Domain Group: Children w/Special Health Care Needs – July 31st Results

Expert Guest(s): Dr. Steve Lauer, Dr. Pam Shaw, Julie Laverack, CHC-SEKS

Lead Staff: Kayzy Bigler **Recorder:** Connie Satzler

Attendees: Kayzy Bigler, Heather Smith, Julie Laverack, Steve Lauer, Kasey Sorell, Deanna Gaumer, Pam Shaw, Katie Schoenhoff, Donna Yadrich, Connie Satzler (recorder)

Discussion Questions	Comments
1. What is the problem/focus issue?	Research indicates that children with a stable and continuous source of health care are more likely to receive appropriate preventive care, are less likely to be hospitalized for preventable conditions, and are more likely to be diagnosed early for chronic or disabling conditions. Only half of Kansas children have a medical home. Children with special health care needs are less likely to have a family-centered medical home than children without special health care needs. **1st objective of state action plan. Supporting families & docs and open communication. Parents and providers want each other to be able to communicate better.**
2. Who is the target audience for the message(s)?	Providers are primary/target audience for the messaging: How can they champion/lead and what opportunities are there for family-centered medical home support (increasing family satisfaction with communication w/dr.); family awareness (target: providers re: nontraditional approaches to improve; communication strategies, engagement, small changes in a practice setting to increase support, for example establishing a patient advisory board). **Family awareness. From family side or provider side? Either/both.**
3. What type of document/product related to outreach/messaging are you preparing (what is the purpose) and why? (action alert, infographic, bulletin, etc.)	Action Alert/Call to Action (Use data, strategies, tips, and reminders to send the messages to impact behavior; intent is to mobilize and activate/create and drive action across sectors – we are all a part of the solution and can do something now.) **See notes on Action Alert worksheet.**
4. What MCH performance measure does this aim to address/support?	NPM 11: Medical Home (% of children with and without special health care needs, 0-17 years, who have a medical home) Numerator: Number of children with and without special health care needs, ages 0 through 17, who meet the criteria for having a medical home (personal doctor or nurse, usual source for care, and family-centered care; referrals or care coordination if needed) Denominator: Number of children, ages 0 through 17
5. Outline the case for need: - Data/negative trends - Behaviors to target for change that are contributing to the issue - System and/or policy issues and barriers contributing to the problem - Other contributing factors	Data: The most current data indicates the care received by 50.6% of Kansas children under the age of 18 met medical home criteria. **Children with special health care needs (46.1%) were less likely to have a medical home** than children without special health care needs (51.8%). (Source: The 2016-2017 National Survey of Children's Health, 2 years combined) *Disparities:* • Children aged 0–5 years (51.0%) and 6-11 years (52.9%) were more likely to have a medical home than children aged 12–17 years (48.1%). • Hispanic children (35.2%) were less likely to have a medical home than non-Hispanic white children (54.4%).

Discussion Questions	Comments
	• Children living in a household with English as the primary language were more likely to have a medical home than children living in a household with a primary language other than English (52.0% versus 37.4 %, respectively). • Children living in a household with two parents (currently married) were more likely to have a medical home than those with two parents (not currently married), those with only a mother (currently married (living apart), formerly married or never married), and those with all other family structures (55.6% compared to 41.6%, 40.2%, and 34.6%, respectively). • 40.0% of children living in households with incomes less than 200 % of poverty had a medical home compared to 62.9% of children living in households with incomes of 400 % or more of poverty. The difference was significant. **Discussion** Why is it so hard to have medical home? SHCN kids have so many providers. Donna: we had one and it made all the difference. Medical home for SHCN kids is a different animal. They have to be willing to reach out. We need a specialization for children with medical complexities. For physicians and nurses: would like to see this population targeted, just like you would an oncologist. Her ideas are, let's have CDC surveil this – ICD10 codes for medical complexity. Barriers/aspects to improve: (1) Health disparities. Things are not culturally competent. Providers can't even provide Spanish-speaking handout for their kids. Spanish, Burmese – providers have to take care of this kids without the resources to take care of it. Need to be culturally competent. If we do something to gives providers support. Have physicians who see children who don't provide immunizations. (2) Coordinated care. Have so many systems set up that people use that don't provide good coordinated care. People can't get coordinate care because the system is fractured. (3) Rural challenges/Family Practice vs. Peds: A lot of providers in rural areas are family physicians. AAP medical home, etc. has policy statement on medical home and other items. Family physicians are not under that. They don't always do that. They support it, but – in practice – there's not the same level of expectation. Coordination example from Dr. Shaw: 11-year-old got his 11-year old vaccines twice. Dr. Shaw's office gave them. School said need immunization record. Went to pharmacy (CVS) second time, and they didn't check with provider. School could have also called to check and didn't. This family lives in MO and couldn't access WebIZ if they wanted. Issue with communication has to do with WebIZ. Not a good sharing system for EMR either. Barrier for families to get good communication. This is not unique to Kansas. From listening, doesn't sound like target is family, more system or provider? What can we do now? Steve Lauer: in short-term, getting the docs to be involved, they have to give them a reason. They really need a care coordinator who can do this stuff and help track down information. Everyone would love to, but they are stretched thin and really need help. How can you target the ones who are willing to do that and provide them the support they need? You can't expect the primary are provider to do this. They need to have payment

Discussion Questions	Comments
	and/or care coordinator. Is there a way to support that person (the CC) directly, if the provider will take on SHCN? Julie does care coordination for about 200 patients – looks up info, etc. She is Title V funded. Model in NC was sustainable – pay for it through Medicaid, care coordination. Medicaid paid for it with practices who took more than 10% in Medicaid. The provided CC to those providers. It worked, but they don't do it anymore. It improved health, vaccine rates, chronic disease, eliminated duplication. It also increased docs who were taking Medicaid. They had been doing it for 10 years and were getting positive outcomes, but the new governor came in and took it away. What can we do? What can we do to insulate ourselves from that happening? What is something small that we could do?
6. What are the "asks" from the audience? What changes/actions can make a difference? Specifically, how should we move forward with this "issue" area that needs to be advanced? (Carry to action alert worksheet.) NOTE: Break strategies/actions for change down by target population and provider or setting type	**Discussion** Make sure providers understand the definition of a medical home (all aspects) and care coordination. Determine what they provide with the standardized definition. Needs assessment, ask the following: what is a medical home, in your definition? What is care coordination, in your definition? Or, do you provide care coordination, considering the definition is this? Do you provide … • Immunization • Medical home using 6 or 7 components of a medical home. Which components do you provide? Identify the top 2-3 that are most important. Figure out what people are doing and what they think about it. Separate out each of the parts of a medical home to talk about that. 1. Medical home survey/check Special work or special outreach to family practice/family practitioners. 2. Figure out how to become more culturally competent. A lot of this is family driven. How to reach out to families. Language skills, patient information in appropriate language or have interpreters you can use. Are providers aware there are resources? Are they aware how to be culturally competent? Infographic – how to help your practice be more culturally competent. Follow-up next – have infographic of each aspect of a medical home. Focus on each one. OB/Gyn – can we target them, too, can they help? Make sure they are asking the families about who their ped will be for their baby. (Too big of a bite for this.) Families have multiple providers, multiple care coordinators. How do families know who is the ultimate care coordinator? Who do they listen to?

Discussion Questions	Comments
	We have to do definitions for families. CC for health is different than CC for schools or work or whatever. But the families don't know, and there are different terms for CCs, which is confusing. With MCOs, for example, names and titles change. Families are trying to understand, who's really in charge? Depends. Adolescent age – they usually don't have active medical issues, so medical home may not have much to contribute. It may be the specialty care provider who is serving as their medical home. Need to look at, what is their primary need? It will vary by family who their primary medical home will be. Here to help connect and be part of that team. Put at the kid at the center of the infographic.
7. What key message(s) or resources (phone numbers, websites, etc.) need to be communicated or promoted?	See above and action alert worksheet.
8. Sources/References	

MCH State Action Plan Objectives:

- Increase family satisfaction with the communication among their child's doctors and other health providers to 75% by 2020.
- Increase the proportion of families who receive care coordination supports through cross-system collaboration by 25% by 2020. **Focus more on this one.**
- Develop an outreach plan to engage partners, providers, and families in the utilization of a shared resource to empower, equip, and assist families to navigate systems for optimal health outcomes by 2020. **Also focus more on this one.**

Comment: Be careful about focusing too much on satisfaction scales.
Look at data source and see if there is better data point that isn't so subjective. If not, could look at SHCN client surveys.
Focus efforts more on second and third objectives.
Look at all percentages (in data) and make sure these are still appropriate measures.

What, if any recommendations, does the group have for the MCH State Action Plan related to this issue? Consider and discuss the following:

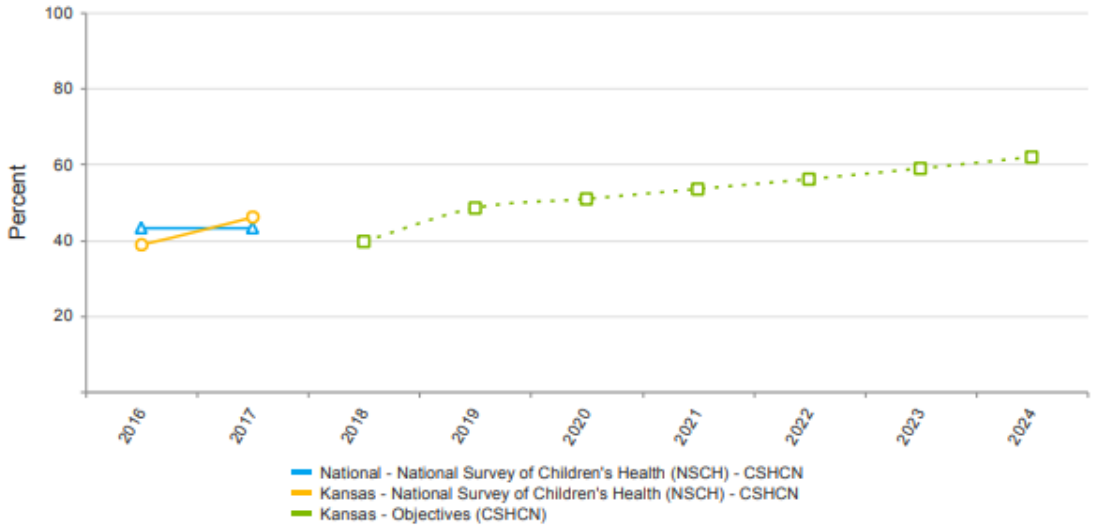
Is the issue/need adequately addressed in the plan? Circle one (yes or no) and explain.	Yes	No
Does the group recommend any strategies to advance the work or improve the outcomes/measures? Circle one (yes or no) and explain.	Yes See discussion notes in this worksheet.	No

Significance & Data:

The American Academy of Pediatrics (AAP) specifies seven qualities essential to medical home care, which include accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective. Providing comprehensive and coordinated care to children in a medical home is the standard of pediatric practice. The Maternal and Child Health Bureau uses the AAP definition of medical home. www.medicalhomeinfo.aap.org

National Performance Measures

NPM 11 - Percent of children with and without special health care needs, ages 0 through 17, who have a medical home
Indicators and Annual Objectives



NPM 11 - Children with Special Health Care Needs

Federally Available Data			
Data Source: National Survey of Children's Health (NSCH) - CSHCN			
	2016	**2017**	**2018**
Annual Objective			39.6
Annual Indicator		38.6	46.1
Numerator		56,808	68,059
Denominator		147,272	147,776
Data Source		NSCH-CSHCN	NSCH-CSHCN
Data Source Year		2016	2016_2017

Historical NSCH data that was pre-populated under the 2016 Annual Report Year is no longer displayed, since it cannot be compared to the new NSCH survey data under the 2017 Annual Report Year.

Annual Objectives						
	2019	**2020**	**2021**	**2022**	**2023**	**2024**
Annual Objective	48.4	50.8	53.4	56.0	58.8	61.8

Resources:

- AAP Definition of Medical Home

  A pediatric medical home is a family-centered partnership within a community-based system that provides uninterrupted care with appropriate payment to support and sustain optimal health outcomes. Medical homes address preventative, acute, and chronic care from birth through transition to adulthood. A medical home facilitates an integrated health system with an interdisciplinary team of patients and families, primary care physicians, specialists and subspecialists, hospitals and healthcare facilities, public health and the community.

- Kansas Family Engagement and Partnership Standards for Early Childhood (Key points as reference handout)
- American Academy of Pediatrics Family Engagement QI Implementation Guide
  - Fact Sheet as reference handout
- AMCHP Family Engagement & Leadership
  - Levels of Family Engagement in Title V as reference handout