

**KANSAS SPECIAL HEALTH CARE NEEDS (KS-SHCN)  
SFY 2017 AID TO LOCAL (ATL) GUIDANCE**

[http://www.kdheks.gov/doc\\_lib/index.html](http://www.kdheks.gov/doc_lib/index.html)

**INTRODUCTION**

The Kansas Department of Health & Environment is responsible for administering the Title V Maternal and Child Health (MCH) Services Block Grant for the State of Kansas [funded through the U.S. Department of Health & Human Services (HHS), Human Resources & Services Administration (HRSA), Maternal and Child Health Bureau (MCHB)]. The MCH Block Grant and affiliated programs are organized within the Division of Public Health, Bureau of Family Health.

The Title V MCH Block Grant plays a key role in the provision of maternal and child health services in Kansas, including the Kansas Special Health Care Needs (KS-SHCN) program. Service or programs funded with Title V funding through the KS-SHCN program must support program priorities, outcomes, and measures while furthering identified mutual objectives and supporting respective responsibilities.

The KS-SHCN program promotes the functional skills of persons, who have or are at-risk for a disability or chronic disease. The program is responsible for the planning, development, and promotion of the parameters and quality of specialty health care in Kansas in accordance with state and federal funding and direction. SHCN provides specialized medical services to infants, children and youth up to age 21 who have eligible medical conditions. Additionally, the program provides services to persons of all ages with metabolic or genetic conditions screened through the Newborn Screening.

**LEGISLATION AND SCOPE**

Enacted in 1935 as a part of the Social Security Act, the Title V MCH Program is the Nation's oldest Federal-State partnership. Specifically, the Title V program seeks to:

1. Assure access to quality care, especially for those with low-incomes or limited availability of care;
2. Reduce infant mortality;
3. Provide and ensure access to comprehensive prenatal and postnatal care to women (especially low-income and at-risk pregnant women);
4. Increase the number of children receiving health assessments and follow-up diagnostic and treatment services;
5. Provide and ensure access to preventive and child care services as well as rehabilitative services for certain children;
6. Implement family-centered, community-based systems of coordinated care for children with special health care needs (CYSHCN); and
7. Provide toll-free hotlines and assistance in applying for services to pregnant women with infants and children who are eligible for Title XIX (Medicaid).

The 2016 Title V MCH Block Grant Application Guidance outlines the constructs of a service system for children and youth with special health care needs (CYSHCN). These include state program collaboration with other state agencies and private organizations, state support for communities, coordination of health components of community-based systems, and coordination of health services with other services at the community level. Additional information regarding these constructs may be found in **Appendix A: Kansas Block Grant Basics**.

Kansas statutes, K.S.A. 65-5a01 through K.S.A. 65-5a16 and K.S.A. 65-180, and regulations, K.A.R. 28-4-401 through 28-4-413 and 28-4-510 through 28-4-514, provide guidance to the program and services provided by the KS-SHCN program. Additionally, services provided through funding from the KS-SHCN program must align with state and federal program objectives and measures to be eligible for funding.

As a recipient of Title V Funding, the KS-SHCN program must adhere and comply with all requirements outlined in *Appendix A: Kansas Block Grant Basics*. The requirements for this funding opportunity are aligned with federal expectations and requirements and outlined throughout this document.

### **TARGET POPULATION FOR SERVICES**

Activities must address needs of the children and youth with special health care needs (CYSHCN) population and is defined as children and youth, age birth through 21 years, “who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.” It is not expected to limited services or supports under this grant proposal to those actively receiving services through the KS-SHCN program.

Services may be extended to adults over age 21 with genetic conditions screened for and diagnosed through the Kansas Newborn Screening program. A complete list of these conditions can be found on the KS Newborn Screening website at [www.kdheks.gov/newborn\\_screening/index.html](http://www.kdheks.gov/newborn_screening/index.html).

### **KS-SHCN ATL REQUIREMENTS**

Higher standards of accountability prevail for the MCH Block Grant due to scarcity of resources from State, Federal and other funding sources. Funding sources require regular, in-depth review of performance and outcome measures, as well as evidence of progress (through use of data) toward outcomes for MCH and SHCN populations. A shift from direct services to community-based, population-based, and infrastructure building services has been identified at the state and federal level.

**Applications for funding must clearly outline the type of service to be addressed by the activities within the proposal.** Definitions can be found in *Appendix B: Title V 2016-2020 MCH Services Pyramid*.

Funding requests are reviewed through a healthy equity lens for alignment with the Title V/Bureau of Family Health and the Division of Public Health’s core values of: health equity, social and environmental determinants of health, life course approach, and systems integration. There is great interest in funding activities that will be implemented as part of a comprehensive approach with potential for improved population health.

**The request for funds must clearly describe the activities and/or services to be provided and alignment with one or more of the outlined priorities, performance measures, populations, and types of service.**

KS-SHCN began an extensive strategic planning process in July 2013 consisting of stakeholder meetings and engagement of families, medical providers, community partners, and program staff. The strategic planning process focused around four key principles: 1) increasing the value of the program for those served; 2) evaluating relevancy of program services offered for families; 3) evaluating cost effectiveness of direct and clinical services; and 4) identifying opportunities for improvement by utilizing quality improvement methodology. Through this process, five new priorities emerged: Cross-System Care Coordination, Addressing Family Caregiver Health Needs, Behavioral Health Integration, Training and Education, and Direct Health Care Services.

**Projects submitted shall directly tie to one or more of the KS-SHCN priorities. Projects not aligned with the priorities will not be considered.** These definitions have been developed to support applicants understanding of the KS-SHCN priorities.

#### Cross-System Care Coordination

Projects addressing this priority must show evidence of existing partnerships or the capacity and plan to build new partnerships, in support of cross-system communication, collaboration, planning and information sharing, referrals, and patient navigation.

*DEFINITION: “Patient and family-centered approach that utilizes team-based and assessment activities designed to meet the needs of children and youth while enhancing the capabilities of families. It addresses interrelated medical, behavioral, educational, social, developmental, and financial needs to achieve optimal health.”*

#### Family Caregiver Health

Projects addressing this priority must show evidence of capacity to address needs or provide support to family caregivers. Services must support the physical, emotional, social, or financial well-being of families.

*DEFINITION: “Supporting the physical, emotional, social, and financial well-being of families with CYSHCN, particularly that of the family caregivers. A family caregiver is any individual, including siblings, who supports and cares for another person and may or may not be a biological relative.”*

#### Behavioral Health Integration

Projects addressing this priority must show evidence of collaborative services for the prevention and treatment of emotional disorders. Services must support the functioning of children, youth, or families.

*DEFINITION: “Collaborative services for the prevention and treatment of emotional disorders that support the functioning of children, youth, and families in all settings, including home, community, school, and work. Efforts should be focused on keeping children in their home and/or community.”*

#### Direct Health Services and Supports

Projects addressing this priority must include services delivered one-on-one between a health professional and patient. This may include primary, specialty, or ancillary health services. This could also include the utilization of telehealth services. Only services that are not billable and/or reimbursable by private or public insurance are eligible for funding under this request. Sufficient evidence must be presented within the proposal that outlines the need for services, inability to bill/obtain reimbursement for services, and fill a specific gap in services for the KS-SHCN population.

*DEFINITION: “Services delivered one-on-one between a health professional and patient, which may include primary, specialty, or ancillary health services, such as: inpatient and outpatient medical services, allied health services, drugs and pharmaceutical products, laboratory testing, x-ray services, and dental care. Access to highly trained specialists or services not generally available in most communities may also be included in this definition.”*

#### Training and Education

Projects addressing this priority must clearly outline a specific training need among one or more of the following: families, community members, medical and community providers, local and state service programs, or legislators. Training and education projects must support diversity in the provision of services for the KS-SHCN population, and include a written plan for the provision and evaluation of training/education activities.

**DEFINITION:** *“Supporting diversity in the provision of services for the special health care needs (SHCN) population through training and education of families, community members, medical and community providers, local and state service programs, and legislators. This includes family and youth leadership development in building a stronger advocacy network in Kansas.”*

The objective of the KS-SHCN program is to support a comprehensive, quality system of care for children and youth with special health care needs (CYSHCN). As such, Title V desires collaborative relationships with partners, such as private insurers, state Medicaid and CHIP agencies, pediatricians and family physicians, community providers and service organizations, and families.

**Preference will be given to applications who show desire and capacity to coordinate with public/private insurers, medical and community providers, developmental/children and family services, education, and other programs providing services and supports to the CYSHCN population or their families.**

In March 2014, The Lucille Packard Foundation for Children’s Health and the Association of Maternal and Child Health Programs (AMCHP) released the “Standards for Systems of Care for Children and Youth with Special Health Care Needs,” a core set of structure and process standards for system of care for CYSHCN. This report can be found online at <http://www.amchp.org/programsandtopics/CYSHCN/Documents/Standards%20Charts%20FINAL.pdf>. Highlights of this publication can be found in **Appendix C: Highlights of the Standards for Systems of Care for CYSHCN.**

**Preference will be given to applications who show ability to address one or more of the system standards to meet the needs of CYSHCN and their families through community and population based services.**

**The applicants’ capacity must show ability to support a strong system of care, build infrastructure, and increase probability for long-term sustainability of improved services for CYSHCN, as related to the system standards.**

## **FUNDING EXPECTATIONS AND LIMITATIONS**

The following are allowable under this funding proposal:

- Any planning, implementation, and evaluation activities associated with the proposed project. Sub-grantees are allowed with prior approval and must be identified in the grant application and submitted budget.
- Administration and grant oversight, limited to no more than 10 percent of funds utilized for this purpose.
- Personnel/staff time for activities provided, with appropriate time and effort reporting.
- Clinical services are allowable only if provided by licensed professionals and are not eligible to bill insurance and/or Medicaid.
  - Clinical service providers are expected and required to bill insurance and/or Medicaid for services, pursuant to K.A.R 28-4-405.
  - In the event the clinical provider is not eligible to bill insurance and/or Medicaid, sufficient evidence outlining an exception to this requirement may be presented for consideration.
  - Provider honorariums are not allowable if the provider is eligible to bill for services and are subject to KS-SHCN review and approval.

## **Local Match Requirement**

**A minimum of 25% is required for non-clinical activities under the grant application. Special consideration will be provided to those with a match greater than 25%.**

Sources that may be used for matching funds are: reimbursement for service from third parties such as insurance and Title XIX; client fees; local funds from non-federal sources; or in-kind contributions. In-kind contributions must be documented in accordance with generally accepted accounting principles. Records for tracking match must be made available for review, upon request.

Non-cash contributions or in-kind donations may be used to meet the required match. In-kind or non-cash support may include:

- Personnel/staff time, space, commodities, or services
- Contributions at a fair market value and documented in the organization accounting records

*IMPORTANT: Non-allowable match funds include those associated with inpatient care or other funds used to match other federal, state, or foundation grants.*

### **Review and Award Timeline**

All required information must be provided in order for the request to be reviewed, by March 15, 2016 and submitted online, accessible through Catalyst ([www.catalystserver.com](http://www.catalystserver.com)).

- For grantees receiving funding in SFY16, your administrative and program contacts will receive a Catalyst user name and password in advance. If a username and password has not yet been received, contact the Catalyst Operations Support Team ([support@shpr.com](mailto:support@shpr.com)).
- New applicants can request a username and password by contacting: [support@shpr.org](mailto:support@shpr.org)
- Before starting your application, please complete the following training courses on Kansas TRAIN ([ks.train.org](http://ks.train.org)):
  1. Catalyst Training 1: Catalyst Navigation (Course #1054439)
  2. Catalyst Training 2: Application Process Overview in Catalyst (Course #1054483)
  3. Catalyst Training 3: Application Management in Catalyst (Course #1054567)
  4. Catalyst Training 4: Applying for Funding Announcement(s) in Catalyst (Course #1054672)

**Applications are available on January 15 and are due on March 15.**

If further information or additional discussion is necessary to assure the needs and desired outcomes for both the requestor and KS-SHCN are addressed, you will be notified by email and provided with a timeline for response. If a response is not received, the application will not be considered.

**Applicants will be notified, in writing, of approval or denial by May 15, 2016.** Upon agreement of terms, a fully executed contract or agreement will be developed and submitted for approval and signature.

**Grant activities are expected to follow the State Fiscal Year timeline and begin on or after July 1, 2016 and end on or before June 30, 2017.** Multi-year projects are allowable and will be granted under certain circumstances. Requests for multi-year projects can be made by entering the start and end dates under A.1.2. "Outline the anticipated timeframe that SHCN funding will be utilized for the proposed activities." Attach a written request, dated and signed on organization letterhead, under A.1.2.

### **REPORTING REQUIREMENTS**

Reports of activities and invoices of services that address MCH/KS-SHCN priorities, measures, outcomes, and indicators shall be submitted regularly throughout the grant period. Specific reporting requirements will be determined based upon the funding request submitted and the KS-SHCN program needs. These details will be included in the contractual agreement. Reports and invoices shall be provided on the form(s) provided by the KS-SHCN program.

Generally, the following requirements will be expected of all accepted grantees. Specific details of reporting needs will be outlined in the contract, based upon information provided in the application.

Documentation or Reporting Requirements	Due Date
Revised Budget, if requested	Within 15 days of accepted grant application
Baseline Data Measures	Within 30 days of contract start date
Preferred Site Visit Dates	Within 30 days of contract start date
Affidavit of Revenues and Expenditures	Quarterly*
Individuals Served Data	Quarterly*
Narrative Progress Report	November 15 and May 15
Annual Report	Within 45 days of contract end date

*\*Items due quarterly will be due 30 days following the end of the quarter (July through September, October through December, January through March, April through June). These dates are applicable, regardless of contract start date.*

## PROGRAM CONTACTS

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### **Kansas Title V MCH Block Grant Basics**

The Kansas Department of Health & Environment is responsible for administering the Title V Maternal and Child Health (MCH) Services Block Grant for the State of Kansas. The MCH Block Grant and affiliated programs are located within the Division of Public Health, Bureau of Family Health.

The Title V MCH Block Grant plays a key role in the provision of maternal and child health services in Kansas. Funds from this grant are distributed among a number of programs which target the improvement of the health of all women, infants, children and adolescents, including children and youth with special health care needs (CYSHCN), and families.

As part of Kansas' Block Grant requirements, the Kansas Department of Health:

- 1) Submits an Application/Annual Report for Federal funds to the Federal Maternal and Child Health Bureau each year in July;
- 2) Adheres to the strict requirements concerning how Title V funds are spent:
  - a) At least thirty percent (30%) for preventive and primary care services for children.
  - b) At least thirty percent (30%) for services for CYSHCN. Funds are to be spent on:
    - i) services described as "family-centered, community-based, coordinated care (including care coordination services); and
    - ii) the development of community-based systems of services for CYSHCN and their families.
  - c) Not more than ten percent (10%) for administering the funds.
  - d) Funding is also to be spent on preventive and primary care services for pregnant women, mothers, and infants up to age one. However, there are no requirements regarding percentage to be spent.
  - e) The State must match federal funds at \$0.75 for every \$1 of federal funding.
- 3) Conducts a statewide needs assessment every five years. The needs assessment identifies state maternal and child health priorities, goals, and performance measures that assess state progress and accountability for a five-year period. The 2016-2020 Needs Assessment is currently in progress and will be completed by June 2015.

As a recipient of Title V Funding, the KS-SHCN program must adhere and comply with all requirements listed above. The requirements for this funding opportunity are outlined throughout this document and may vary slightly from the above guidelines.

### **Maternal and Child Health Block Grant Transformation**

The Federal Maternal and Child Health Bureau (MCHB) began a process to transform the Title V MCH Block Grant to reduce burden, maintain flexibility and improve accountability. By working in partnership with State Title V leaders, families and other stakeholders, they expect the transformation of the block grant to help achieve their mission to improve the health and well-being of all of America's mothers, infants, children, and youth – including children and

## Appendix A: Kansas Title V MCH Block Grant Basics

youth with special health care needs (CYSHCN) and their families. The improvements will be phased in, beginning with the 2015 MCH Block Grant application.

### Reduce Burden: Streamline the Annual Report and Application

- Require only a needs assessment summary and integrate into the application
- Pre-populate State data
- Eliminate Health Systems Capacity Indicator
- Reduce the number of forms from 21 to 11
- Simplify, clarify and reduce redundancies

### Maintain Flexibility: Apply a Logic Model

- Continuously analyze performance and reassess performance measures and strategies
- Implement 3-tiered performance measurement with national outcome measures, national performance measures and structural-process measures
- Include measures for six domains: maternal and women's health, perinatal and infant health, child health, adolescent health, life course, and children with special healthcare needs

### Improve Accountability: New Accountability Framework

- Develop a one-stop maternal and child health data center
- Support States in developing evidence-based and -informed structural process measures
- Realign Special Projects of Regional and National Significance (SPRANS) and other HRSA programs to "move the needle" on maternal and child health

Additionally, MCHB has amended the MCH Services Pyramid (Figure 1, next page). Previously, this pyramid included four types of services. This pyramid has been modified to include the following three services: (1) Direct Services; (2) Enabling Services; and (3) Public Health Services and Systems and are defined as outlined below:

1. *Direct Services* are directly provided to individuals, by state or local agency staff or by grantees or contractors. Title V programs commonly support prenatal care, well-child and school-based health services, and specialty services for children and youth with special health care needs.
2. *Enabling Services* are non-clinical services that enable individuals and families to access health services and improve health outcomes. These services are usually targeted to families that have special needs or face specific barriers.
3. *Public Health Services and Systems* include activities and infrastructure to carry out the core public health functions of assessment, assurance, and policy development and the 10 essential public health services. These generally encompass the functions that indirectly benefit families by laying the foundations for the policies and programs that can improve the health and well-being of the individuals and families.

## Public Health Services for MCH Populations: The Title V MCH Services Block Grant

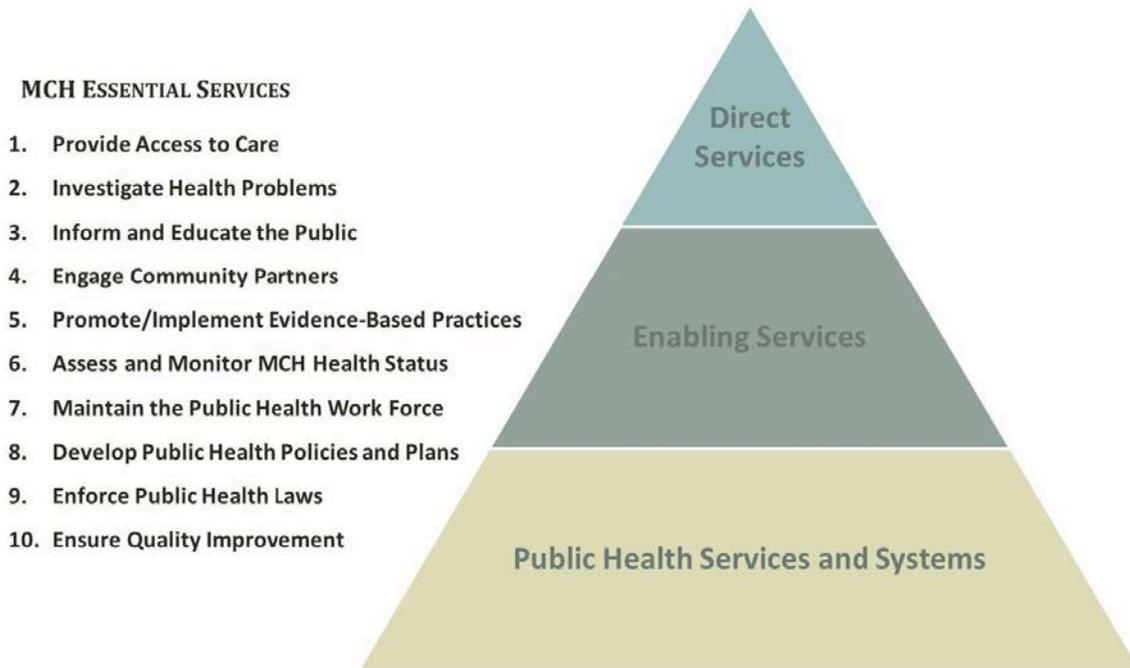


Figure 1: MCH Pyramid

### Performance Measurement Process and Reporting Expectations

As indicated, MCHB has implemented a 3-tiered performance measurement process, including national outcome measures, national performance measure, and state-identified evidence-based or –informed strategy measures. In addition, States are expected to develop state performance measures to address the priorities identified through the five-year needs assessment. As part of the 2016-2020 Kansas Title V Needs Assessment, new state priorities will be selected and will inform the work related to this performance measurement process.

- The national outcome measures (NOMs) are the ultimate focus and desired results of any set of public health program activities and interventions. These are usually longer term and tied to the ultimate program goal. NOMs are provided by MCHB.
- The national performance measures (NPMs) are narrative statements that describe a specific population need that, when successfully addressed, will lead to a specific health outcome within a community or population. These generally have a specified time frame and include specific objectives. MCHB proposed 15 NPMs, allowing states to choose 8 NPMs based on their identified state priorities.
- The state-identified evidence-based or –informed strategy measures (ESMs) assess the impact of State Title V strategies and activities and directly measure the State’s impact

## Appendix A: Kansas Title V MCH Block Grant Basics

on the selected national performance measures. States will develop ESMs based upon the selected NPMs.

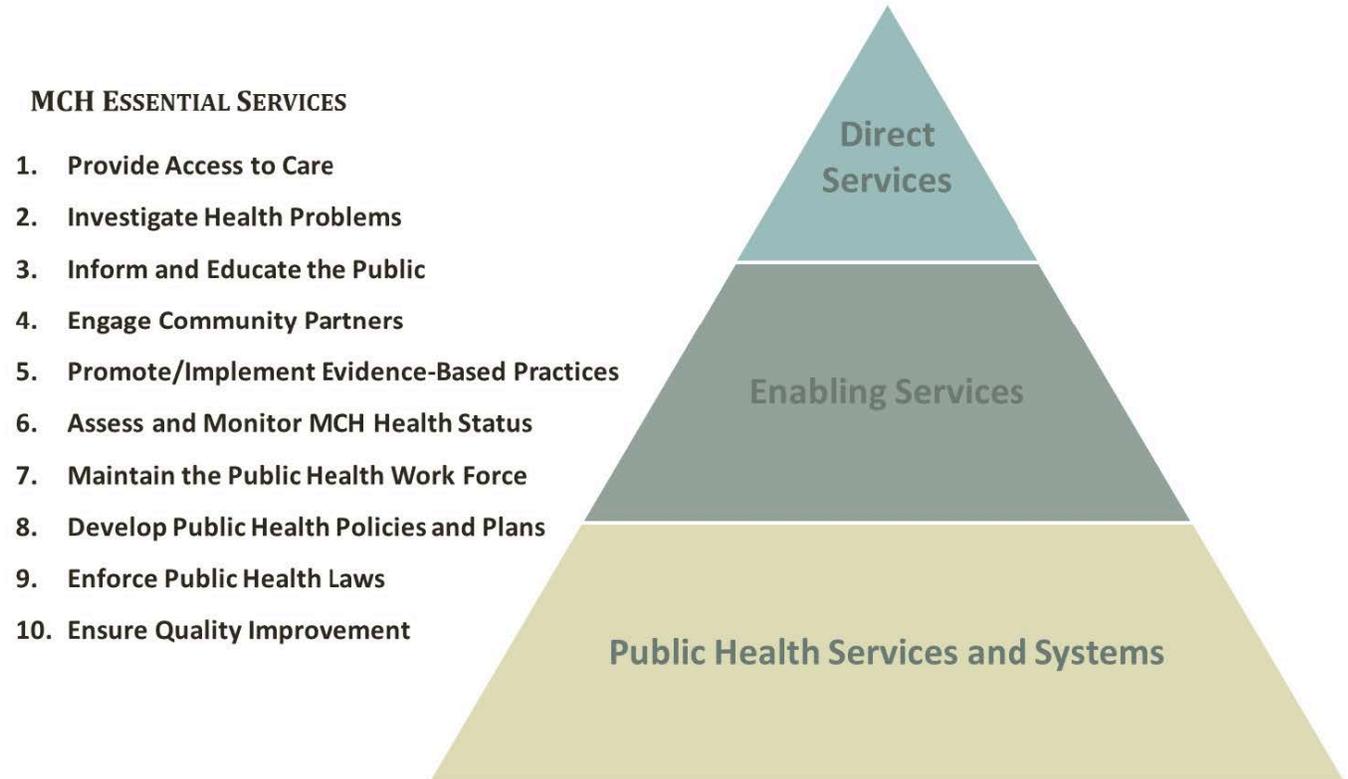
- The state performance measures (SPMs) are used to address priorities identified through the five-year needs assessment. State will develop these based on state priorities not fully addressed through the selected NPMs and developed ESMs.

As you may conclude, the State is expected to assure compliance with a fairly complicated performance measurement system, as well as hold partners in which funding is provided to accountable for these measurements as well. All work approved through this funding process must assist the state in moving towards identified objectives through this performance measurement system.

### **For information on Title V, the Bureau of Family Health, and the KS-SHCN program:**

- KDHE Bureau of Family Health/MCH: [www.kdheks.gov/bfh](http://www.kdheks.gov/bfh)
- KDHE Kansas Special Health Care Needs Program: [www.kdheks.gov/shcn](http://www.kdheks.gov/shcn)
- KDHE Title V Block Grant Information and Resources: <http://www.kdheks.gov/c-f/mch.htm>
- Federal Maternal & Child Health Bureau: <http://mchb.hrsa.gov/>
- MCH 3.0 Block Grant Transformation: <http://mchb.hrsa.gov/blockgrant/index.html>

## Public Health Services for MCH Populations: The Title V MCH Services Block Grant



**Direct Services** are directly provided to individuals, by state or local agency staff or by grantees or contractors. Title V programs commonly support prenatal care, well-child and school-based health services, and specialty services for children and youth with special health care needs.

**Enabling Services** are non-clinical services that enable individuals and families to access health services and improve health outcomes. These services are usually targeted to families that have special needs or face specific barriers.

**Public Health Services and Systems** include activities and infrastructure to carry out the core public health functions of assessment, assurance, and policy development and the 10 essential public health services. These generally encompass the functions that indirectly benefit families by laying the foundations for the policies and programs that can improve the health and well-being of the individuals and families.

## Utilization of the Standards for Systems of Care for CYSHCN

The Title V Program strives to support a comprehensive, quality system of care for the children and youth with special health care needs (CYSHCN) population. In Kansas, this is the responsibility of the Kansas Special Health Care Needs program (KS-SHCN).

Historically, KS-SHCN has provided a variety of services under the Title V MCH Block Grant, as well as with the support of the State through State General Funds. While the vision and mission of the program has not changed, the national and state health care systems have evolved dramatically over the last two decades. Therefore, KS-SHCN has undergone an extensive strategic planning effort to assure program activities and initiatives are aligned with the needs of families in our State. Additionally, changes in the Title V MCH Block Grant are supporting the shift from direct health services to enabling and public health services and systems.

KS-SHCN is dedicated to meeting the needs of families, as defined in section 501(a)(1) of the Title V legislation, to enable each state:

- To provide and to assure mothers and children (in particular those with low income or with limited availability of health services) access to quality MCH services;
- To reduce infant mortality and the incidence of preventable diseases and handicapping conditions among children, to reduce the need for inpatient and long-term care services, to increase the number of children (especially preschool children) appropriately immunized against disease and the number of low income children receiving health assessments and follow-up diagnostic and treatment services, and otherwise to promote the health of mothers and infants by providing prenatal, delivery, and postpartum care for low income, at-risk pregnant women, and to promote the health of children by providing preventive and primary care services for low income children;
- To provide rehabilitation services for blind and disabled individuals under the age of 16 receiving benefits under title XVI, to the extent medical assistance for such services is not provided under title XIX; and
- To provide and promote family-centered, community-based, coordinated care (including care coordination services, as defined in subsection (b)(3)\*) for children with special health care needs (CSHCN) and to facilitate the development of community-based systems of services for such children and their families.

*\*The term "care coordination services" means services to promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for children with special health care needs and their families. ~ Section 501(b)(3) of Title V Legislation*

As part of the extensive strategic planning process, KS-SHCN has committed to utilizing the "Standards for Systems of Care for CYSHCN," published in March 2014 by the Lucille Packard Foundation and the Association of Maternal and Child Health Programs. This was a product of the National Consensus Framework for Systems of Care for CYSHCN Project. For many years,

## Appendix C: Highlights of the Standards for Systems of Care for CYSHCN

the MCH field has called for structure and process standards for systems of care for CYSHCN, to support their work. These standards are intended to be used by a range of national, state and local stakeholder groups including state Title V CYSHCN programs, health plans, state Medicaid and CHIP agencies, pediatric provider organizations, children's hospitals, insurers, health services researchers, families/consumers, and others. The KS-SHCN program, as the Kansas Title V CYSHCN Program, is dedicated to working with partners to support stronger systems of care and acknowledge that these standards are in no way intended to be addressed independently or in a silo.

### Overall System Outcomes for CYSHCN

The standards are grounded in the six core outcomes for systems of care for CYSHCN, developed by the federal Maternal and Child Health Bureau (MCHB), and an added outcome based on the collaborative work of stakeholders during development of the standards. These seven overall system outcomes for the CYSHCN population include:

- 1. Family Professional Partnerships:** Families of CYSHCN will partner in decision making at all levels and will be satisfied with the services they receive.
- 2. Medical Home:** CYSHCN will receive family-centered, coordinated, ongoing comprehensive care within a medical home.
- 3. Insurance and Financing:** Families of CYSHCN have adequate private and/or public insurance and financing to pay for the services they need.
- 4. Early and Continuous Screening and Referral:** Children are screened early and continuously for special health care needs.
- 5. Easy to Use Services and Supports:** Services for CYSHCN and their families will be organized in ways that families can use them easily and include access to patient and family-centered care coordination.
- 6. Transition to Adulthood:** Youth with special health care needs receive the services necessary to make transition to all aspects of adult life, including adult health care, work, and independence.
- 7. Cultural Competence:** All CYSHCN and their families will receive care that is culturally and linguistically appropriate (attends to racial, ethnic, religious and language domains).

### Core Domains for System Standards

In addition to the guiding principles outlined above with the system outcomes, the standards are broken down into 10 core domains. Throughout the publication, the system standards (structure and process) are outlined based on these core domains. Additionally, the existing national principles and frameworks, federal requirements of relevant federal laws, and the overall availability of relevant quality measures are cross-referenced for each core domain. A list of the core domains and overall system outcomes can be found on the next page.

## Appendix C: Highlights of the Standards for Systems of Care for CYSHCN

### Overall System Outcomes for CYSHCN:<sup>3,4</sup>

1. **Family Professional Partnerships:** Families of CYSHCN will partner in decision making at all levels and will be satisfied with the services they receive
2. **Medical Home:** CYSHCN will receive family-centered, coordinated, ongoing comprehensive care within a medical home
3. **Insurance and Financing:** Families of CYSHCN have adequate private and/or public insurance and financing to pay for the services they need
4. **Early and Continuous Screening and Referral:** Children are screened early and continuously for special health care needs
5. **Easy to Use Services and Supports:** Services for CYSHCN and their families will be organized in ways that families can use them easily and include access to patient and family-centered care coordination
6. **Transition to Adulthood:** Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence
7. **Cultural Competence:** All CYSHCN and their families will receive care that is culturally and linguistically appropriate (attends to racial, ethnic, religious, and language domains)

### Core Domains for System Standards

1. Screening, Assessment and Referral
2. Eligibility and Enrollment
3. Access to Care
4. Medical Home, including:
  - Pediatric Preventive and Primary Care
  - Care Coordination
  - Pediatric Specialty Care
5. Community-based Services and Supports, including:
  - Respite Care
  - Palliative and Hospice Care
  - Home-based Services
6. Family Professional Partnerships
7. Transition to Adulthood
8. Health Information Technology
9. Quality Assurance and Improvement
10. Insurance and Financing

*~Table pulled from 2015 AMCHP Conference Presentation, "Translating the National Standards for CYSHCN – Application and Implementation at the State Level" by Treeby Brown, Meredith Pyle, and Karen VanLandeghem*

### Overview of Standards by Core Domain

This section will outline some general examples of standards

Screening, Assessment and Referral	<ul style="list-style-type: none"> <li>- Early identification, including newborn screening</li> <li>- Needs identified by insurance plans</li> <li>- EPSDT (Early Periodic Screening, Diagnosis, and Treatment) and Bright Futures</li> <li>- Documented, transportable plans of care</li> </ul>
Eligibility and Enrollment	<ul style="list-style-type: none"> <li>- Outreach and coordination with community organizations</li> <li>- Policies for transition between plans and for gaps in coverage</li> <li>- Comprehensive member services with specialty staff</li> </ul>
Access to Care	<ul style="list-style-type: none"> <li>- Statewide access</li> <li>- Physical, mental health, dental, and specialty care – with provider choice</li> <li>- Transportation and interpreter supports</li> </ul>
Medical Home <i>(including pediatric preventive and primary care, care coordination, and pediatric specialty care)</i>	<ul style="list-style-type: none"> <li>- Medical team; care coordination</li> <li>- 24-7 access; additional time for visits</li> <li>- Prevention and Treatment</li> <li>- Routine, emergent and urgent needs are met</li> </ul>

Appendix C: Highlights of the Standards for Systems of Care for CYSHCN

Community-Based Services and Supports	<ul style="list-style-type: none"> <li>- Patient and family centered</li> <li>- Respite services; home-based services</li> <li>- Palliative and hospice care</li> <li>- Transportation and interpreter supports</li> </ul>
Family Professional Partnerships	<ul style="list-style-type: none"> <li>- Families are active members of the team</li> <li>- Connection with family organizations, peer support</li> <li>- Strength-based; Informed</li> <li>- Culturally and linguistically appropriate</li> </ul>
Transition to Adulthood	<ul style="list-style-type: none"> <li>- Youth engagement</li> <li>- Transition and transfer of care policies and processes</li> <li>- Transition assessment and plan in place and current</li> <li>- Coordination between pediatric and adult providers</li> </ul>
Health Information Technology (HIT)	<ul style="list-style-type: none"> <li>- Use of electronic health record systems; meaningful use</li> <li>- Families are partners in electronic health information (EHI)</li> <li>- HIT incorporates Medicaid health policy priorities</li> <li>- EHI is accessible and shared across care settings</li> </ul>
Quality Assurance and Improvement	<ul style="list-style-type: none"> <li>- Quality assurance and improvement processes for CYSHCN</li> <li>- Child medical record reviews include sample of CYSHCN</li> <li>- Utilization review/appeals for CYSHCN include integrated care team</li> </ul>
Insurance and Financing	<ul style="list-style-type: none"> <li>- Plans are affordable and no risk for loss of benefits</li> <li>- Coverage/payment facilitates access to needed providers</li> <li>- Comprehensive habilitative services coverage</li> <li>- Promote care coordination and medical homes</li> </ul>

Other existing national principles and/or frameworks were identified for each of the ten domains. These other frameworks include:

- Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents
- Core Set of Children’s Health Care Quality Measures for Medicaid and CHIP
- Joint Principles of the Patient Centered Medical Home
- National Quality Forum Framework for Care Coordination
- Key Elements of High-Performing Pediatric Care Coordination Framework
- The Functions of Care Coordination
- The Ten Steps for Plan of Care Development
- Ease of Use Framework
- National Respite Guidelines: Guiding Principles for Respite Models and Services
- Principles of Quality Respite Care
- NHPCO Guiding Principles for Pediatric Palliative Care and Hospice
- Six Core Elements of Health Care Transition
- National Association of Insurance Commissioners



**KDHE BUREAU OF FAMILY HEALTH**  
**TITLE V MATERNAL & CHILD HEALTH (MCH) SERVICES BLOCK GRANT PROGRAM**  
*FFY 2016 APPLICATION / 2014 ANNUAL REPORT*

**State Priorities**

*States conduct a 5-year needs assessment to identify 7-10 state MCH priorities.*

1. Women have access to and receive coordinated, comprehensive care and services before, during and after pregnancy.
2. Services and supports promote healthy family functioning.
3. Developmentally appropriate care and services are provided across the lifespan.
4. Families are empowered to make educated choices about nutrition and physical activity.
5. Communities and providers support physical, social, and emotional health.
6. Professionals have the knowledge and skills to address the needs of maternal and child health populations.
7. Services are comprehensive and coordinated across systems and providers.
8. Information is available to support informed health decisions and choices.

**National Performance Measures (NPMs)**

*States select 8 of 15 that address the state priority needs; at least one from each population domain\* area.*

- NPM1: Well-woman visit (Percent of women with a past year preventive medical visit)
- NPM4: Breastfeeding (A. Percent of infants who are ever breastfed and B. Percent of infants breastfed exclusively through 6 months)
- NPM6: Developmental screening (Percent of children, ages 10 through 71 months, receiving a developmental screening using a parent-completed screening tool)
- NPM7: Child Injury (Rate of hospitalization for non-fatal injury per 100,000 children ages 0 through 9 and adolescents ages 10 through 19)
- NPM9: Bullying (Percent of adolescents, 12 through 17, who are bullied or who bully others)
- NPM10: Adolescent well-visit (Percent of adolescents, 12 through 17, with a preventive medical visit in the past year)
- NPM11: Medical home (Percent of children with and without special health care needs having a medical home)
- NPM14: Smoking during Pregnancy and Household Smoking (A. Percent of women who smoke during pregnancy; B. Percent of children who live in households where someone smokes)

**Evidence-Based or -Informed Strategy Measures (ESMs):** To be developed by May 2016.

*States create ESMs designed to impact the NPMs. These measures would assess the impact of State Title V strategies and activities contained in the State Action Plan.*

**State Performance Measures (SPMs):** To be developed by May 2016.

*States select 3-5 measures to address state priorities not addressed by the National Performance Measures.*

**\*MCH Population Domains**

1. Women/Maternal Health
2. Perinatal/Infant Health
3. Child Health
4. Adolescent Health
5. Children & Youth with Special Health Care Needs
6. Cross-cutting or Life Course

*Background: The Title V Maternal and Child Health (MCH) Block Grant is the linchpin for MCH services in the United States. Administered by the Health Resources and Services Administration's Maternal and Child Health Bureau (MCHB), the block grant operates through a Federal/State partnership in all 50 States, the District of Columbia and 9 jurisdictions. Title V was authorized in 1935 as part of the Social Security Act to stem the declining health of mothers and children in the midst of the Great Depression. Title V became a block grant program as part of the Omnibus Budget Reconciliation Act (OBRA) of 1981.*