

Care Coordination at the Primary Care Offices  
Yakov Sigal, MD  
Janelle Towslee, RN Care Manager  
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## Objectives

- Care coordination at the Primary Care settings
- Definition of CMC and gaps in care for these children
- Main categories of models of care for Children with Medical Complexity
- Linking care coordination with CSHCS services and Medicaid Health Plans
- Benefits of care coordination for the family







## Case 1

17 year old AA male

History of severe CP, profound global developmental delay, nonverbal, severe spasticity, recurrent aspirations, T tube placement, G tube dependent feeding, severe GI bleeding secondary to erosive esophagitis and gastritis, moderate persistent asthma, seizure disorder

Multiple meds including anti seizure medications, PPI, muscle relaxant, anticholinergic medication

Multiple DME

Private Duty Nursing







## Case 1 continued:

Social situation: Mother has a history of drug dependence and addiction, intermittent relapses and diverting his medications.  
Father currently has custody and works nights







## Case 2

5 years old AA boy

History of severe eczema, severe persistent asthma, GERD, intermittent blood in his stool, severe form of Autistic Spectrum Disorder, non verbal, obstructive sleep apnea and serious sleep problems, aggressive behavior, unexplained paroxysmal events: seizures vs stereotypic behavior related to his autism







## Case 2 continued:

Social situation: Mother has history of multiple medical problems as well as mental health issues

His mother has limited support in taking care for her son

Transportation issues - specialty care is out of town





## Case 3

20 year old white female

History of congenital herpes infection, severe herpes encephalitis, cerebral palsy, profound global developmental delay, recurrent herpes keratitis, seizure disorder, recurrent UTIs, GERD s/p surgery and now g tube dependent








Case 3 continued:

Social situation: parents married and very involved in care, have full guardianship and always want everything to be done in any circumstances







## Definition of Children with Medical Complexity

CMC are a subset of Children and Youth with Special Health Care needs, who have or are at increased risk for a chronic physical, developmental, behavior, or emotional condition and who also require health and related services of a type and amount beyond that required by children generally

CMC are those who are “clinically recognized by at least 1 or more chronic conditions resulting in high family–identified service need, medical equipment addressing functional difficulties, multiple subspecialist involvement, and elevated health service needs.”







## Knowledge gaps in a care of CMC

Definition of CMC is still elusive

Difficulties of collecting data on these children

Underestimation of behavior and mental health issues, social needs of these children and their families

Some medical conditions are rare and unique







## Categories of Models of Care for CMC

Primary care – centered (PCC) models

Consultative – or co-management centered (CC) models

Episode – based (EB) models







## Gaps in current models of care:

Poor integration of medical and community services, especially regarding to addressing social determinants of health

Limited focus on mental and behavioral health care


Difficulties in achieving a smooth transition to adult care

Lack of sustainability strategies

Inadequate support for family caregivers







## Medical co-management

Facilitate multidisciplinary care team discussions and disease management

Assist with polypharmacy with emphasis on interactions and side effects

On call services with providers familiar with patients







## Medical co-management continued:

Triage acute medical issues, provide guidance to referring facilities, ED, and home care agencies

Support providers unfamiliar with patient's medical history and conditions







## Care coordination

Coordinate procedures, appointments and tests to reduce redundancy or multiple sedations

Follow up phone calls and check ins to answer questions and ensure parental understanding of discharge instructions

Create shared care and emergency plans







## Care coordination continued:

Communicate with schools regarding medical and educational care plans

One of goals to move from care coordination to care integration







## Family and caregiver support

Provide a key point person who is familiar with child's journey and is go-to for the family

Facilitate goals of care discussions

Work with caregivers to ensure their own health and emotional needs are addressed







## Family and caregiver support continued:

Assist families with insurance issues and financial resources

Connect families in efforts to create community and peer support systems

Advocate on multiple levels for expanded in-home services and parental support systems









## A story of one family

The reality is that no one really understands the hoops we jump through, the time and energy required to follow us on our child's medical needs, and all we do to continue the best quality of life for our kids







## A story of one family continued:

In the last few weeks, we have:

- been interviewed separately by the county and provider company for an assessment of home services;
- applied for a grant to send our child to a camp;
- written a Behavior plan for home services







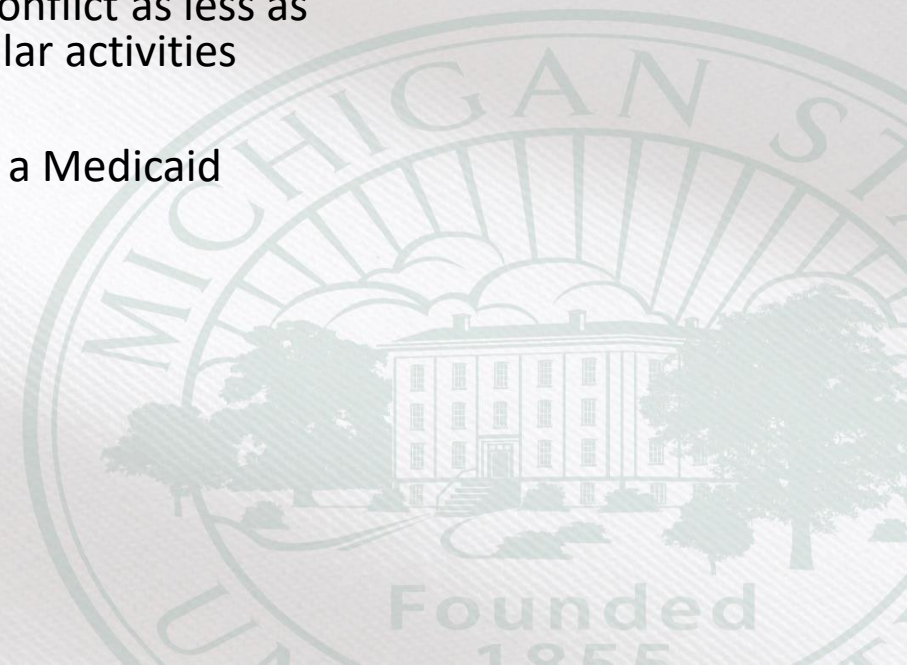
## A story of one family continued:

oriented a substitute at the school as her regular case manager is out

completed the 6 page form for a state Health Care Programs Renewal packet to hire an additional home health provider

scheduled 4 follow-up appointments with specialists to conflict as less as possible with my child's school schedule and extracurricular activities

all while she has been on the waiting list for 12 years for a Medicaid waiver





## A story of one family continued:

This is what it takes to assure our child is integrated and functions well in our community

