Pediatric Home Health Care

History
- Home health care was the fastest growing division of personal health care spending in the early 1990's
- The Center for Medicare and Medicaid Administrator designated pediatrics as the fastest growing segment within home health care.

FACTORS
- Cost Shifting: lower cost at home. States are shutting down institutions and shifting to community facilities i.e. group homes or in home placement
- Increase need for service
  - Growing number of infants and children dependent on life sustaining technology for survival ventilators/oxygen/gastrostomy tubes/tracheotomy tubes
  - Increase number of premature infants with associated respiratory, cardiac, and feeding problems
  - More than 40% of extremely small <800 gms and premature infants <26 week will survive
  - 1 in 5 of these infants has a major neurodevelopment disorder- C.P., M.R., Visual or Hearing Impairment
  - Average cost for caring for a low birth weight infant in NICU is $72,000
  - Estimated savings of $20,000 after transitioning from NICU to home

Reference: GUIDELINES FOR PEDIATRIC HOME HEALTH CARE 2nd edition AAP
Why is Home Health Care Important To Professionals?

Sometimes primary care providers as well as parents and other care team members, incorrectly assume the comprehensive needs of a child with medical complexity are being addressed by someone else. As a result, omissions and other errors in care occur.

Reference: The Landscape of Medical Care for Children with Medical Complexity, special report by the Children's Hospital Association June 2013 page 6

Why is Home Health Care Important to Primary Care?

- **Medical Home Model (AAP)**
  - The primary health care professional can help the family and patient access and coordinate specialty care, other health care services, educational services, in and out of home care, family support, and other public and private community services that are important to the overall health of the child and family.
  - The overarching goal of home health care is to optimize each child’s health and function while minimizing recurrent or prolonged hospitalizations through the provision of comprehensive, cost-effective, family-centered health care rendered in a nurturing home environment. (Elias, Murphy, and the Council on Children with Disabilities, Pediatrics 2012; 129; 996)

- **Health Home Model (Centers for Medicare and Medicaid Service)**
  - **Section 2703 of the Affordable Care Act**, entitled “State Option to Provide Health Homes for Enrollees with Chronic Conditions”
    - “Health home providers with which the State collaborates—caring not just for an individual's physical condition, but providing linkages to long-term community care services and supports, social services, and family services.”
    - “CMS envisions a health home model of services delivery with either a fee-for-service or capitated payment structure”

Mandated service under EPSDT (HCY)
Beneficial to patients and their families
Stressors

- Emotional impact on families
  - Increase in single parent household
  - Increase in divorce
  - Siblings: increase in behavioral problems and academic failure

- Social Isolation

- Increase in abuse and neglect

- Long-term follow up demonstrated that family stress can increase over time when caring for a child with disabilities (Glidden and Jonson, Mental Retardation; 1999;37:16-24)

- Financial Strain
  - Limitation of employment
    - 54% reported that a family member stopped working because of the child's health
    - 48% reported that a family member cut back on working hours to care for child
  - For families that incurred out of pocket medical cost for their child with special health care needs (CSHCN), their costs represented 2.2-3.9% of income (Burstein and Dugas, Pediatrics 2011;128:892)
  - >20% of families raising a CSHCN report financial problems attributed to their child's condition (Burstein and Dugas)

- Financial Strain Cont.

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Providers

- Skilled Nursing:
  - Intermittent or hourly on a short term basis
  - Accounts for approximately 90% of home health visits vs. continuous care
  - Duties
    - Phototherapy and daily lab draws
    - Neonatal follow-up and general newborn care
    - Mother/baby follow-up visit with breast feeding education
    - Infusion/antibiotic therapy including growth hormone
    - Wound care
    - Instruction in the use of feeding pumps and G-tube care, suction equipment, tracheostomy care, ventilator, apnea monitors, and oxygen
  - Shift 1-4 hours

Private Duty Nursing

- Complex nursing care for a patient with CONTINUOUS need for skilled services
- RN or LPN depending on the skills needed
- Shifts (8 to 12 hours)
- Level of care exceeds the family’s ability to care for the patient at home
- Medical necessity will determine services

Private Duty Nursing

- Duties
  - Medications-IV, IM, PO
  - Parenteral Nutrition
  - Tracheostomy Care
  - Oxygen Supplement/Monitoring
  - Enteral Feedings
  - Peritoneal Dialysis
  - Ventilator Dependency
Private Duty Nursing

- Medical diagnosis may be related, but not limited to:
  - Severe neuromuscular, respiratory or cardiovascular disease
  - Chronic liver or gastrointestinal disorders associated with nutritional compromise
  - Multiple congenital anomalies or malignancies with severe involvement of vital body functions
  - Severe infections that require prolonged treatment
  - Severe immune deficiency diseases and metabolic diseases, including AIDS

Gastostomy

- Improved weight gain after G-tube placement has been demonstrated in children with cerebral palsy who were previously failing to thrive. Controversy exists over increased risk of death and gastroesophageal reflux following G-tube placement. Maternal caregivers for children with a gastostomy tube may spend up to 8 hours per day on care activities, compared with 3 hours for children without gastostomy tubes. Parents of children with gastostomy tubes also experience higher out-of-pocket expenses for their child when compared to children without gastostomy tubes.

Personal Care Aide

- Assist with activities of daily living (ADLs)
  - Dressing and grooming
  - Bathing and personal hygiene
  - Toileting and continence
  - Ostomy and catheter hygiene
  - Transferring
  - Eating
Eligibility is determined by medical necessity

Examples
- Poorly controlled seizures (other than grand mal)
- Assistance with orthotic bracing, body casts
- Incontinence of bowel and/or bladder after age three (chronic bedwetting and enuresis excluded)
- Significant CNS damage affecting motor control
- Assistance with age-appropriate activities of daily living (children with a diagnosis of developmental delay or intellectual disability may be eligible for personal care. If their ability to perform age-appropriate care is impaired)

Specific for only Medicaid eligible patients through EPSDT program

The presence of a parent or other caretaker does not preclude eligibility for personal care. If a parent must be gone from the home when the personal care is needed, a personal care aide may deliver the service while the parent is absent, as long as the child has a medical need for the service

It does not cover respite care

“Historically the service has been utilized by few children”
Reference: The MO HealthNet Personal Care Manual, Section 13.10

“The EPSDT program is an important but underused Medicaid benefit because of poor awareness and understanding of the program”
Reference: Guidelines for Pediatric Home Health Care, 2nd edition AAP Page 39
A 13-year-old who uses a wheelchair, and needs assistance with breakfast and getting ready for school.

The parent must leave for work at 6:30 in the morning, too early to get the child ready for the bus. The child is of an age appropriate to get his own breakfast and get dressed for school. Personal care is appropriate for this child with disabilities and with a care plan specific to his needs.

A 15-year-old child with disability who weighs 150 lbs. needs personal care.

The parent is at home, and is available to provide the care; however, the child is too large for the parent to manage safely alone. Personal care is appropriate in this case.

A parent has four children, ages 5 and under.

The 5-year-old child needs personal care due to a medical condition. The other three children have no medical problems. If the child were an only child, personal care is questionable, in spite of the disability, because of the availability of the parent. However, the needs of the 3 additional children render the parent unavailable to meet the extra personal care needs of the child with disabilities.
Personal Care Aide cont.
The following describes cases where personal care is NOT appropriate.

- Cases that require skilled nursing services.
- Personal care for any child when there is no documented medical need for the care
- Respite or baby-sitting services
- Homemaker-only service

Personal Care Aide
Clients by Diagnosis

- Total: 50
  - Muscular Dystrophy: 6
  - Autism: 9 (1 Down Syndrome, 1 Shaken Baby Syndrome)
  - Rett Syndrome: 1
  - Rhabdomyosarcoma: 1
  - Myotonic Dystrophy: 2
  - Hydrocephalus: 1
  - Cerebral Palsy: 19
  - Shaken Baby: 2 (1 Autism)
  - Metabolic: 2
  - Chromosome Anomaly: 3 (2 Down Syndrome)
  - Multiple Congenital Anomalies: 1
  - Intellectual Disability (MR): 3
  - Spina Bifida: 2
  - Brain Injury: 1

Survey Results

- Personal Care Aides
  - 1 of 8 referred by doctor
  - 1 of 8 referred by hospital

- Private Duty Nursing
  - 8 of 42 patients referred by doctor
  - 3 of 42 patients referred by doctor/hospital
  - 10 of 42 patients referred by hospital

- Conclusions
  - There is a significant delay between diagnosis and referral for home health services—average(7 years PCA) and(6 years PDN)
  - Majority of referrals do not involve doctors or therapists
  - We can prevent that delay
Funding

- **Private Duty Nursing**
  - Private Insurance—variable
  - Medicaid
    - HMO—may not cover but is a mandated service
    - EPSDT Medicaid
    - CHIP—state specific, may not cover
    - MEDICAID WAIVERS

- **Personal Care Aide**
  - Medicaid
    - Medicaid HMO—may not cover but is a mandated service
    - EPSDT Medicaid
    - CHIP—state specific, may not cover
    - MEDICAID WAIVERS (HCBS) SARAH LOPEZ, AUTISM WAIVER

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**Funding**

- Medicaid >21 (varies by state)
- SCHIP (varies by state)
- Home Health Care

**HCBS Waiver**

- Medicaid 0-21 (EPSDT)
- TEFRA/Katie Beck

**Insurance**

- PDN—limited
- PCA—no (EPSDT)

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**EPSDT**

Early and Periodic Screening, Diagnostic and Treatment

- Medicaid’s comprehensive and preventive child health program

**Five separate screens required:**

- Physical and Mental Health, Vision, Hearing, and Dental
- Performed by Primary Care Physician
- Children and Youth under age of 21
- Mandatory services even if the services are not available for adults
**EPSDT**

**Powerful Federal Law for Children 0-21**

- Medicaid rules are different for children 0-21
- Covers the full range of Health Care and Long Term Care Services and Supports
- States are required to cover services and supports under EPSDT even if coverage for the same service/support is optional or limited for adults under the state plan.
- There are NO optional Medicaid services for children 0-21 years under EPSDT.
- Confusion comes from state-specific variability in program implementation and interpretation of federal law.

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**The EPSDT Benefits**

- Physician services
- Hospital services (outpatient and inpatient)
- Federal qualified health center services
- Medical care or any other type of remedial care recognized under state law or furnished by licensed practitioners within the scope of their practice, as defined by state law
- Home-based care
- Private duty nursing services
- Personal care services
- Dental Services
- Physical, Occupational, and Speech Therapy
- Prescribed drugs
- Dentures
- Prosthetic devices
- Other diagnostic, screening, preventive, and rehabilitative services
- Nurse midwife and certified pediatric nurse practitioner services, to the extent that such services are authorized under state law
- Case management
- Respiratory care
- Any other medical or remedial care recognized by the Secretary of Health and Human Services

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**Significant Case Law**

- States’ attempts to ignore or circumvent the law have resulted in numerous federal cases that support the underlying mandates of EPSDT.
- EPSDT requires states to do more than merely offer to cover services. States are obligated to arrange for treatment and states that children who need personal care services actually receive them (Chisholm v. Hood).
- The state is responsible for ensuring that EPSDT services are delivered when using Medicaid managed care (Frew v. Gillet).
- After plaintiffs challenged waiting lists for services for children with mental retardation and developmental disabilities, the state agreed to improve services (Chisholm v. Hood).
- Both the state and treating physician have roles in determining the services/treatments needed to correct and/or ameliorate medical conditions. The state must provide for the amount of private duty nursing services that the child’s treating physician deems necessary (Blowers v. Blowers).
Using EPSDT = Easy ...1,2,3

- List the condition/diagnosis pertinent to the prescription on the EPSDT Screen form.
- List amount, duration, scope of service or support needed.
- Write Letter of Medical necessity documenting need per EPSDT mandate.

EPSDT

All Medically Necessary Services Must be Provided for Conditions Discovered by the Screen

- Key is “Conditions discovered by the screen”...
- When PCP conducts the Healthy Children and Youth Evaluation, condition must be listed on the EPSDT screen to be covered.
- Medical necessity for home care requires level of care which exceeds family’s ability to care for the individual at home.
- EPSDT contains outreach and education requirements for each state.
  “States must seek out eligible families and inform them of the benefits of EPSDT and the health and long-term care services and assistance available under the broad parameters of EPSDT law.
  42USC1396a(a)(43) (examples of state-to-state variation in HO—OH & AR)

EPSDT

Criteria for Medical Necessity

- Habilitative in addition to curative/rehabilitative are eligible:
  - Services that maintain or improve the current health condition
  - Maintenance services (services that sustain or support rather than cure or improve) may be eligible
  - Services which prevent a condition from worsening or prevent additional health problem
  - Physical and occupational therapy services can be covered when they have an ameliorative or maintenance purpose.

CMS: EPSDT, a Guide for States, June 2014, page 10
Funding-Medicaid Waivers

- TEFRA/Katie Beckett Waivers - Not available in Missouri
  - Meet State's definition of institutional level of care
  - Children must be 18 years old or younger
  - Have medical care needs that can be safely provided outside of institutional setting
  - Cost of care in the community cannot exceed cost of institutional care
  - Children qualify without regard to family income for Medicaid
  - Is optional for each state/EPSPIT is not optional
  - States cannot cap enrollment

Caveat: State participation is optional. State specific data at http://www.hdg.org/catalyst/online-chartbook/

Funding: Medicaid Waivers

- Home and Community-Based Services (HCBS Waivers)
  - also known as 1915(c) waivers
  - Provides Medicaid and additional support services (case management and home modification)
  - Children may qualify without regard to family income in some waivers
  - Require an institutional level of care
  - Eligibility and availability vary by state
  - Target specific diagnosis or conditions
  - Cap enrollment
For many, no government funded services are available and people with I/DD and their families languish on waiting lists for years.
One-third (32%) of parents/caregivers report that they are on waiting lists for government funded services, with an average wait of more than five years. They are waiting for personal assistance, respite, housing, therapy, employment supports, transportation and more.
A conservative estimate is that there are more than 1 million people with I/DD waiting for services that may never come.

"Still In The Shadows With Their Future Uncertain"
www.thearc.org/document.doc?id=3672
SCHIP Program

- Medicaid buy in program for families with modest incomes that do not qualify for Medicaid
- Must be without insurance for 6 months
Letters of Justification

- When you write a letter to Medicaid delineating medical necessity, it may help to cite the category of the federal Medicaid Law.

- Consider using the following language citing the federal law when prescribing care in the home setting: “As you are aware, federal EPSDT law requires states to cover all services within the broad scope of Medicaid. Specifically home health services are mandated pursuant to 42 USC 1396d(a)(7).

- Document why it is medically necessary. (Sample LOMN in this document).

Sample LOMN:
Suggested “language” to document medical necessity per EPSDT mandates

I am writing to request (insert service or equipment request) for my patient (name and age of patient) who has the following diagnoses relevant to this request: (list)

(If home care hours are prescribed, write number of hours per week, duration needed, and scope of services needed. Federal EPSDT law requires states to cover all services within the broad scope of Medicaid when medically necessary. Specifically, home health services are mandated pursuant to 42 USC 1396d(a)(7).

Sample LOMN:
Suggested “language” to document medical necessity per EPSDT mandates

- The request is medically necessary for the following reasons: (choose one or more).
  - It will, or is reasonably expected to, prevent the onset of an illness, condition or disability. (Provide details).
  - It will, or is reasonably expected to, reduce or ameliorate the physical, mental, or developmental effects of an injury, illness, or disability. (Provide details).
  - It will assist the individual to achieve or maintain maximum functional capacity in performing daily activities, taking into account both the functional capacity of the individual and those functional capacities that are appropriate for individuals of the same age. (Provide details).

Alternatives which have been tried and/or rejected and why they failed or will fail to address the underlying condition include:

Please let me know if you require additional information from my records.
EPSDT:
“Medical Necessity should be determined by the Child’s Physician”

- Determination that a service is medically necessary lies primarily with the treating physician or other care provider.
- State can review the physician’s determination as to medical necessity.
- If the state’s expert does not agree the service is medically necessary for a particular child, the state is responsible for making a decision based on evidence.
- Decision can be appealed by the child or the family under the State’s fair hearing procedure.

EPSDT - A Guide for States:
Coverage in the Medicaid Benefit for Children and Adolescents

The role of states is to make sure all covered services are available as well as to assure that families of enrolled children, including children with ASD, are aware of and have access to a broad range of services to meet the individual child’s needs; that is, all services that can be covered under section 1905(a), including licensed practitioners’ services; speech, occupational, and physical therapies; physician services; private duty nursing; personal care services; home health; medical equipment and supplies; rehabilitative services; and vision, hearing, and dental services.
Denials

If a state or managed care entity takes an action to deny, terminate, suspend, or reduce a requested treatment or service, it must give the beneficiary written notice of the action and of their right to a hearing.


Denials...

- Every State has a “Protection and Advocacy System”
  - free legal and advocacy for people with disability
- 501c3, public interest, legally-based advocacy agency. Empowered by federal law to advocate for the civil and legal rights of people with disabilities
  - Official Protection and Advocacy System,
  - Part of the national network of federally mandated and funded protection and advocacy systems.
  - Special powers to investigate abuse and neglect
  - Empowered and funded to, within their priorities, to provide legal and advocacy services to people with disabilities (ex: ADA, the Rehabilitation Act, Medicaid Act, IDEA, Special Education, etc.)
- Web site: http://www.acl.gov/Programs/AIDD/Programs/PA/Contacts.aspx

Additional Advocacy Option
When Medically Necessary Services/DME are denied for children covered by EPSDT Mandates

- Request a physician peer-to-peer review by person with specific specialty background when possible
  - Obtain information about the reviewers’ credentials and expertise at time of arranging meeting (if possible).
  - Be prepared to give additional data, evidence based when possible, at time of the review.
- Advise Parent to file an appeal
  - Adhere to deadlines
  - For urgently needed care, request an expedited appeal
- Involve Medical-Legal Partnership—262 partnerships in 36 states.
  http://medical-legalpartnership.org/partnerships/
When the Diagnosis Is:
Child with Special Health Care Needs

- Treatment May Include Home Health Care
- Private Duty Nursing
  - Private Insurance
  - Medicaid-order to primary care provider or to state agency (i.e. Missouri BSHCN)
  - HMO—may not cover but is mandated service
  - Medicaid
  - Medicaid Waivers
  - Home and Community Based 1915(c) Missouri DEPT of MENTAL HEALTH
  - TEFRA/Katie Beckett Waiver—not in Missouri
  - SCHIP—Varies by State

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