September 17, 2018

Q&A: A Conversation on Care Coordination for Children with Medical Complexity: Whose Care Is It, Anyway?

Below are responses to questions the panel was unable to answer during the webinar.

Respondents

- **Dennis Z. Kuo, MD, MHS -** Associate Professor, University at Buffalo and Chief, Division of General Pediatrics, UBMD
- **Michele Juda -** Executive Director, Parent to Parent of New York State
- **Chris Stille, MD, MPH -** Professor of Pediatrics and Section Head, General Academic Pediatrics, University of Colorado School of Medicine, Children's Hospital Colorado

Q&A

Definitions:

Thank you for clarifying the definitions of care coordination, care management, case management and care integration. Is there discussion about having a standard name for those who coordinate care as "care coordinators" or "care managers"?

Dennis: I am not aware of any discussions about standardization; we present the discussion to ensure folks are aware of the differences in scope of training and oversight.

Resources:

Do you have suggestions for complex medical scheduling to avoid multiple trips to the hospital, which is sometimes out of state?

Dennis: An in-house care coordinator likely works the best in this scenario, looking at the shared plan of care. I suggest working with providers to see what truly needs to be seen and examined by a provider, versus phone management and coordination between providers, to avoid excess visits. Additionally, overnight housing such as Ronald McDonald House can help spread the appointments out over more than one day.

Michele: If a dedicated care coordinator is not available, scheduling staff from one service can serve as the coordinator by contacting scheduling staff for all other providers and establishing a reasonable plan that works for the patient and caregivers.

What can families do if providers refuse to take Medicaid patients, even those that have private insurance as their primary coverage?

Dennis: This is a difficult issue with no easy answer if providers will not accept insurance. For children with medical complexity there’s a reasonable likelihood that there is access to social work or a care coordinator who can help identify additional resources or “go to bat” that will help gain access to providers. In some cases, it’s not a refusal to take Medicaid in general, but specific to a Medicaid managed care organization.

Michele: It is important to fully understand the refusal: does the provider refuse all Medicaid patients or is the refusal specific to a type of Medicaid coverage, such as benefits managed by a Medicaid managed care organization? The ability to advocate will be essential, if not to solve the problem, but to raise

awareness. Check to see if your state's Medicaid program offers a referral service to providers who accept Medicaid.

Also consider reaching out to family-based organizations that advocate at the statewide or national level regarding access to care and recognize your voice may be needed to promote change. If you are unable to access a necessary service due to a lack of providers accepting Medicaid, state and federal lawmakers and regulators need to hear from you.

Are there blank care maps for supporting multidisciplinary teams on behalf of a specific child / family?

Dennis: Boston Children's Hospital has a care mapping tool available here.

We talk a lot about the quality of life for CMC but without adequate support in care coordination, quality of life of parents and/or siblings of CMC is adversely affected, having negative ramifications of their own. How is this area being considered in integrated care?

Dennis: The assessments and tools being considered should ideally ask questions about family functioning and wellness.

Michele: Federal regulations on health homes identify Patient and Family Support as one of six required services.

Care Coordinators:

Do you envision care coordinators helping families coordinate the intersection between their health care and education, the provision of health care services and navigating the health insurance/health financing of care? If yes, how?

Dennis and Michele: Ideally care coordinators should help families coordinate those intersections between different sectors. Families are doing this already and have identified this as an area of need. That will take a bit of training and culture change, for both providers and families. Broader use of tools and assessments will likely help drive this discussion and change, as it's best to utilize a tool if you can do something with the results.

Is a registered nurse (RN) the best person to be a care coordinator?

Dennis: For children with medical complexity, an RN care coordinator is probably the most common model and I do think the clinical training and experience is important for CMC care coordination. For non-CMC, the RN training is probably not necessary.

An Advanced Practice Registered Nurse care coordinator essentially operates much like a primary care provider (PCP). In this case, what is the role of the PCP?

Dennis: Assuming a community-based PCP, the role is thus to be the community liaison and first point of contact, as well as routine and preventive care.

Is there literature or research that states what a manageable patient caseload is for a care coordinator?

Dennis: There is no dedicated literature but a lot of discussion. The consensus is about 100-150 CMC for each care coordinator, but it depends on the level of complexity. If the case load is on the high side of medical complexity – for example, all technology dependent, at least 5 specialists (instead of 2 or 3 minimum) – the manageable caseload may be closer to 50.

Do you consider the care coordination for children with special health care needs that is mandated federally through Maternal Child Health Bureau grants a big partner with coordinating this care?

Dennis: Yes. State Title V organizations, for example, should be a key partner in care coordination.

Michele: There are various models that have been developed regarding where care coordinators might be based, and the individualized nature of person and family services will likely mean there are many persons/entities that could fulfill this role.

Communication:

When the care coordination occurs at the payer, how can you foster communication with care providers?

Dennis: From a practitioner perspective, this issue applies to any external care coordinator or case manager, whether located at the payer (e.g. Medicaid service coordinator), an external organization (e.g. health home organization), Title V, or elsewhere. Leadership level discussion between the practice/hospital and the payer about ensuring alignment between organizations is needed – and then it's a matter of picking up the phone or having a face to face meeting to put a face to the name. There are longer term conversations at leadership levels about shared data, shared data platforms, and universal assessments, but piloting a co-management protocol entailing communication expectations with a defined shared population can always be done now.

Michele: "Care Coordination" done by Utilization Managers at insurance companies is not representative of the comprehensive and holistic care management that children with medical complexity require.

Can Chris please send info on the health information exchange (HIE) legislation passed in Colorado?

Chris: You can get a PDF of the actual bill signed by the Governor.

Are there best practices in support of care coordination that are built into any popular electronic health record (EHR) systems?

Dennis: I'm not aware of care coordination supports that are built into any popular EHR systems.

New York:

What payment models are being used in New York?

Dennis: A mix of models, mostly fee-for-service but some MCOs have implemented care coordination payments and incentives for quality metrics and there's a handful of capitation models. New York wants 80% of the Medicaid population to be in a value-based payment arrangement by 2020.

NY State has recently begun care coordination. Is this different than your presentation since the goal of NY State is to reduce cost to Medicaid through care coordination?

Dennis: New York is exploring how to ensure integration of service delivery, which is very much in line with our presentation, but it also has not made CMC a specific focus yet. There are various initiatives such as the Pediatric Health Home that touch on CMC, and children with disabilities that receive service coordination are moving towards managed care. There's also the First 1000 Days initiative that is focused on kindergarten readiness – and reduced cost is not an explicit goal.

Michele: While better integration of services is expected to reduce costs, this is not a singular goal. The move towards health home-based care management also aims to improve service quality, shift service systems to a focus on measurable and meaningful outcomes, and ensure person-centered, holistic planning that supports individuals and their caregivers with care needs across service systems.