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CARE (Coordinating All Resources Effectively): A Model for System Innovation for the Care of Children with Medical Complexity

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Context for the CARE Award

- Delivery system transformation
 - Payment reform
 - Care delivery reform

Payment Reform

- Negotiations with 6 states and D.C
- Payment reform will most likely vary from state to state
- CMS perspective: anything but FFS
- Technical support to states from Truven and Milliman

System and Care Model Innovation for Children with Medical Complexity

- The target population
- Tiered care
- Care coordination: tailored care
- Access to Care: Navigating complex systems
- CARE: Coordinating All Resources Effectively

The Target Population: Why Children with Medical Complexity?

- These children exact a considerable burden on families
 - 13.5% of families spend 11 hours per week spend on care coordination
 - 57% of families experience financial problems
 - 54% had a family member stop working to care for their child
 - 49% needed additional income for medical expenses

Kuo DZ Arch Pediatr Adolesc Med 2011

The Target Population: Why Children with Medical Complexity?

- These children account for a large proportion of health care costs
 - 10% of children account for 64% of medical expenditures
 - 1% of children account for 20% of expenditures

System and Care Model Innovation: Tiered Care

- The majority of programs for children with medical complexity (CMC) are based in children's hospitals
- Its important for families to receive care close to home which may be far from the hospital
- It is less expensive to care for the child in the community

BUT most community practices feel:

- They do not feel they do not have the clinical expertise to care for CMC
- They lack the necessary care coordination and mental/behavioral health services
- When they do care for CMC they are not reimbursed for many of the services these children need

Tiered System of Care

- Tier 1: community pediatrician
 - Children who are typically stable with minimal impact on functional status e.g. asthma or ADHD
 - Care occurs in pediatric or family practice
- Tier 2: advanced medical home
 - Health status varies from stable to unstable or slowly improving; sees two or more pediatric specialists; may require visits to ED or hospitalizations e.g. Cerebral palsy with developmental delay
 - Care occurs in community based medical home
- Tier 3: Hospital based complex care clinic
 - Children whose Health status is unstable and health trajectory is declining or variable; sees 3 or more specialists and frequent hospitalizations and ED visits
 - Care takes place in a hospital based complex care clinic

Tailored Care Coordination and Case Management

- Need for real time assessment of care coordination needs
- Patient centered evaluation – survey of care coordination needs and assets
- Helps to address the variability in care coordination needs not predicted by severity of the child's condition
- Helpful to identify key community services and DME vendors to develop relationships and facilitate referral

Dynamic Care Teams

- The family is a member of the DCT
- Determination of DCT membership is a shared-decision that includes parents, patients and providers
- DCT membership is representative of the care continuum that includes healthcare, community and educational providers.
- Two tier care team: Core team and Advisory team
- DCT changes with change in locus of care management
- Rapid communication of changes in health status to all team members

Tailored Access Plan

- For CMC there are often > 6 providers involved with care
- Confusing for families to know who to call and when
- Frequent contact is with a provider who does not know the patient well
- Default decision is to go to the ED → admission to hospital
- Patients need a tailored access plan detailing who to call for which problem, how to reach the appropriate provider and when to call