




## D-70 Grant Objectives

**Create inclusive community-based systems for CYSHCN**

**Implement a plan to achieve appropriate community based service systems, as defined by the following components:**

1. family professional partnership;
2. comprehensive health care through a medical home;
3. access to adequate health insurance;
4. early and continuous screening;
5. organization of community services for easy use by families; and
6. transition to adult health care work and independence.

~ HRSA Application ~

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## D-70 Grant Requirements



### Applicants must:

- be or work closely with the State Title V CYSHCN;
- have a statewide needs assessment that addresses each of the 6 systems components;
- work with partners to develop and implement a statewide plan to achieve a community based system of services for CYSHCN; and
- use evidenced based and best practices models recommended by the Maternal and Child Health Bureau.

~ HRSA Application



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## Kansas Demographics



- Kansas ranks 32 in size to other states
- Has 105 counties with 69 of the counties being categorized as either rural or frontier
- Members of racial/ethnic minority groups now comprises 1/5 Kansans
- State-wide telemedicine sites with video and firewall protection access



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A map of Kansas divided into its 105 counties. The counties are labeled with their names. Two cities are marked with red stars: Topeka in Jackson County and Wichita in Sedgewick County.

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 1000 UNIVERSITY AVENUE  
 LAWRENCE, KS 66044

## Kansas D-70 Grant

Class of 2012: June 2009 – May 2012

**Current Status**

- Year 2 of 3
- Partnership with the KU Center on Developmental Disabilities
- Branded as “Systems in Sync”

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## KS Supporting Data



- Only 50% of children and youth (age 12-17) with special health care needs (CYSHCN) stated they received the services necessary to transition into adulthood
- 31% of families did not experience family-centered care
- 66% of CYSHCN felt that they were partners in decision making and were satisfied with the services they received

**90% of children with special health care needs are now surviving into their adult years**



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- 55% received coordinated, ongoing comprehensive care within a medical home
- 22% of families with CYSHCN reported that their child's medical condition had caused financial problems
- 20% of families with CYSHCN had to cut back or stop working due child's medical needs *~ NSCHCN, 2005-1006*

**4 out of 10 people with severe disabilities are not at all involved in their communities.**


*~ National Organization on Disabilities, 2000*





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## Problem



- Access or navigation through service delivery systems challenging for families of CYSHCN
- Lack of interaction between the various systems in planning or facilitating services.
- Youth report not having the information or skills to transition into independent adult roles.



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## Target Population for Project




- Youth ages 14-25 with SHCN
- Family Members
- Support Team
- Health Care Providers
- Educators
- Transition Specialists
- Work Force Development
- Community Partners




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## “Systems in Sync” Objectives



- Strengthen Partnerships
  - State agency partnerships and patient/provider partnerships
- Medical Home
  - Enhance access to services
- Transition
  - Incorporate transition supports into practices and policies for YSHCN
- Sustainability



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## Goal 1: Strengthen Partnerships

*Individual, Patient and Professional Partnerships*



### Evaluate statewide practices and promote partnerships

- Stakeholder Advisory Council
- Youth Advisory Council
- Host regional town hall meetings and workshops
- Provide funding opportunities (Call for Investments)




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## Goal 1: Strengthen Partnerships

*Individual, Patient and Professional Partnerships*




**Provide training for youth, families and professionals**

- Trainings conducted for families and youth through Families Together, Inc. and the KS Youth Empowerment Academy
- Development of resource guide and navigational tool-kit




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## Goal 2: Medical Home

*Support access and services*




**Information sharing and TA for providers**

- Fact sheets, brochures, information in newsletters, etc.
- Exhibit booths and community outreach about medical home
- Presentations to students and providers
- Development of Disability Awareness course at KUMC



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## Goal 2: Medical Home

*Support access and services*



### Link related professionals to promote integrations

- Engage stakeholders through networking opportunities and participate on various work groups and councils
- Make a Difference Information Network (MADIN)
- Exhibit booths about CYSHCN program, MADIN, and the SIS project



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## What is a Medical Home?



Medical home in Kansas means:

“A health care delivery model in which a patient establishes an ongoing relationship with a physician or other personal care provider in a physician-directed team, to provide comprehensive, accessible and continuous evidence-based primary and preventive care, and to coordinate the patient's health care needs across the health care system in order to improve quality and health outcomes in a cost effective manner.”

*~KS Statute 75-7429*




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**Goal 3: Transition**  
*Promote transition into adulthood*




**Enhance independence through self-directed curriculum**


- Computerized health care transition curriculum for youth with special health care needs
- Utilize technology to promote the use of personal health histories and transport to providers
- Provide TA to students and teachers on incorporating health into transition planning meetings



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**Goal 3: Transition**  
*Promote transition into adulthood*




**Address challenges associated with health care transition**

- Collaborating with others to develop a model for health care transition within the medical home
- Pilot project in Kansas with 2 pediatric and 2 primary care providers on transition strategies and roles of medical offices with regard to transition within the medical home



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## What is a Transition?



### KS D-70 Transition Definition

“Transition is the process of moving from one service system to another to maximize lifelong functioning and potential through high-quality, developmentally appropriate services. Transition services are a coordinated set of activities for an individual with a disability that supports integration from pediatric to adult health care providers and obtaining knowledge and competencies about adult related services within the medical, school to post-school activities, vocational training, integrated employment, continuing and adult education, adult services, independent living, and/or community participation.”



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## Missouri D-70 Grant

Class of 2011: June 2008 – May 2011



### Project Partners:


- MO Bureau of Special Healthcare Needs (BSHCN) - State Title V Agency
- MO Family Voices
- University of Missouri – Institute for Human Development



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## MO Project Overview




**Goal**


- “To improve and sustain access to quality, comprehensive, coordinated community-based systems of services for CYSHCN and their families in Missouri.”

**Objective**


- Implement a statewide plan of integrated services at the individual, community and state levels.



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## Recent Updates




**Provide technical assistance to the BSHCN**


- To ensure that families are receiving information to assist them, as well as receiving training on how to partner for care

**Family and youth trainings and connections**

- Train and connect to leadership opportunities at the state and local levels



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### Youth Leadership Council

- Developing a training on medical transition which provides basic information for YSHCN and their family members.
- Training delivered at 4 regional and state-wide conferences
- Developed an outline for a medical transition website

### Consumer Education

- Developed packet with information related to insurance, finding an adult doctor, health care options for college students, and emergency medical services



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## Project Goals



1. Family-Professional Partnerships
  - Facilitate collaborative and respectful partnerships
2. Transition
  - Support YSHCN and their families to make a successful transition to adulthood
3. Sustainability
  - Ensure sustainability post-project



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**Goal 1: Partnerships**  
*Create and facilitate collaborative partnerships*



- Consumer-Family-Professional Leadership Council (CFPLC)
- Collaborations with MO Family-to-Family Health Information and Education Center
- Ongoing needs assessment through Bureau of Special Health Care Needs
- Develop series of Medical Home Technology and Education Training Modules



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**Goal 1: Partnerships**  
*Create and facilitate collaborative partnerships*




- Link screening to medical homes, family to family support, and interventions.
- Collaboration on emergency preparedness trainings for community EMS systems and families of CYSHCN.
- Family Professional Learning Collaborative developed to focus on building a strong, united voice for parents and families of CYSHCN.




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**Goal 2: Transition**  
*Support YSHCN and their families in successful transitions*




- Youth Leadership Council
  - Needs assessment related to medical transition for youth
  - Develop and deliver a training for YSHCN and their families on health self-management, leadership and advocacy skills, and partnerships with medical providers.
- Partner with existing state efforts to provide leadership training to families of CYSHCN




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**Goal 2: Transition**  
*Support YSHCN and their families in successful transitions*



- Collaborate with MO HealthNet to provide information regarding insurance options for YSHCN and their families
- Promote the use of developmental screenings for YSHCN that improves access to timely and needed services as they transition into the adult health care system.
- Support the inclusion of YSHCN in leaderships development activities.



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## Goal 3: Sustainability

*Ensure sustainability post-project*



- Consumer-Family-Professional Leadership Council
  - create and implement a plan to expand project initiatives to all areas of the state
  - Developed sustainability plan that addresses funding and support through additional funding sources, research, and continued partnerships with organizations who will disseminate project materials after the project ends



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## What does this have to do with Heartland Genetics?



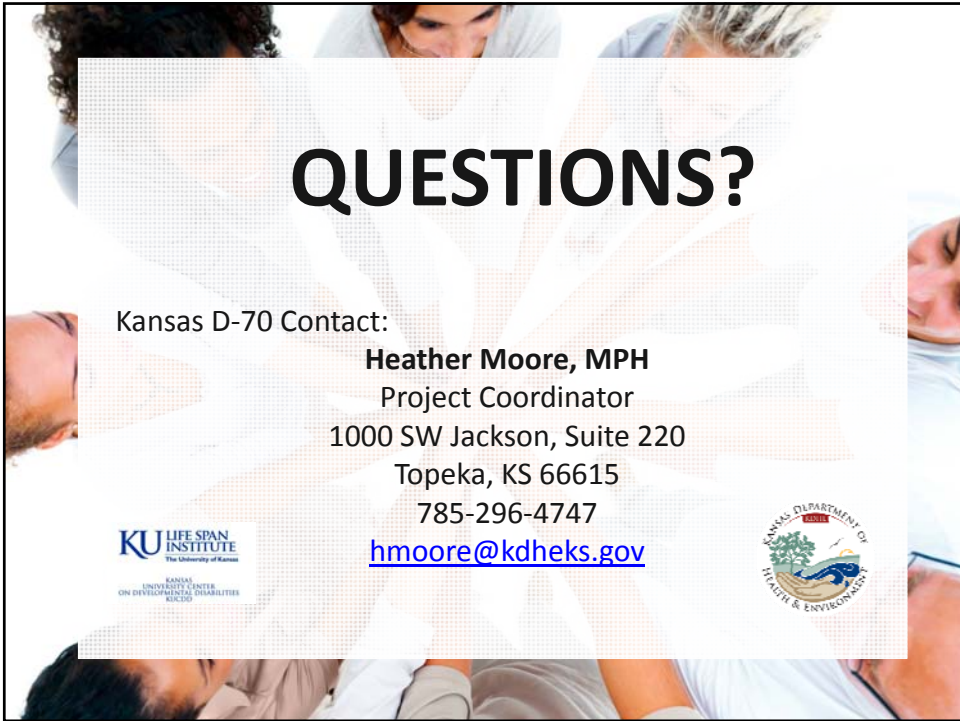
D-70's are here to...

- provide a “systems change” approach to Collaborative initiatives
- support Collaborative initiatives and engage the genetic community in D-70 efforts
- promote integration of systems across states and help ensure our transition initiatives are parallel to those in the region



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# QUESTIONS?

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