bulletin, Vol. XII, Number 4, 2009.


Shriver, E. Presentation on behalf of the Joseph P. Kennedy Jr. Foundation, in a presentation to participants in a workshop convened by the National Institute of Neurological Disorders and Stroke, the National Institute of Child Health and Human Development, the National Institute of Mental Health, the National Institute of Health Office of Rare Diseases, and the Kennedy Foundation, 2001.

Appendix A

Community Developmental Disability Organizations (as of 5/6/15)

Sources: https://kcdcinfo.ks.gov/resources/service-maps and CDDO websites

Area 1: Achievement Services for Northeast Kansas
Atchison – (913) 367-2432
Counties served: Atchison and Jackson
http://asnek.org

Area 2: Arrowhead West, Inc.
Dodge City – (620) 227-8803
Counties served: Barber, Clark, Comanche, Edwards, Ford, Gray, Harper, Hodgeman, Kingman, Kiowa, Meade, Ness, and Pratt
http://www.arrowheadwest.org

Area 3: Big Lakes Developmental Center, Inc.
Manhattan – (785) 776-9201
Counties served: Clay, Riley, Pottawatomie, and Geary
https://biglakes.org
Appendix A continued – CDDOs

Area 4: Brown County Developmental Services, Inc.
Hiawatha – (785) 742-3959
Counties served: Brown and Doniphan
Email: lock@rainbowtel.net

Area 5: CDDO SEK
Columbus – (620) 429-8985
Counties served: Cherokee, Crawford, Labette, and Montgomery
http://www.cddosek.org

Area 6: ECK CDDO
Ottawa – (785) 242-7200
Counties served: Coffey, Franklin, and Osage
http://www.eckaaa.org/cddo-services.html

Area 7: Sedgwick County Developmental Disability Organization
Wichita – (316) 660-7630
County served: Sedgwick
http://www.sedgwickcounty.org/cddo/

Area 8: Cottonwood, Inc.
Lawrence – (785) 842-0550
Counties served: Douglas and Jefferson
http://www.cwood.org

Area 9: Cowley County Community Developmental Disability Organization
Winfield – (620) 221-5404 and Arkansas City – (620) 441-4504
County served: Cowley
http://www.cowleycounty.org/cddo

Area 10: Developmental Services of Northwest Kansas
Hays – (785) 625-5678
Counties served: Cheyenne, Decatur, Ellis, Gove, Graham, Logan, Norton, Osborne, Phillips, Rawlins, Rooks, Russell, Sheridan, Sherman, Smith, Thomas, Trego, and Wallace
https://www.dsnwk.org

Area 11: OCCK
Salina – (785) 827-9383
Counties served: Cloud, Dickinson, Ellsworth, Jewell, Lincoln, Mitchell, Ottawa, Republic, and Saline
http://www.occk.com
Area 12: CDDO of Butler County
Augusta – (316) 322-8777
County served: Butler
http://www.cddobutlercounty.org

Area 13: Futures Unlimited, Inc.
Wellington – (620) 326-8906
County served: Sumner
http://www.futures-unlimited.org

Area 14: Hetlinger Developmental Services, Inc.
Emporia – (620) 342-1087
Counties served: Chase, Lyon, Morris, and Wabaunsee
http://hetlinger.org

Area 15: Johnson County Developmental Supports
Lenexa – (913) 826-2626
County served: Johnson
http://www.jocogov.org/dept/cddo/home

Area 16: McPherson County CDDO
McPherson – (620) 241-6693
County served: McPherson

Area 17: Nemaha County Training Center, Inc.
Seneca – (785) 336-6116
County served: Nemaha
http://www.nemahactc.org

Area 18: New Beginnings Enterprises, Inc.
Neodesha – (620) 325-3333
Counties served: Chautauqua, Elk, Greenwood and Wilson
http://nbecddo.org

Area 19: Harvey-Marion County CDDO
Newton – (316) 283-7997
Counties served: Harvey and Marion
Email: elizabeths@harveymarioncddo.com
Appendix A continued – CDDOs

Area 20: Riverside Resources, Inc.
Leavenworth – (913) 651-6810
County served: Leavenworth
http://www.riversideresources.org/wp/

Area 21: Southwest Developmental Services, Inc.
Garden City – (620) 275-7521
Counties served: Barton, Finney, Grant, Greeley, Hamilton, Haskell, Kearny, Lane, Morton, Pawnee, Rice, Rush, Scott, Seward, Stafford, Stanton, Stevens, and Wichita
http://www.sdsicddo.com

Area 22: Shawnee County CDDO
Topeka – (785) 232-5083
County served: Shawnee
http://www.sncddo.org

Area 23: Reno County CDDO
Hutchinson – (620) 663-2219
County served: Reno
http://renocountycddo.org/index.shtml

Area 24: Tri-Ko, Inc.
Osawatomie – (913) 755-3025
Counties served: Anderson, Linn, and Miami
http://www.tri-ko.com

Area 25: Tri-Valley Developmental Services, Inc.
Chanute – (620) 431-7401
Counties served: Allen, Bourbon, Neosho, and Woodson
http://www.tvds.org

Area 26: Twin Valley Developmental Services, Inc.
Greenleaf – (785) 747-2251
Counties served: Marshall and Washington
http://www.twinvallethriftshop.com/index.html

Area 27: Wyandotte County CDDO
(913) 573-5502
County served: Wyandotte
Appendix B

Community Mental Health Centers

Information current as of 5/6/15

Community Mental Health Centers (numbers before name correspond to above map)

# 1: Compass Behavioral Health
Garden City – (620) 276-7689
Counties served: Finney, Ford, Grant, Gray, Greeley, Hamilton, Hodgeman, Kearny, Lane, Morton, Scott, Stanton and Wichita
http://compassbh.org

#2: Bert Nash CMHC, Inc.
Lawrence – (785) 843-9192
County served: Douglas
www.bertnash.org

#3: Central Kansas Mental Health Center
Salina – (785) 823-6322
Counties served: Dickinson, Ellsworth, Lincoln, Ottawa and Saline
www.ckmhc.org
#4: Community Mental Health Center of Crawford County
Pittsburg – (620) 231-5141
County served: Crawford
www.crawfordcohd.org

Appendix B continued – CMHCs

#5: COMCARE of Sedgwick County
Wichita – (316) 660-7600
County served: Sedgwick
Website: www.sedgwickcounty.org/comcare

#6: Elizabeth Layton Center, Inc.
Ottawa – (785) 242-3780
Counties served: Franklin, Miami
www.laytoncenter.org

#7: Family Service & Guidance Center
Topeka – (785) 232-5005
County served: Shawnee
www.fsgctopeka.com

#8: Four County Mental Health Center
Independence – (620) 331-1748
Counties served: Chautauqua, Cowley, Elk, Montgomery and Wilson
www.fourcounty.com

#9: High Plains Mental Health Center
Hays – (785) 628-2871 or (800) 432-0333
Counties served: Cheyenne, Decatur, Ellis, Gove, Graham, Logan, Ness, Norton, Osborne, Phillips, Rawlins, Rooks, Rush, Russell, Sheridan, Sherman, Smith, Thomas, Trego and Wallace
www.highplainsmentalhealth.com

#10: Horizons Mental Health Center
Hutchinson – (620) 663-7595
Counties served: Barber, Harper, Kingman, Pratt and Reno
www.hmhc.com

#11: Iroquois Center for Human Development Inc.
Greensburg – (620) 723-2272
Counties served: Clark, Comanche, Edwards and Kiowa
www.irqcenter.com
#12: Johnson County Mental Health Center
Mission – (913) 715-7700
County served: Johnson
http://mentalhealth.jocogov.org
Appendix B continued – CMHCs

#13: Kanza Mental Health & Guidance Center
Hiawatha – (785) 742-7113
Counties served: Brown, Doniphan, Jackson and Nemaha
www.kanzamhgc.org

#14: Labette Center for Mental Health Services
Parsons – (620) 421-3770
County served: Labette
www.lcmhs.com

#15: Mental Health Center of East Central Kansas
Emporia – (620) 343-2211
Counties served: Chase, Coffey, Greenwood, Lyon, Morris, Osage and Wabaunsee
www.mhceck.org

#16: Pawnee Mental Health Services
Manhattan – (785) 587-4300
Counties served: Clay, Cloud, Geary, Jewell, Marshall, Mitchell, Pottawatomie, Republic, Riley and Washington
www.pawnee.org

#17: Prairie View, Inc.
Newton – (316) 284-6410
Counties served: Harvey, Marion and McPherson
www.prairieview.org

#18: South-Central Mental Health Counseling Center Inc.
Augusta – (316) 775-5491
County served: Butler
www.scmhcc.org

#19: Southeast Kansas Mental Health Center
Iola – (620) 365-8641
Counties served: Allen, Anderson, Bourbon, Linn, Neosho and Woodson
Email: rchase@sekmhc.org
Appendix B continued – CMHCs

#20: Southwest Guidance Center
Liberal – (620) 624-8171
Counties served: Haskell, Mead, Seward and Stevens
www.swguidance.org

#21: Spring River Mental Health & Wellness
Riverton – (620) 848-2300
County served: Cherokee
www.srmhw.org

#22: Sumner County Mental Health Center
Wellington – (620) 326-7448
County served: Sumner
www.sumnermentalhealth.org

#23: The Center for Counseling and Consultation
Great Bend – (620) 792-2544
Counties served: Barton, Pawnee, Rice and Stafford
www.thecentergb.org

#24: The Guidance Center Inc.
Leavenworth – (913) 682-5118
Counties served: Atchison, Jefferson and Leavenworth
www.theguidance-ctr.org

#25: Valeo Behavioral Health Care
Topeka – (785) 233-1730
County served: Shawnee (NOTE: serves adults only)
www.valeotopeka.org

#26: Wyandot Center for Community Behavioral Health Inc.
Kansas City – (913) 328-4600
County served: Wyandotte
www.wyandotcenter.org
Appendix C

Managed Care Organizations

The State of Kansas currently contracts with three Managed Care Organizations to provide services to Medicaid consumers in the KanCare program:

1. Amerigroup Kansas, Inc.
   Phone: 1-877-434-7579
   Website: https://providers.amerigroup.com/pages/ks.aspx

2. Sunflower Health Plan
   Phone: 1-877-644-4623
   Website: http://www.sunflowerhealthplan.com

3. UnitedHealthcare Community Plan of Kansas
   Phone: 1-877-542-9235
   Website: http://www.uhccommunityplan.com/health-professionals/KS/provider-information

For more detailed information about each of these MCOs, see:
http://www.kancare.ks.gov/health_plan_info.htm

Current as of 5/6/15
Appendix D

Foster Care Providers

The State of Kansas contracts with two foster care providers:

1. KVC Behavioral HealthCare, Inc. (KVC Kansas)
21344 W. 153rd Street
Olathe, KS 66061
(913) 499-8100
http://kansas.kvc.org

2. Saint Francis Community Services
509 E. Elm Street
Salina, Kansas 67401
(785) 825-0541

Foster Care, Adoption and Reintegration Services Providers

West: St. Francis Community Services
East: KVC Behavioral HealthCare, Inc.
Wichita: St. Francis Community Services
Kansas City: KVC Behavioral HealthCare, Inc.

Source: http://www.dcf.ks.gov/Newsroom/Pages/7_4_13.aspx
Current as of 5/6/15
Appendix E

Additional Resource for HIPAA and Kansas Law


Appendix F

SAMPLE MEMORANDUM OF UNDERSTANDING

This is an example of a Memorandum of Understanding (MOU) between (Agency A) and (Agency B).

The following information is expressly understood and agreed by both parties.

**Purpose**
The purpose of this MOU is to strengthen the working relationship of each agency and its staff with the goal of more effectively serving children and youth who are clients of both agencies.

**Terms**
This MOU will take effect on (enter DATE) for one year. It is renewable indefinitely. Either party can terminate the provision of the MOU with 10 days written notice.

**Description of Activities**
Each party will:

a. Implement a shared referral system to create a more seamless process for connecting children and families to be screened for services, as needed.

b. Provide an in-person training session for the other party’s staff including but not limited to information about: services offered, general eligibility for those services, and what to look for when considering a need to make a referral.

c. Have a front-line staff and a supervisor attend a cross-agency coordination meeting every 2-3 months for the purpose of identifying and addressing barriers to working together, exploring new opportunities for partnering, and discussing/problem solving challenging cases.

__________________________________________  __________________________________
Agency A Name (Printed)                       Agency B Name (Printed)

__________________________________________  __________________________________
Agency A Signature                            Agency B Signature

__________________________________________  __________________________________
Agency A Date                                 Agency B Date
## Appendix G

Matrix for Identifying Representatives to Explore Integrated Care for Youth with Dual IDD and MH

<table>
<thead>
<tr>
<th>Perspective</th>
<th>Name #1</th>
<th>Name #2</th>
<th>Name #3</th>
</tr>
</thead>
<tbody>
<tr>
<td>CDDO</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental Health</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Schools</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family representatives</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amerigroup</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sunflower</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UnitedHealthcare</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary Care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child Welfare</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Service</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Homeless/Housing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Juvenile Justice</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix H

Integrated Care for Youth with Dual MH and IDD:
Local Activity and Readiness

Integrated Care involving children and youth with both Intellectual/Developmental Disabilities (IDD) and mental health needs can involve many agencies and perspectives such as mental health, IDD, family voice, managed care, school, primary care, social services, foster care, juvenile justice, housing/homeless, vocational rehabilitation, etc.

In the space below, write down which of the above agencies or perspectives you interact with, not for a specific child but as part of an overall integrated systems approach:

a. Currently interact with: ________________________________________________________

b. Previously interacted with but not now: ____________________________________________

c. Haven’t worked with before but would like to: ______________________________________

d. Other: _______________________________________________________________________

Looking at your list above, write in the following spaces how you interact with those agencies or perspectives or how you would like to.

Attend a regularly scheduled meeting for sharing information, addressing needs, exploring ideas, etc.: 
_________________________________________________________________________________
_________________________________________________________________________________

Do cross training to share information and learn from each other:
_________________________________________________________________________________
_________________________________________________________________________________
Share data or other administrative type information (with or without a Memorandum of Understanding):

_____________________________________________________________________________________
_____________________________________________________________________________________

Team up to provide community presentations or community-type education:

_____________________________________________________________________________________
_____________________________________________________________________________________

Team up to explore new opportunities for interacting:

_____________________________________________________________________________________
_____________________________________________________________________________________

Screening and Referrals

What screening process exists for identifying a) the mental health needs of children/youth with IDD and/or b) intellectual or developmental delays for children/youth with mental health challenges?

_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

What referral process exists for connecting children/youth with needed services?

_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

As you reflect on activities that have been done around integrated care for this population, what has:

**Worked well?**

_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

**Been a challenge?**

_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

**Moving Forward**

What gaps or opportunities exist from your perspective?

_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

Who needs to be involved or what is needed to address gaps or create opportunities?

_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
Appendix I

The Definition of “Medical Necessity” Under Kansas Administrative Regulations (K.A.R.) Section 30-5-58(ooo)

30-5-58. Definitions. The following words and terms, when used in this article, shall have the following meanings, unless the context clearly indicates otherwise.

***

(ooo) (1) “Medical necessity” means that a health intervention is an otherwise covered category of service, is not specifically excluded from coverage, and is medically necessary, according to all of the following criteria:

(A) “Authority.” The health intervention is recommended by the treating physician and is determined to be necessary by the secretary or the secretary’s designee.
(B) “Purpose.” The health intervention has the purpose of treating a medical condition.
(C) “Scope.” The health intervention provides the most appropriate supply or level of service, considering potential benefits and harms to the patient.
(D) “Evidence.” The health intervention is known to be effective in improving health outcomes. For new interventions, effectiveness shall be determined by scientific evidence as provided in paragraph (ooo)(3). For existing interventions, effectiveness shall be determined as provided in paragraph (ooo)(4).
(E) “Value.” The health intervention is cost-effective for this condition compared to alternative interventions, including no intervention. “Cost-effective” shall not necessarily be construed to mean lowest price. An intervention may be medically indicated and yet not be a covered benefit or meet this regulation’s definition of medical necessity. Interventions that do not meet this regulation’s definition of medical necessity may be covered at the choice of the secretary or the secretary’s designee. An intervention shall be considered cost effective if the benefits and harms relative to costs represent an economically efficient use of resources for patients with this condition. In the application of this criterion to an individual case, the characteristics of the individual patient shall be determinative.

(2) The following definitions shall apply to these terms only as they are used in this subsection (ooo);

(A) “Effective” means that the intervention can be reasonably expected to produce the intended results and to have expected benefits that outweigh potential harmful effects.
“Health intervention” means an item or service delivered or undertaken primarily to treat a medical condition or to maintain or restore functional ability. For this regulation’s definition of medical necessity, a health intervention shall be determined not only by the intervention itself, but also by the medical condition and patient indications for which it is being applied.

“Health outcomes” means treatment results that affect health status as measured by the length or quality of a person’s life.

“Medical condition” means a disease, illness, injury, genetic or congenital defect, pregnancy, or a biological or psychological condition that lies outside the range of normal, age-appropriate human variation.

“New intervention” means an intervention that is not yet in widespread use for the medical condition and patient indications under consideration.

“Scientific evidence” means controlled clinical trials that either directly or indirectly demonstrate the effect of the intervention on health outcomes. However, if controlled clinical trials are not available, observational studies that demonstrate a causal relationship between the intervention and health outcomes may be used. Partially controlled observational studies and uncontrolled clinical series may be considered to be suggestive, but shall not by themselves be considered to demonstrate a causal relationship unless the magnitude of the effect observed exceeds anything that could be explained either by the natural history of the medical condition or potential experimental biases.

“Secretary’s designee” means a person or persons designated by the secretary to assist in the medical necessity decision-making process.

“Treat” means to prevent, diagnose, detect, or palliate a medical condition.

“Treating physician” means a physician who has personally evaluated the patient.

Each new intervention for which clinical trials have not been conducted because of epidemiological reasons, including rare or new diseases or orphan populations, shall be evaluated on the basis of professional standards of care or expert opinion as described below in paragraph (ooo)(4).

The scientific evidence for each existing intervention shall be considered first and, to the greatest extent possible, shall be the basis for determinations of medical necessity. If no scientific evidence is available, professional standards of care shall be considered. If professional standards of care do not exist, or are outdated or contradictory, decisions about existing interventions shall be based on expert opinion. Coverage of existing interventions shall not be denied solely on the basis that there is an absence of conclusive scientific evidence. Existing interventions may be deemed to meet this regulation’s definition of medical necessity in the absence of scientific evidence if there is a strong consensus of effectiveness and benefit expressed through up-to-date and consistent professional standards of care or, in the absence of those standards, convincing expert opinion.
# Appendix J
Overview of Services through IDD Waiver and the SED Waiver

## IDD Waiver Services

<table>
<thead>
<tr>
<th>Service</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistive Services</td>
<td>Wheelchair modifications, ramps, home modifications, van lifts, and assistive technology.</td>
</tr>
<tr>
<td>Day Supports</td>
<td>Out of the home services for adults to increase a person’s productivity, independence, integration, and community inclusion. <em>This is a licensed service.</em></td>
</tr>
<tr>
<td>Financial Management Services</td>
<td>Provides billing and payroll services to individuals who self-direct their services. An agency directed option for this service also exists.</td>
</tr>
<tr>
<td>Medical Alert Rental</td>
<td>A devise that will alert an emergency response center for adults with special needs.</td>
</tr>
<tr>
<td>Overnight Respite Care</td>
<td>Designed to provide relief to the person’s family member who serves as the primary unpaid caregiver.</td>
</tr>
<tr>
<td>Personal Assistant Services (PAS)</td>
<td>Personal attendant care services for individuals who self-direct their Day, Residential, or In-Home support services although cannot be provided in schools.</td>
</tr>
<tr>
<td>Residential Supports</td>
<td>Services for adults living in a non-family home to retain and/or improve skills related to activities of daily living. <em>Children’s Residential Services: Services for children not in state custody placed out of the family home in a licensed KDHE home. This is a licensed service.</em></td>
</tr>
<tr>
<td>Sleep Cycle Support</td>
<td>Overnight attendant worker for medical needs to assist with repositioning, etc.</td>
</tr>
<tr>
<td>Specialized Medical Care</td>
<td>Long-term nursing support for medically fragile and technology dependent.</td>
</tr>
<tr>
<td>Supported Employment</td>
<td>Supported Employment is competitive work in an integrated setting with on-going support services. They assist the individual to sustain paid employment in the community and cannot be provided in a sheltered workshop setting.</td>
</tr>
<tr>
<td>Supportive Home Care</td>
<td>Personal attendant care services for individuals who receive agency directed attendant care services and live in the “family home.” They provide support in daily living, community activities, and activities other than employment.</td>
</tr>
<tr>
<td>Wellness Monitoring</td>
<td>Bi-monthly visits by a nurse to monitor significant medical needs.</td>
</tr>
</tbody>
</table>

Source: Shawnee County Community Developmental Disability Organization Resource Guide; CDDO of Southeast Kansas Service Descriptions

Note: Targeted Case Management is not a waiver service but rather a state plan service. For individuals with IDD, this service is designed to assist the individual in gaining access to medical, social, educational or other needed services. It is for coordination, not direct service.
# SED Waiver Services

<table>
<thead>
<tr>
<th>Service</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attendant Care</td>
<td>A staff person who helps the child with daily tasks. Can be in the home or in the community including in a school.</td>
</tr>
<tr>
<td>Independent Living/Skills building</td>
<td>Staff supported development of the skills needed in order to live independently</td>
</tr>
<tr>
<td>Short Term Respite Care</td>
<td>A service given inside or outside the home to provide caregivers and the child a break from their normal routines.</td>
</tr>
<tr>
<td>Parent Support and Training</td>
<td>Services designed to provide education, assistance, and other support to parents and families.</td>
</tr>
<tr>
<td>Professional Resource Family Care</td>
<td>Considered crisis stabilization, it is intensive support services provided to the child outside the home in a licensed home with “co-parenting” (education and support) between the resource home and the child’s parents.</td>
</tr>
<tr>
<td>Wraparound Facilitation</td>
<td>A person who works with the family and their identified supports to set treatment goals and decide on services for the child and family.</td>
</tr>
</tbody>
</table>

Sources:


Appendix K

List of Common Acronyms

CC       Care Coordinator
CDDO     Community Developmental Disability Organization
CMHC     Community Mental Health Center
DD       Developmental Disabilities
HCBS     Home and Community Based Services
IID      Individuals with Intellectual Disabilities
IDD      Intellectual/Developmental Disabilities
IDEA     Individuals with Disabilities Education Act
KDADS    Kansas Department of Disability and Aging Services
KDHE     Kansas Department of Health and Environment
MCO      Managed Care Organization
QMHP     Qualified Mental Health Professional
SED      Serious Emotional Disturbance
WAF      Wrap Around Facilitator