Learning Objectives

- Appreciate the primary care perspective regarding healthcare and behavioral issues in children/youth with epilepsy and other CYSHCN
- Describe Children and Youth with Special Health Care Needs (CYSHCN)
- Describe Children’s Special Health Care Services beneficiaries
- Describe Children with Medical Complexity
Learning Objectives

- Locate community and family resources to assist with CYE and other CYSHCN
- Recognize behavioral health needs of children and youth
- Identify YOUR ROLE in the care of CYSHCN, CSHCS and CMC
- Identify YOUR ROLE in the care of children/youth with social/emotional challenges
Primary care clinic: March 13

- 7:45 JD 2 m WCC
- 7:45 RN 12 y/o ADHD
- 8:00 FL 4 d/o newborn
- 8:15 MM 15 y/o ED f/u
- 8:30 DW 6 m WCC, seizure
- 8:45 JT 6 y cough
- 9:00 GG 4 y/o fever
- 9:15 EG 24 m WCC, TS
- 9:30 JJ 18 m throwing up
- 9:45 MS 17 y trouble breathing
- 10:00 RA 11 y behaviors
- 10:15 ES 7 y WCC ASD
- 10:30 MM 4 y ear pain
- 10:45 BP 11 y WCC
- 11:00 SM 14 y rash
- 11:15 CR 4 m WCC f/u hosp for colic
Children and Youth with Special Health Care Needs

CYSHCN are

“those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”
Prevalence Profile: 2011/12 NSCH & 2009/10 NS-CSHCN

Source: 2011-12 NSCH Source: 2009-10 NS-CSHCN

- % CSHCN → 19.8
  - Children 0-17 years: 80.2

- % CSHCN → 23.0
  - Households with Children: 77.0
Common conditions in CYSHCN

- ADHD 32%
- Asthma 30%
- Learning Disabilities 27%
- Dev Delay 15%
- ASD 8%
- Bone, joint, muscle 8%
- Epilepsy 3%

41% experience two or more conditions.

According to the 2011/12 National Survey of Children with Special Health Care Needs:
Children’s Special Health Care Services

CSHCS is an important component of Michigan’s Title V program (Maternal Child Health) that addresses the medical needs of children and youth with special health care needs.

The mission of the program is spelled out in Michigan’s public health code.
Criteria for Medical Eligibility

- Diagnosis
- Severity of Condition
- Chronicity of Condition
- Need for Treatment by a Physician Specialist (pediatric subspecialist)
Diagnosis

• The individual must have a CSHCS qualifying diagnosis where his activity is or may become so restricted by disease or deformity as to reduce his normal capacity for education and self-support.

• Psychiatric, emotional and behavioral disorders, attention deficit disorder, developmental delay, mental retardation, autism, or other mental health diagnoses are not covered by the CSHCS Program.
Sample CSHCS diagnoses

- Cancer
- Cerebral palsy
- Cleft lip/palate
- Liver disease
- Club foot
- Hypospadius
- Spina bifida
- Paralysis
- Hemophilia

- Cystic fibrosis
- Hearing loss
- Insulin-dependent diabetes
- Muscular dystrophy
- Certain heart conditions
- Epilepsy
- Kidney disease
- Sickle cell anemia
- Certain vision problems
Severity

The severity criteria are met when it is determined by the MDCH medical consultant that **specialty medical care is needed** to prevent, delay, or significantly reduce the risk of activity becoming so restricted by disease or deformity as to reduce the individual’s normal capacity for education and self-support.
Need for Treatment by a Physician Specialist

The condition must require the services of a medical and/or surgical subspecialist at least annually, as opposed to being managed exclusively by a primary care physician.
Chronicity

- A condition is considered to be chronic when it is determined to require specialty medical care for not less than 12 months.
Children with Medical Complexity

- Multiple significant chronic health problems that affect multiple organ systems
- Child/youth experiences functional limitations
- Health care costs are high
- Medical technology is often needed
- Approximately 1% of children account for up to one-third of health care costs
Children with Medical Complexity

- Evidence suggests that CMC have the highest risk for adverse medical, developmental, psychosocial and family outcomes.
- There is no one best way to identify CMC
  - High utilization
  - Multiple subspecialty providers
  - Functional limitations
  - Social and psychological and family complexities
Children with Medical Complexity

- Children with medical complexity see a median of 13 outpatient physicians from a median of 6 distinct medical specialties (Cohen 2012).
- 13% of patients use 47% of hospital services!
Let’s take a look at my patients and see who has typical needs, who has special health care needs, who is eligible for CSHCS and who has medical complexity.

As we go through the list, think about your role, if any, in providing care for this child/youth and family.
7:45 Johnny D 2 month old for WCC

- Mother’s score on depression screen = 13
- Father is incarcerated
- Mother describes Johnny as “just like his Dad – cranky and demanding”
7:45 Robbie N 12 y/o ADHD

- Very thin but growing
- Stimulant meds help with focus
- Moody, especially after weekends with Dad
- In and out of counseling
- Lives with Mom, grandmother helps
- Occasional weekends with Dad and his girlfriend
8:00 Felicity N 4 d healthy newborn

- Weight down 7% from birth weight
- Breast feeding
8:15 Marisa 15 y f/u ED visit for headaches

- Hx syncope
- Hx respiratory distress
- Hx of PICU stay with dx “pseudoseizures”
- Seen at Sparrow, DeVos, U of M
- MRI, EKG, Holter monitor – all reassuring
8:30 Denzel W 6 m WCC

- Hospitalized at 2 weeks for seizure
  - Evaluated for possible child abuse
  - Found to have extra fluid around the brain
- On Keppra
- Has small heart lesion
8:45 Jenny 6 y cough

- NO SHOW!
- Time to take a breath...... and return a phone call......
9:00 Greg 4 y fever

- Temp to 102 for two days
- Runny nose and cough
- No appetite but drinking ok
- Past medical history unremarkable
9:15 Myles 24 m WCC

- Myelodysplasia (spina bifida)
- Care has been fragmented
- Mother moves often
- Father incarcerated
- Mother has problems with substance abuse
- Currently in foster care – working on reunification
9:30 Jack 18 m throwing up

- Generally healthy child
- Last WCC at 13 months
9:45 Mark 17 y/o trouble breathing

- Epilepsy – Lennox-Gastaut syndrome
- Cerebral Palsy
- G-tube
- Chronic and recurrent respiratory problems
- Fever and cough – working hard to breathe today
- Oxygen sats low overnight
10:00 Ralph 11 y behaviors

- Suspended from school for fighting
- Grades have dropped
- Dad is incarcerated
10:15 Eric 7 y WCC

- Autism Spectrum Disorder
- ADHD – stimulant medicine helps
- Services in the school
- Mother has not pursued evaluation by CMH for ABA
10:30 Molly 4 y ear pain

- Congestion for 3 days
- Woke up in the night with ear pain and fever
10:45 Brianne 11 y WCC

- No concerns
- No psychosocial risks
- Healthy preteen
- Father has concerns about HPV vaccine
11:00 Sophia 14 y rash

- Diabetes type 1
- Hgb A1C 11
- Missing school – has a truancy officer
- Depressed
- Mother is overwhelmed
11:15 Caleb  4 m WCC

- WCC and follow up for hospitalization
- Admitted for “spells”
- Discharge diagnosis: “colic”
- Losing developmental milestones
  - Was starting to roll over – not now
  - Doesn’t smile like he used to
Now what?

- How do we assure that each child gets what he/she needs when he/she needs it?
- How do we coordinate services across systems?
  - Education
  - Health care
  - Behavioral/mental health
  - Community and recreation
Coordination of Care

- Practice level coordination
  - care manager and practice team
- Plan level coordination
  - MHPs case managers
- Local Health Department
  - CSHCS nurse
- CMDS clinic care plan
- PARENT coordinates the child’s care
Family-Centered Care

- How do we support families so they can achieve THEIR goals?
- How do we reduce the burden of chronic health conditions on families?
- How do we build on the strength and resilience of families?
- How do we support inclusion and self-determination for all?
Preview of the afternoon

- We will create care maps to look at ways to coordinate care.
- Care maps will help us identify ways case managers and care coordinators can assist children/youth and families.
- We will hear from families about their experiences to learn ways we can better provide Family Centered Care.
9:15 Myles 24 m WCC

- Myelodysplasia
- Father incarcerated
- Mother has problems with substance abuse
- Mother moves often
- Currently in foster care – working on reunification
Myles – 24 m myelodysplasia
BREAK for LUNCH
11:15 Caleb  4 m WCC

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PARENT PANEL

- Latrieva Collins-Boston
- Rubontay Johnson
- Kathy Forrest