Strengthening Kansas Family's Ability to Navigate Systems of Care for CYSHCN Through a Holistic Care Coordination Program

KAYZY BIGLER

PROGRAM MANAGER

SPECIAL HEALTH CARE NEEDS PROGRAM

KANSAS DEPARTMENT OF HEALTH AND ENVIRONMENT

Today's Learning Objectives

Our Vision

- Purpose
- Family Engagement
- Why Care Coordination?
- Definition

Implementation

- Timeline
- Program Development
- Care Coordination Process
- Evaluation

The Future

- Collaborative Efforts
- Integration Across MCH
- Expansion Opportunity

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Our Vision

FAMILY ENGAGEMENT

WHY CARE COORDINATION?

DEFINITION

We Believe...

Children with special health care needs are children first.

Families must be at the center to everything we do.

Collaboration is critical to service provision.

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Kansas Title V Family Engagement

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Families as Leaders as Experts

Why Care Coordination?

Strategic Plan – Identified as #1 need

Holistic Approach

Families wanted:

- Help navigating, but not someone to do everything for them
- To be listened to
- To be a partner

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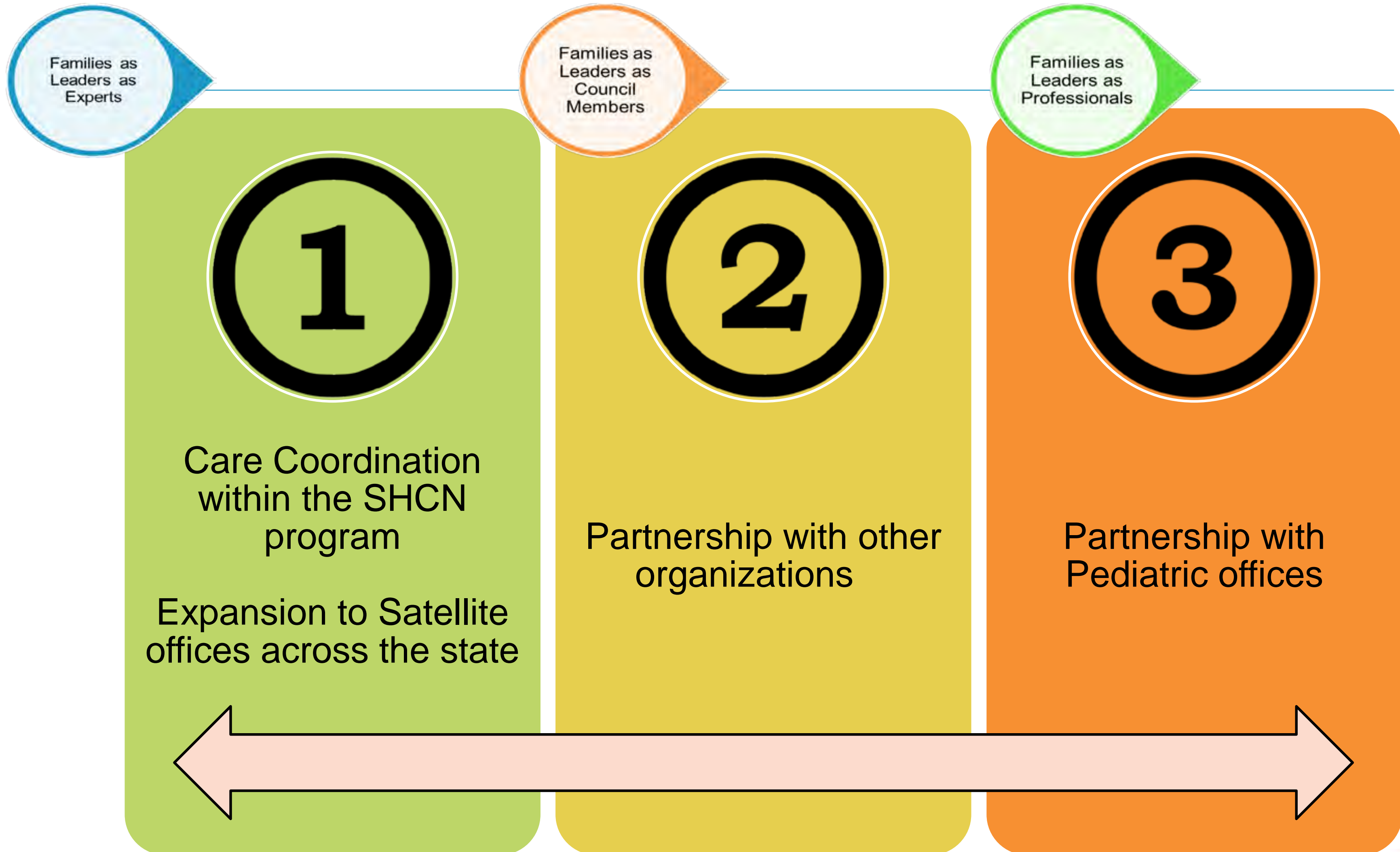
Care Coordination is.....

"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."

Multi-Tiered Approach



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implementation

TIMELINE

PROGRAM DEVELOPMENT

CARE COORDINATION PROCESS

EVALUATION

Care Coordination Timeline

Families as Leaders as Council Members

Planning/Development
Spring 2014 – 2016

Training for Topeka Team
Fall/Winter 2016 & 2017

Care Coordination Pilot
February – June 2017

Partnership with FQHC
July 2017

Satellite Office Team Training
July – September 2017

Statewide Implementation
October 2017

New Data System Development
Spring 2018

Statewide Data System Launch
Fall 2018

Partnership with CP/MC Clinic & School For the Deaf
Winter 2018/Spring 2019

Pediatric Partnerships Development & Implementation
Coming in 2020!

Patient Portal
Coming soon in 2019!

Families as Leaders as Experts

Program Development

Models

- Boston Children's
- Health Homes
- Kansas Medicaid Case Management
- Others

Pilot Process

- Uninsured
- Medicaid
- Private Insurance

Families as Leaders as Experts

Families as Leaders as Professionals

Training Process

All Team In-Person Training

1-on-1 On-Site Trainings

Case Studies

Ongoing Technical Assistance

Role Playing

Brain Trust Calls

Webinars

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Who Receives Care Coordination Services…..

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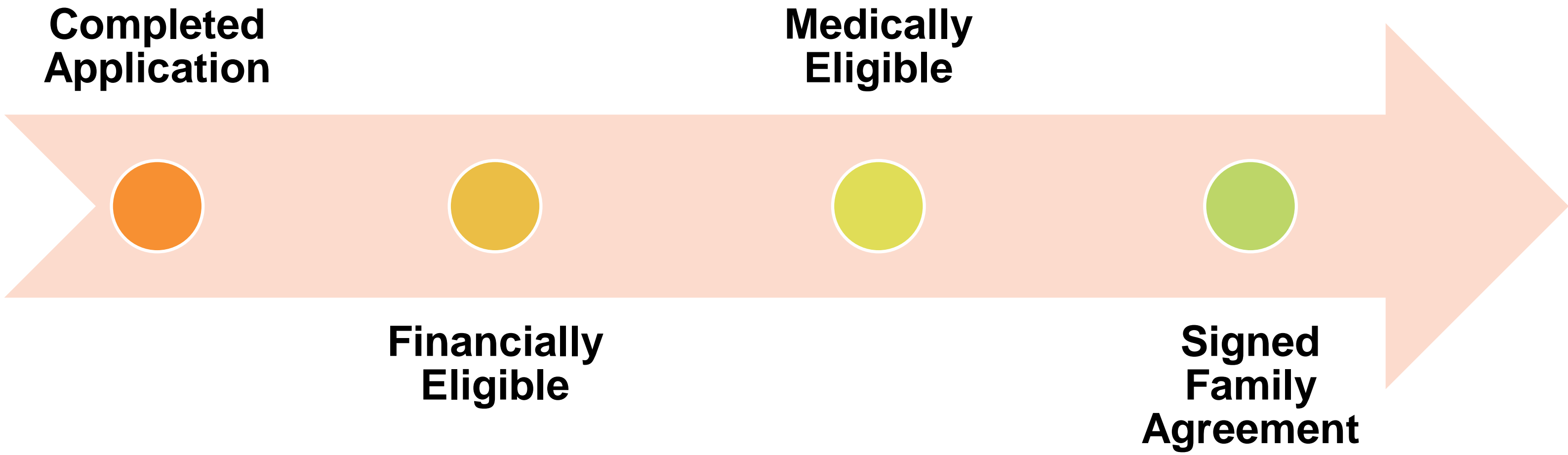
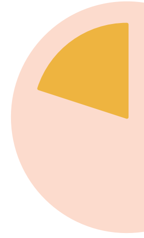
Eligibility Determination

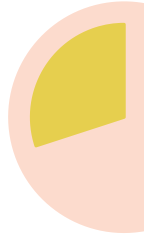


Care Coordination Process

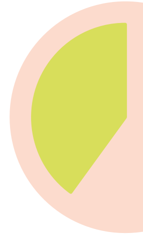
Eligibility Determination



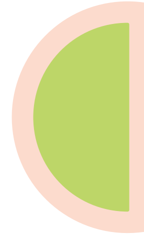
Initial Assessment



Coordinator Assignment



DAP Recommendations



Action Plan Development

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Initial Assessment

Special Health Care Needs

Care Coordination Assessment

Identified Level ______

Date ______

Child's name ______ Family Name ______

Do you or your child receive care coordination/case management from other sources (Kancare, Private Insurance, Physician/Specialist, etc)? Yes ☐ No ☐

If yes, please list: ______

I see here that you/your child has condition. I know condition but could you tell me what that looks like for you and your family?

1) Tell me about you/your child's strengths and needs?

2) Do you have any concerns or worries for you or your child? (Some examples below – ask them to tell you more on any that are noted as concerns)

- ☐ Their growth/development
- ☐ Learning
- ☐ Sleeping
- ☐ Self-care
- ☐ Making and keeping friends
- ☐ Sibling/Families issues
- ☐ Doing things for themselves
- ☐ Falling behind in school
- ☐ Behavior
- ☐ The future
- ☐ Interacting with friends
- ☐ Other (fill in): ______

3) Have there been any recent changes in your family such as:

- ☐ Brother or sister leaving home?
- ☐ Move to a new town/home?
- ☐ Sickness or death of a loved one?
- ☐ New job or job change?
- ☐ Separation or divorce?
- ☐ Other (fill in below)?

Modified from Boston Children's Hospital version

Rev. 05/2018

- Strengths based
- Needs driven
- Holistic
  - Medical
  - Legal
  - Social
  - Financial
  - Educational

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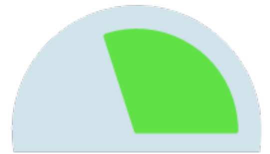
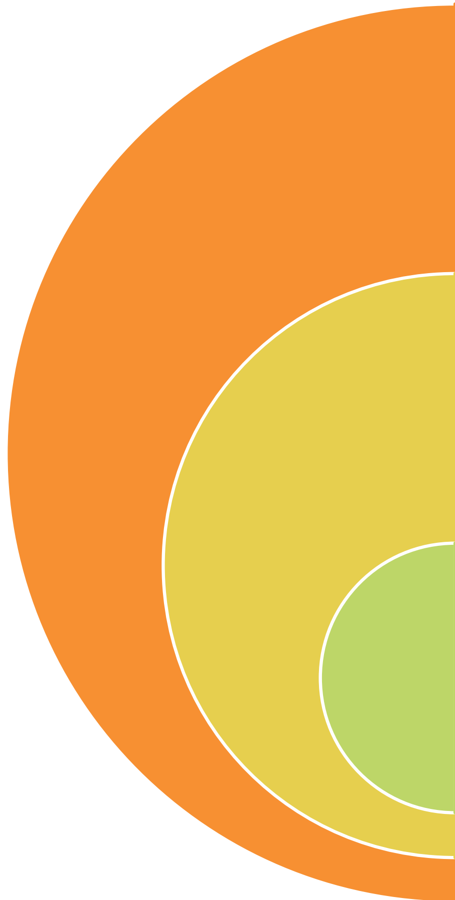
Coordinator Assignment





Introduction Letter

Notice and Acknowledgment of Requirements & Responsibilities by Client/Family

Direct Assistance Program Overview Chart

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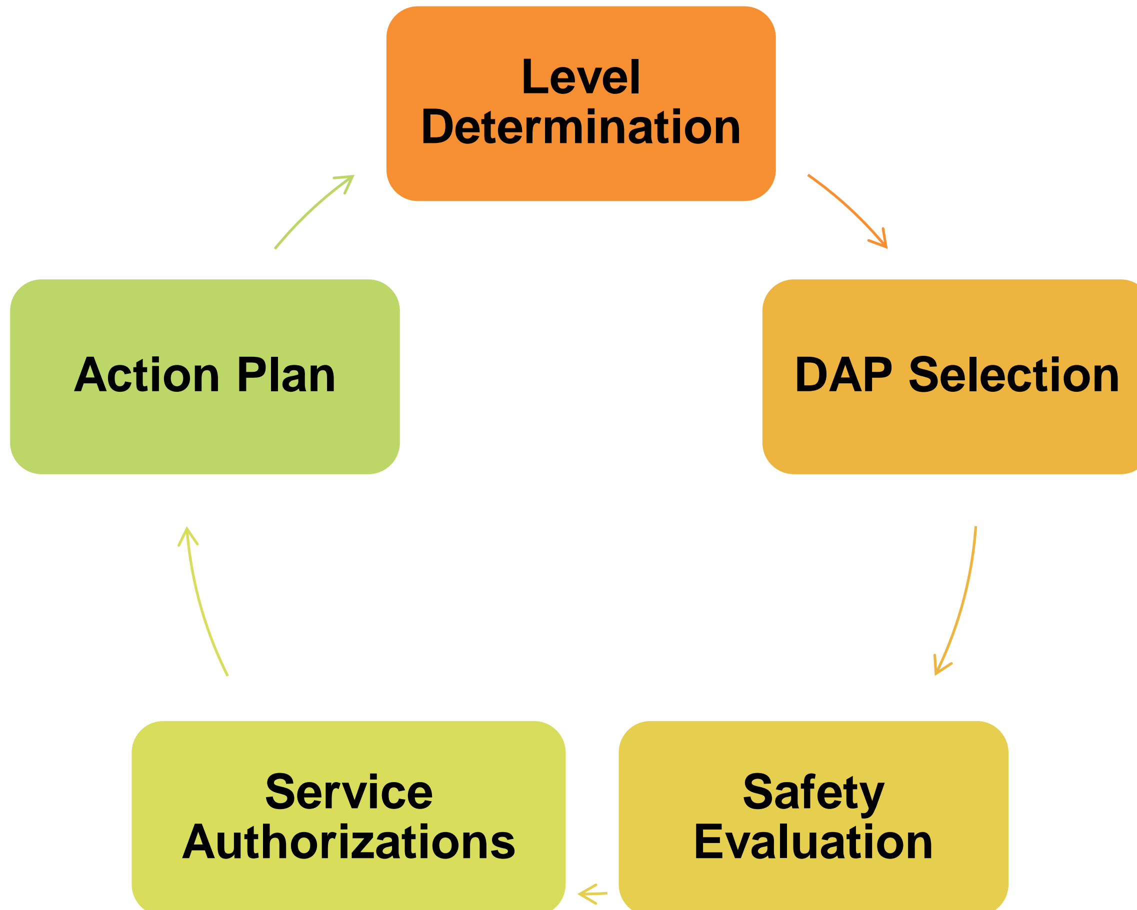
Primary Care Coordinator (PCC)

PCC provides ongoing follow-up per agreed upon schedule



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DAP Recommendations

For All: (Selection of 2 programs)

- Family choice
- Needs-based
- Adaptable

For Care Coordination Clients:

- More direct contact with CC to make changes throughout the year

**Note: SSI only clients are not eligible for a DAP*

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KS-SHCN Direct Assistance Program Chart **Last Revised: 05/2018**

DAP	Support Available	General Guidelines (100% Coverage)
Medication (DAP-Rx)	Prescribed Medication (For medications not covered by insurance) ***The client must pay a $5 co-pay for every $100 of medication per prescription at the time of pick-up.***	Up to $10,000
	Nutritional Supplements, Vitamins, or OTC medications (limited to specific medical conditions)	Up to $500
Medical Equipment and Supplies (DAP-ME/S)	Prescribed Durable Medical Equipment (DME) *The client must pay a co-pay as follows* *$25 co-pay for DME under $500* *$50 co-pay for DME $501 to $1,000* *$100 co-pay for DME over $1,000*	Up to $5,000 Includes a minimum of one (1) or up to four (4) KS-SHCN Clinic appointments
	Medical Supplies: - Up to a maximum of $1,200 for up to 12 boxes of catheters. - Up to a maximum of $600 for ostomy supplies. - Up to a maximum of $1,500 for diabetic testing equipment and supplies (only for Cystic Fibrosis-related diabetes). - Up to a maximum of $500 for diapers or pull-ups (only for age 5-21). - Up to a maximum of $250 for special bottles or feeding supplies. - Up to a maximum of $500 for hearing aid molds, repairs, and batteries. - Up to a maximum of $1,000 for glasses, lens replacement, or prosthetic eyes. - Other medical supplies, not otherwise identified, up to $250.	Up to $2,000
Travel (DAP-T)	Reimbursement at State rate	Up to $1000
Co-Payments/ Deductibles/ Co-Insurance (DAP-C/D/CI) *Must have private insurance with a co-payment and/or deductible limit.*	Co-Pays	Up to $1,000
	Deductibles/Co-Insurance	no more than 50% of deductible/Co-Insurance Up to $5,000
Hemophilia (DAP-H) *Must be diagnosed with hemophilia disorder, or other bleeding disorder, requiring treatment of factor.*	One (1) comprehensive treatment center visit	
	Factor (limited to $2,500 per authorization)	Up to $7,500

DAP	Support Available	General Guidelines (100% Coverage)
Medical Services (DAP-MS) *Must be uninsured, or ineligible for KanCare and/or insurance through the health insurance marketplace.*	Medical Appointments: - One (1) well-child/well-adolescent, or preventive care appointment, with established provider. - Up to six (6) specialty care appointments ***Client must pay a $15 co-pay per appointment***	Up to $500
	Medical Testing: - Laboratory Tests - X-rays	Up to $500 Up to $500
	Specialty tests	Up to $1,500
	Hospitalization/Surgery - Hospital Bill ***Client must pay $500 towards hospital bill*** - Hospital/Surgery Related Service	Up to $4,500 Up to $2,500
	Other Services - Physical, Speech, Occupational Therapy ***Client must pay a $15 co-pay per appointment*** - Interpreter Services (limited to authorized appointments)	Up to $1,200 Up to $700
	Other specialty care services, not listed	Up to $800
Orthodontic Treatment Services (DAP-OTS) *Must be diagnosed with a craniofacial anomaly, such as Cleft Lip/Cleft Palate*	KS-SHCN CL/CP Clinic: A minimum of one (1) or up to four (4)	
	Orthodontic Evaluation	Up to $300
	Orthodontic Treatment Plan	Up to $5,000
Metabolic Products (DAP-MP) *Must be diagnosed with PKU, or other amino acid disorders, requiring treatment with metabolic products.*	Formula (limited to $750 per month) *PKU clients with special circumstances may be eligible for additional assistance per program approval.* **PKU clients who are pregnant or nursing (limited to $1,000 per month)**	Up to $9,000 Up to $12,000
	Low-Protein Food Items (limited to individuals 18 or younger)	Up to $1,500
Caregiver Relief (DAP-CR) *Client must be diagnosed with a complex medical condition that requires specialty medical care. Eligibility will be determined by the KS-SHCN program.*	Reimbursement for trained and approved care providers (limited to $250 per month) *Services cannot be reimbursed for primary caregivers*	Up to $2,000

Safety Evaluation

Smoke & Carbon Monoxide Detectors

How many levels does your home have? _______

How many bedrooms does your home have? _______ Are they all located on the same level? _______

Are there any special smoke or carbon monoxide detector accommodations that you need? (Strobe light detector due to hearing impairment, etc.)

Hearing Impaired _______ Vision Impaired _______ Other (explain) _________________________

Detector(s) Requested:

Smoke & CO2 detectors _______ Smoke detector only _______ CO2 detector only _______

What is the best day and time for the fire service provider to install your detector(s)?

____

After completing this form please send to kelly.totty@ks.gov for processing. If installation is needed, a service provider will contact the family to schedule an installation date and time. This process may take up to 4 weeks to complete.

If only a standard CO2 detector(s) is needed, the device will be shipped directly to the family. The Care Coordinator will follow-up with the family to ensure they have no questions or concerns.

Fire Safety Quiz

This is used to identify the parent's knowledge on fire safety protocols prior to submitting their application for a smoke detector

1. How often should a smoke alarm be tested?

   Monthly Every 3 months Every 6 months Once per year

2. How many routes out of the house should each member of your family know?

   One Two Three Four

3. After you and your family are outside of the house do you have a designated meeting place?

   No Yes

4. Do you and all your family members know what to do if there is a fire? How to get out safely?

   No Yes

5. Where should you be before calling the fire department?

Share the fire safety information with the client located on the Safe Kids Kansas website. This can be printed and mailed with the action plan or you can give them the e-mail link.

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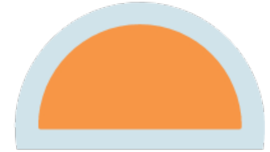
Action Plan Development



Goals
(w/ SMART Objectives)

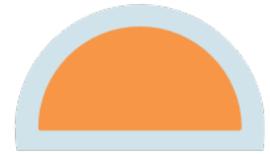
Family Driven

Focused

Adaptable

Continuous

Action Plan Development



Goal Example #1
Identify an adult care provider
Objectives/Objetivos #1:
Talk to primary care doctor about adult doctors he would recommend.
Objectives/Objetivos #2:
Look up information about the referred doctor on line.
Objectives/Objetivos #3:
Schedule an appointment to meet with the referred doctor.

Goal Example #2
Plan college visits that include Student Services
Objectives/Objetivos #1:
Identify what colleges you want to visit.
Objectives/Objetivos #2:
schedule a visit with Student Services.
Objectives/Objetivos #3:
Make a list of questions for Student Services.
Objectives/Objetivos #4:
Gather paperwork you want to take with you to show Student Services.
Objectives/Objetivos #5:
Got to the college appointments and talk to Student Services.

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Evaluation

Evidence-Based Strategy Measures

National Performance Measures

Ongoing Quality Assurance

Continuous Quality Improvement

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Tracking and Monitoring

Families as Leaders as Council Members

Families as Leaders as Experts

Families as Leaders as Professionals

Direct Assistance Programs & Budget

Care Coordination Time & Activities

Number of Clients Served

Client Level Activity (Opt-out, Levels 1 through 3)

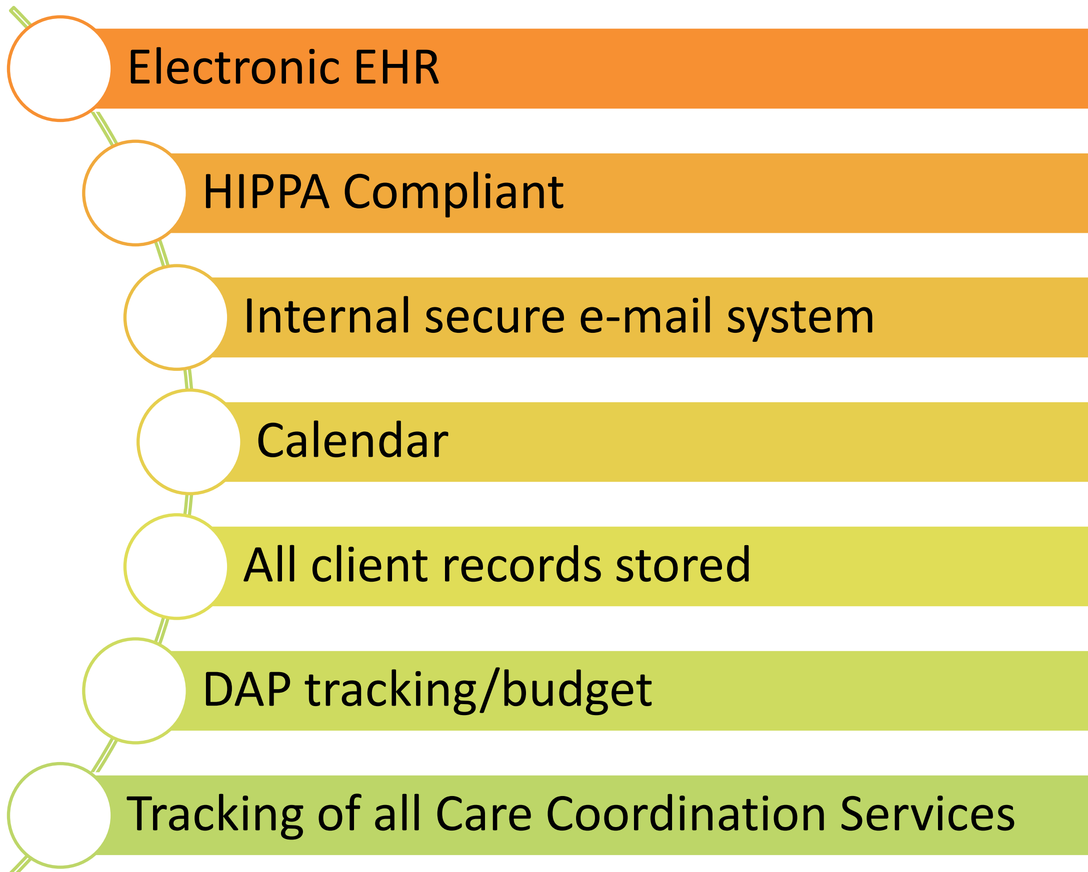
Focus of Care Coordination Services

Client/Family Outcomes (from Action Plan)

Service Authorizations

Electronic Record System

Welligent© data system designed to meet the needs of Care Coordination Services



Coming soon…
Patient Portal!

The Future

COLLABORATIVE EFFORTS

INTEGRATION ACROSS MCH

EXPANSION OPPORTUNITY

Collaboration is the Foundation for the Future

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KanCare (Medicaid)

CURRENT	FUTURE

• MCO Shared Client Report
  • Shares SHCN and MCO Care Coordinators (including contact information)
  • Outlines services being provided to client
• Collaborative Planning with MCO Care Coordinator and client/family
• Single Case Agreements
	• Prior Authorizations
	• Extended Single Case Agreements
	• OneCare Kansas (revived Health Homes initiative)
	• Medicaid Expansion
	• Family Engagement Partnerships

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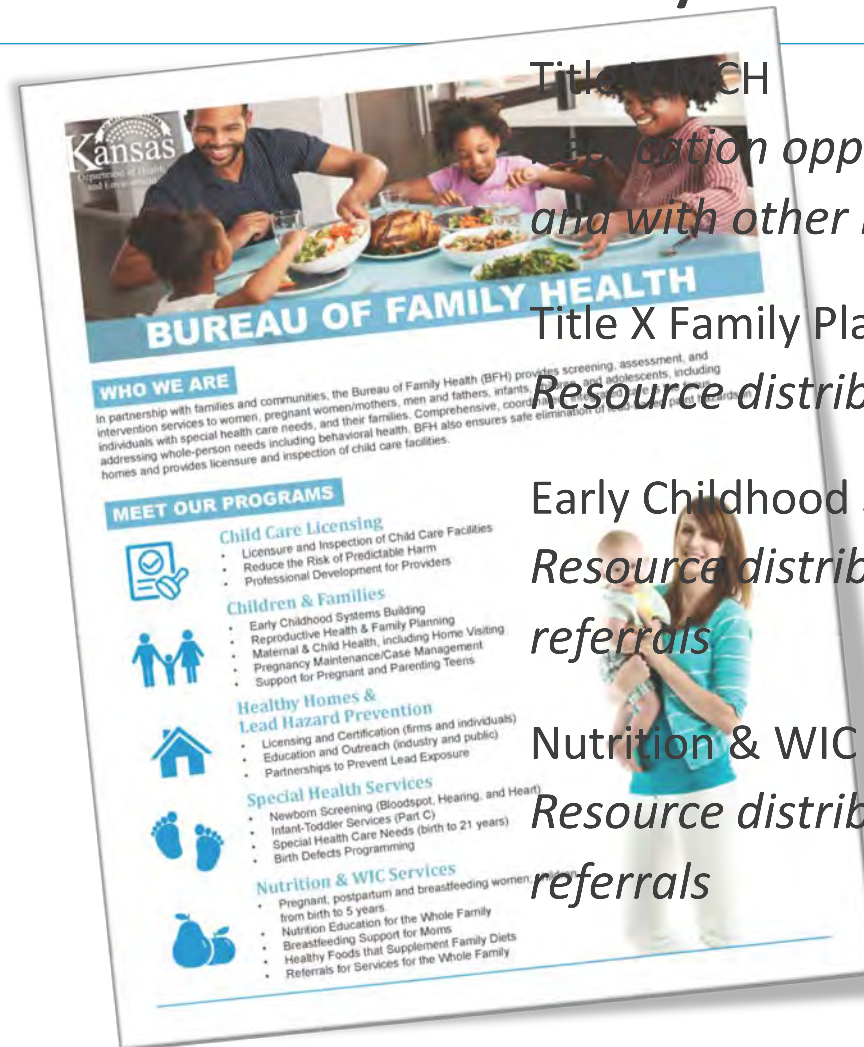
Integration Across Systems


Kansas

BUREAU OF FAMILY HEALTH

WHO WE ARE

In partnership with families and communities, the Bureau of Family Health (BFH) provides screening, assessment, and intervention services to women, pregnant women/mothers, men and fathers, infants, children, and adolescents, including individuals with special health care needs, and their families. Comprehensive, coord... addressing whole-person needs including behavioral health. BFH also ensures safe eliminatio... homes and provides licensure and inspection of child care facilities.

MEET OUR PROGRAMS

Child Care Licensing
- Licensure and Inspection of Child Care Facilities
- Reduce the Risk of Predictable Harm
- Professional Development for Providers

Children & Families
- Early Childhood Systems Building
- Reproductive Health & Family Planning
- Maternal & Child Health, including Home Visiting
- Pregnancy Maintenance/Case Management
- Support for Pregnant and Parenting Teens

Healthy Homes & Lead Hazard Prevention
- Licensing and Certification (firms and individuals)
- Education and Outreach (industry and public)
- Partnerships to Prevent Lead Exposure

Special Health Services
- Newborn Screening (Bloodspot, Hearing, and Heart)
- Infant-Toddler Services (Part C)
- Special Health Care Needs (birth to 21 years)
- Birth Defects Programming

Nutrition & WIC Services
- Pregnant, postpartum and breastfeeding women, ... from birth to 5 years
- Nutrition Education for the Whole Family
- Breastfeeding Support for Moms
- Healthy Foods that Supplement Family Diets
- Referrals for Services for the Whole Family

Title V MCH

Replication opportunities at local level and with other MCH populations

Title X Family Planning

Resource distribution & screenings

Early Childhood Systems & Child Care

Resource distribution, screenings, & referrals

Nutrition & WIC

Resource distribution, screenings, & referrals

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Caregiver Health

Caregiver Toolkit

- Self-Assessment
- Evaluation Survey
- Resources & Tools

Family Supports

- Supporting You
- Standards of Quality
- Family Leadership Activities

"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.*

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Supporting You

What is Supporting You?

- This **peer-to-peer network** provides a place where individuals and **families who have similar needs can communicate with each other and gain support** from one another.
- **Our goal is for Kansans to gain emotional support from a caring and compassionate peer** who share a connection and is willing to tell their own personal story, while they walk alongside someone else as they tell theirs.
- We believe **people desire to be supported by others who have experienced similar situations where they can express their grief, concerns and questions, without feeling judged.** We also know that peer support is one of the strongest measures of individual/family support.

For more information, visit www.supportingyoukansas.org.

SHS Family Advisory Council

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Charting the LifeCourse™

www.lifecoursetools.com/planning/

Charting the LifeCourse™

Guiding Principles

Core Belief: All people have the right to live, love, work, play and pursue their life aspirations just as others do in their community

supporting positive life trajectories

preventing negative life events

Focusing on ALL

100%

4.9 million citizens with developmental disabilities

75%

25%

25% national percentage receiving state DD services

Life Stages and Life Domains

Meaningful Day & Employment: What you do as part of everyday life– school, employment, volunteering, communication, routines, life skills.

Community Living Where and how you live– housing and living options, community access, transportation, home modifications.

Safety & Security Staying safe and secure– emergencies, well-being, guardianship options, legal rights and issues.

Healthy Living Managing and accessing health care and staying well– medical, mental health, behavior, developmental, wellness and nutrition.

Social & Spirituality Building friendships and relationships, leisure activities, personal networks, faith community.

Citizenship & Advocacy Building valued roles, making choices, setting goals, assuming responsibility and driving how one's own life is lived.

Prenatal/Infancy Early years, wondering if meeting developmental milestones

Early Childhood Preschool age, getting a diagnosis

School Age Everyday life during school years

Transition Transitions from school to adult life– Realizing school is almost over!

Adulthood Living life as an adult

Aging Getting older and preparing for end of life (parent/family/individual)

November 2017

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Plans for the Future

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Questions?

KAYZY BIGLER

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SPECIAL HEALTH CARE NEEDS PROGRAM

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